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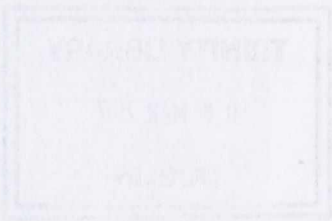
Aligning with the flow of control: A classic grounded theory study of choice and control in the lives of people with intellectual disabilities

A thesis presented to the University of Dublin, Trinity College for the Degree of Doctor in Philosophy

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Summary

Aligning with the flow of control: A classic grounded theory study

Background

Since the relatively recent acknowledgement that people with intellectual disabilities are restricted in making life decisions, ensuring choice throughout their adult lives has gradually come to be seen as a legitimate area of concern for all supporters across disciplines and communities. Over the last ten years, with the growing awareness of the needs of these people and their advocacy network, the discourse around choice has significantly come to the fore. Nevertheless, there is very limited available research that specifically engages with the issue of choice in the realities of the lives of people with intellectual disabilities.

Aim

The twofold aim of this research study was to explain how adults with intellectual disabilities make choices and exercise autonomy in their lives and to develop a substantive explanatory theory.

Methodology

This study was guided by a critical-realist epistemology and the principles of classic grounded theory as delineated by Dr. Barney Glaser. Data was gathered from a single intellectual disability service in the Republic of Ireland. Participants consisted of twelve adults who were attending day services and accessing a variety of other services within the organization. Data was collected through multiple interviews conducted as chats or meetings, ranging from a few minutes up to one hour and thirty-five minutes, in different contexts and settings, and analyzed using the concurrent processes of constant comparative analysis; data collection, theoretical sampling and memo writing.

Emergent Theory

Control in environments that are controlling of them emerged as a main concern for adults participating in this research study. These adults responded to this concern by aligning with the flow of control. The pattern of 'aligning' explains how they regimentally respond to the control they have of their own lives. This theory provides an explanation of interactions in the way adults frame control, connect emotionally and make adjustments in compliance behaviours within the boundaries of their actual doing while being told. Although presented as five discrete categories, the relationship between the categories was neither hierarchical nor linear, but rather iterative and cyclical. Each category shaped and influenced the other, all categories being connected through an interactive family theoretical code.

Conclusions

The emergent theory provides an explanation and assists a better understanding of the intricate and complex issues which surround the area of choices in the lives of adults with intellectual disabilities accessing service provision. The emergent theory generates some valuable insights into the strategies that adults with intellectual disabilities use to address issues of decision in the daily realities of making choices, and provides further enlightenment into how these patterns of response were developed. The emergent theory also contributes to our understanding of the motivators for such adults when responding to issues of choice and control, as well as the interactions which helped produce and maintain the patterns of behaviour and thinking which result in the aligning actions. By so doing, the emergent theory also offers guidance both for adults with intellectual disabilities and people in supporting roles. Several possible directions for future policy, research, practice and education are identified in this under-developed and under-researched area of intellectual disability practice.

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Abbreviations

ABA	An Bord Altranais
ADMB	Assisted Decision-Making (Capacity) Bill (Ireland)
ADHD	Attention Deficit Hyperactivity Disorder
AIA	Adults with Incapacity (Scotland) Act
BC-CLAG	British Columbia Community Living Action Group
CACL	Canadian Association for Community Living
CCRF	Canadian Charter of Rights and Freedoms
CDLP	Centre for Disability Law and Policy
CHA	Canada Health Act
CHRC	Canadian Human Rights Commission
CIA	Citizens Information Act
CIB	Citizens Information Board
CIL	Centre for Independent Living
CLAA	Community Living Authority Act
CPI	College of Psychiatrists of Ireland
CT	Choice Theory
DDPCIC	Developmental Disabilities Primary Care Initiative
DECLG	Department of Environment, Community and Local Government
DOH	Department of Health
DOHC	Department of Health and Children
GOC	Government of Canada
GOI	Government of Ireland
GONS	Government of Nova Scotia
GP	General Practitioner
HIQA	Health Information Quality Authority
HSE	Health Service Executive
HOC	House of Commons
ICB	Irish Council for Bioethics
IRN	Irish Research Network
LRC	Law Reform Commission
MCA	Mental Capacity Act (England and Wales)
MCB	Mental Capacity Bill (Northern Ireland)
MCSS	Ministry of Community and Social Services
MHR	Mental Health Reform
NESC	National Economic and Social Council
NMBI	Nursing and Midwifery Board Ireland
ODI	Office for Disability Issues
QAM	Quality Assurance Measures
RAA	Representation Agreement Act (Canada)
RCT	Rational Choice Theory
RNID	Registered Nurse Intellectual Disability
RT	Reality Therapy
SDA	Substitute Decisions Act (Canada)
UN	United Nations
UNCRPD	United Nations Convention on the Rights of Persons with Disabilities
VPLMDA	Vulnerable Persons Living with a Mental Disability Act (Canada)
WHO	World Health Organisation

Concepts explained

The following presents in alphabetic format explanation of concepts which emerged in the theory aligning with the flow of control

Ability perceptions

- adults perceptions of how well they do what they do
- has properties of finding it easy, finding it doable, finding it difficult, finding it hard
- is a property of power frames

Actual doing

- the diverse nature and extent of what adults actually do when making choice
- conditions relating to individual circumstances which have a profound impact on choices
- related category conditions shaping aligning the flow of control
- interactive family with what adults are being told to do
- has properties of functional diversity, support, engagement

Adjusting compliance

- the nature and extent to which adults adjust to what they are being told to do
- how adults adjust to comply with what they are being told to do within the boundaries of what they actually do
- related category which counterbalances the nature and direction of aligning with the flow of control
- has properties of dissentious complying, selective complying, functional complying, model complying

Aligning cycles

- regularly repeated sequences of movement in either positive or negative directions as adults oscillate between what they are being told to do and what they actually do
- interactive family between what adults are being told to do and the realities of their actual doing while they are framing control, emotional connecting and adjusting compliance.
- has properties of resisting the flow of control, getting carried by the flow of control, going with the flow of control, embracing the flow of control

Aligning with the flow of control

- core category explaining how adults frame control, emotionally connect and make adjustments in what they do while being told what to do
- has properties of framing control, emotional connecting, adjusting compliance

Enacting practices

- the nature and extent of conditions of agency communications which direct adult behaviours, which has a profound impact on their choices
- has properties of attitudes (respectful and dis-respectful) and practices (verbal directives, non-verbal directives, rules (written, unwritten)
- is a property of being told

Being told

- conditions that set the requirements for adult behaviour
- interactive family with actual doing
- related category conditions shaping aligning with the flow of control
- has properties of external influences, enacting practices

Bounded understanding

- limiting levels of knowledge and thinking.
- the nature and extent of their knowledge and thinking
- related category conditions for positioning control
- has properties of discriminatory knowing (illogical knowing, dependency knowing, routine knowing, knowing rules exist, knowing problems exist) and selective thinking (limited thinking, limited questioning, naïve thinking, not thinking, problematical thinking)
- is a property of interpreting

Choice arrangements

- the structural conditions of adult choices inclusive of, exclusive of or arranged by adults themselves within the boundaries of what they are being told to do.
- has properties of pre-arranged, arranged, self-arranged
- is a property of support

Consultation

- the level of consultation facilitated by agency for adults to make choices
- has properties of lacking consultation, limiting consultation, reasonable consultation, full consultation
- is a property of support

Dissentious complying

- their behaviours when adjusting to what they are being told to do when they are mentally opposed
- has properties of resistant complying and non-complying
- is a property of adjusting compliance

Embracing the flow of control

- their behaviours when they are in control, emotional stabilizing and adjusting by model complying to what they are being told to do within the boundaries of their actual doing

Emotional connecting

- levels of their emotional connections with what they are being told to do in the boundaries of their actual doing
- how they regulate emotions with regard to how they frame control and adjust to what they are being told to do
- related category which counterbalances the nature and direction of aligning with the flow of control
- counterbalances the equilibrium by how they are connecting their emotions with their perceptions of control
- has properties of emotional de-stabilizing, emotional self-preserving, emotional self-protecting, and emotional stabilizing.

Emotional de-stabilizing

- how adults experience stress, continually re-visit stressful experiences, and despair
- has properties of stressing, ruminating, despairing
- is a property of emotional connecting

Emotional self-preserving

- how adults seek safety in uncertain environments
- has properties of accommodating obscurity and keeping fear at bay
- is a property of emotional connecting

Emotional self-protecting

- how adults who are continually gaining confidence ensure its sustainability by self-protecting
- has properties of emotional shielding, emotional gratifying, emotional rationalising
- is a property of emotional connecting

Emotional stabilizing

- how adults are ensuring continued confidence in maintaining emotional wellbeing
- has properties of alleviating stress, and feeling optimal performance.
- is a property of emotional connecting

Engaging in self-control

- conditions relating to individual adult circumstances
- related category conditions shaping aligning with the flow of control.
- has properties of increasing self-direction, influencing choices, gaining control
- is a property of positioning control

Engagement

- the nature and extent of conditions which impact on how they engage in choices, which
- has properties of-non-engagement, selective engagement, partial engagement, full engagement
- is a property of actual doing

External influences

- the nature and extent of conditions outside the immediate control of adults or the agency, yet which have a profound impact on how they make choices
- has properties of policy and legislation, social norms
- is a property of being told

Frames of reference

- subliminal and overt ideas which they draw upon and project onto choice situations
- has properties of identity frames, power frames, mind-set frames
- is a property of framing control

Framing control

- the nature and extent of conditions which continually inform adults of their general control beliefs and perceptions of control of specific choice situations
- sub-core category of the theory of aligning with the flow of control
- conditions relating to individual adult circumstances
- is a consequence of the interactions between what they are being told to do and their actual doing and is a causal factor in determining the direction of aligning with the flow of control
- has properties of frames of reference, interpreting and positioning control

Freedom to choose

- their perceptions of the degree of freedom they have to choose
- has properties of restrictive, selective, liberating, empowering
- is a property of power frames

Functional complying

- their behaviours when complying sufficiently and cautiously with what they are being told to do
- has properties of tentative complying and sufficient complying.
- is a property of adjusting compliance

Functional diversity

- the nature and extent of domains and levels of functioning
- has properties of physical health, psychological health, social health, occupational activity, cognitive intellectualising, materialistic malleability, aesthetic acceptance, pacing and aspirations.
- is a property of actual doing

Getting carried by the flow of control

- explains greater external control, emotional self-preserving and selective complying when being told what to do within the boundaries of their actual doing
- is a property of aligning cycles

Going with the flow of control

- explains that they are engaging in self-control, emotional self-protecting and functional complying with being told what to do within the boundaries of their actual doing.
- is a property of aligning cycles

Greater external control

- conditions relating to their individual circumstances
- conditions shaping aligning with the flow of control
- their perceptions that there is greater external control of choices
- has properties of being externally directed, having less influence, accepting external control, externalising control
- is a property of positioning control

Identifying powerlessness

- low levels of knowledge and thinking knowing they are powerless and not knowing what to do
- has properties of powerless knowing and non-productive thinking.
- is a property of interpreting

Identity frames

- the nature and extent of how they continually formulate and draw upon subliminal and overt ideas from past and current experiences with regard to being a human and being an adult.
- has properties of human identity frames, (belonging, contribution recognition, isolation, objectification, lacking contribution recognition) and adult identity frames (accessing opportunities for adulthood, satisfactory adult status, being treated like a child, lacking satisfactory adult status)
- is a property of frames of reference

Interpreting

- their levels of knowledge and thinking
- the nature and extent of their knowledge and thinking - consequences for positioning control
- has properties of identifying powerlessness, bounded understanding, tracking transparency, targeting set practices
- is a property of framing control

In control

- conditions relating to individual adult circumstances
- related category conditions shaping aligning with the flow of control.
- has properties of being self-directed, effecting actions, self-controlling
- is a property of positioning control

Mind-set frames

- the inherent mind-sets of the adults.
- has properties of oppressed mind-set, dependent mind-set, pragmatic mind-set independent mind-set
- is a property of frames of reference

Model complying

- their behaviours when complying fully and confidently with expectations of behaviour
- has properties of committed complying and compliance seeking
- is a property of adjusting compliance

Non-verbal directives

- the non-verbal communications from agency which direct adults behaviours
- has properties of: body language, tone of voice, spatial distance, time use
- is a property of enacting practices

Not in control

- perceptions of not being in control
- conditions relating to individual adult circumstances which explains
- conditions shaping aligning with the flow of control
- has properties of lacking self-direction, ineffectual actions, lacking control.
- is a property of positioning control

Positioning control

- perceptions of their influence on the choice being made.
- conditions relating to individual adult circumstances
- related category conditions shaping aligning with the flow of control.
- has properties of not in control, greater external control, engaging in self-control, in control
- is a property of framing control

Power frames

- ideas about power, their perceptions of the likely/actual power they have to control choices.
- has properties of situating power positions, freedom to choose, and ability perceptions
- is a property of frames of reference

Resisting the flow of control

- not in control, emotional de-stabilizing and dissentious complying occurs as adults are being told what to do within the boundaries of their actual doing -is a property of aligning cycles

Resources

- the available provisions to adults when choices are made.
- has properties of information, supervision, time, equipment, funding
- is a property of support

Rules

- written and unwritten formats of communication which are highly influential in directing adult behaviours in making choices
- has properties of: written, unwritten
- is a property of enacting practices

Situating power positions

- their perceptions of where they fit in hierarchical power structures.
- is a property of power frames

Support

- the nature and extent of conditions which impact on how they make choices,
- has properties of choice arrangements, consultation and resources (agency, information, supervision, time, equipment, funding)
- is a property of actual doing

Selective complying

- their behaviours when complying partially and/or submissively with what they are being told to do
- has properties of partial complying and submissive complying.
- is a property of adjusting compliance

Targeting set practices

- high levels of knowledge and thinking
- the nature and extent of their knowledge and thinking - consequences for positioning control
- has properties of automatic knowing (competent knowing, experiential knowing, factual knowing) and determined thinking (inquisitive thinking, meticulous thinking, procedural thinking)
- is a property of interpreting

Tracking transparency

- sufficient levels of knowledge and thinking
- the nature and extent of their knowledge and thinking has consequences for positioning control
- has properties of vigilant knowing root learning/knowing, practising, self-telling, knowledge repeating, verbalising) and vigorous thinking (visualising, planning and organising, futuristic thinking, anticipating consequences, insightful thinking, reasoned thinking, reflective thinking).
- is a property of interpreting

Verbal directives

- verbal communications from agency which direct adult behaviours
- has properties of orders, telling, instructing, advising
- is a property of enacting practices

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1 Introduction Chapter

1.1 Introduction

This thesis explores issues which arise around the choices of adults with intellectual disabilities, and develops a theory to explain how they attempt to resolve their main concern. Historically people with intellectual disabilities have been segregated from the societies they lived in and spent their lives in institutional care settings, which resulted in limiting opportunities for them to live a similar life to the general population. The knock-on effect of living segregated lives and accessing group-managed services inevitably subjected them to restrictions of choice in their lives. More recently, as societies have tried to undo the wrongs that have been done to this group of people, both legislative and policy-making bodies are driving agendas of re-absorbing such individuals back into their communities, thereby increasing choice opportunities for many adults whose lives have been previously restricted.

This thesis delineates an investigation into this phenomenon and the consequent theory that emerged from that investigation. The twofold aim of the research study was firstly, to ascertain the core concern (most important issue) for adults with intellectual disabilities who have been living a life subjected to limited choice and who now live in societies compelled to promote greater opportunities for choice and secondly, to develop a classic grounded theory explaining how these adults who access support services attempt to resolve their core concern. This chapter therefore introduces the concept of disability, models of disability, and situates intellectual disability in the context of disability studies. The focus and significance of this research study is introduced and the layout of the thesis is presented.

1.2 Conceptualisations of disability

The field of disability studies is represented by multiple discourses of disability, with origins in very different, academic, political and social and psychological traditions. Such studies provide an arena for analyzing disability and examining the cultural, political and social ramifications of disability in society (Rocco and Fornes 2010; Meekosha and Shuttleworth 2009).

“Disability is part of the human condition as almost everyone will be temporarily or permanently impaired at some point in life, and those who survive to old age will experience increasing difficulties in functioning”
(WHO 2011, p.7)

Disability has been, and continues to be, a hotly debated concept, which is dynamic, complex and multifaceted in nature, whereby multiple context-dependent interventions are engaged so as to overcome or work around the associated inconveniences (WHO 2011). Furthermore, the brief of disability studies has now widened, to include queer and feminist agendas (Shakespeare 2013). As the scope of disability studies widen, so too does the debate for a need to devise a paradigm which can be referenced in the disability decision-making process. Silvers (2010) advocates that models of disability help determine such questions as: What disability is? Why it exists? And how do people come to be disabled? Grappling with such questions gives rise to the debates between medical and social conceptualizations of disability and impairment, critical disability theory and approaches to disability, which contribute to the ever-evolving construct of disability (Grue 2011; WHO 2011).

1.2.1 The medical model of disability

The medical model frames disability as a phenomenon that can be wholly explained in terms of individual biophysical properties (Grue 2011), whereby “some physiological or chemical system might be missing or atrophied, or might have been damaged through illness, accident, or some other trauma” (Glover 2006, p.6) and the absence of which causes the malfunctioning of such a system results in the person being compromised to cope with life (Terzi 2004). In focusing on this perspective of disability the medical model establishes a causal relation between individual impairment, seen as deviation from human normality. The disability itself is similarly evaluated against the norms of average human functioning in terms of impairment and limitations in abilities to perform tasks (Terzi 2004). The medical model acts on the presumption that disability is a deficit of natural assets rather than social assets, and that the entitlement and the responsibility to fix such malfunctioning lies within the remit of medical professionals, facilitated through medical intervention (Silvers 2010).

In its summation of the main criticisms of the medical model of disability the WHO (2011) stipulates that disability should not be viewed as purely medical. Grue (2011) stipulates that the medical model stresses impairment to be the person's sole problem, appropriates total responsibility to the disabled individual for his or her own disabilities while ignoring the contingent nature of the environment, and is limiting for the scope of theorists seeking to explain the multidimensional nature of disabilities.

1.2.2 The social model of disability

The social model views disability as being socially created. As such, it is the environment that is disabling, rather than the physical, cognitive, or mental variation of the individual (Hahn 1988). Disabling environments are understood as spaces which have been created without due regard to the needs and aspirations of people with disabilities (Rocco and Delgado 2011).

The social model challenges the fundamental beliefs of the medical model of disability which connects bodily impairment and disability and is predicated on the assumption that disability is social rather than physical, as “disablement is....caused by the oppression of social and economic structure on disabled individuals who are, consequently, an oppressed group in society” (Terzi 2004, p.143).

Significantly, Cole (2007) believes that the social model favours of the concept of difference rather than normality, abhorring “any idea of normality seen as ideologically constructed in order to control and exclude disabled people from the structure of a society” (Terzi 2004, p.153). Embedded in the assumptions that disability is fundamentally a deficit of social assets rather than of natural assets, the social model engages with disability as a political problem and seeks corrective action by individual and group activists in order to alter attitudes and reform state practices (Cole 2007; Silvers 2010). The goal of the social model of disability is to explain the production of disability through multifaceted social arrangements (Grue 2011) and to subsequently modify such environments (Asch 2001) to thereby remove the role of dependent patient from individuals with disabilities and recast them as independent citizens with rights (Oliver 1983; Silvers 2010).

In its attempts to have people with disabilities recast as independent citizens the social model of disability has been criticized for suppressing rather than showcasing disabled people’s differences, and of advancing an ideal of independence that that some disabled people’s dysfunctions make unobtainable for them (Silvers 2010). In over-socializing disability, the social model of disability loses sight of the connections between disability and bodily impairment (Terzi 2004). Furthermore, by neglecting the subjective experience and psycho-emotional aspects of impairment, the marginalization of disabled people cannot be tackled effectively (Scully 2008).

Conversely, there are commonalities between the medical model of disability and the social model of disability, who each acknowledge that both biological and social conditions contribute to disablement. Both models also treat disability as an arrangement of difficulties (Silvers 2010). In combining both models, disability has been characterized as limitations associated with impairments which incorporate biological features, environmental factors, and the persons own goals (Wasserman 2001: 225; Barclay 2011). In recognising the emergence of this synthesis in models of disability the World Report on Disability advocates more interactive approaches to disability which may reconcile the

existing dichotomies between the social and medical model (WHO 2011). To this end the International Classification of Functioning, Disability and Health provides ‘an international, scientific tool for the paradigm shift from the purely medical model to an integrated bio psychosocial model of human functioning and disability’ (WHO 2002, p.19).

1.2.3 Critical disability theory

While the social model of disability suggests that differences between disabled and non-disabled people are socially produced, critical disability theory challenges these assumptions in arguing that these binary opposite constructs are also created for political reasons; namely to maintain dominance (Goodley 2011, p.113) which ensures that disabled people are regarded as deviant and inferior, while non-disabled enjoy positions of privilege and power (Campbell 2009). It is by deconstructing such binary opposites as dis-abled and non-disabled that alternative concepts of disability and impairment can be produced and the problems arising from relationships between impairment and oppression which continuously confront disabled people can be revealed (Vehmas and Watson 2014). Additionally, in demonstrating how the rigid terms of dis-abled and non-disabled obfuscates the connections between those with and without impairment, the ultimate aim of critical disability theory is to create a more reflective and theoretically vigilant approach to disability studies (Vehmas and Watson 2014).

Pothier and Devlin (2006) stipulate that a primary concern for critical disability theorists is an interrogation of the language used globally to conceptualise disability. General labels such as “the disabled” and “persons with disabilities” “disabled persons,” are used interchangeably, while other possibilities of: “people with impairments,” “people who experience activity limitations,” and “people who live with impairments” are also used (Rocco and Delgado 2011). More specifically with regard to those with born with cognitive impairments, “mental handicap” and “retardation”, “learning/intellectual/developmental” disabilities and ‘special needs’ are in usage across the globe. Such labels are contentious phenomena, as while they may be necessary to apply for access to supports and services, they also infer the devaluation of these people by the societies in which they live (Goodley and Runswick-Cole 2015). Conversely, the use of such language as “people with disabilities” or “disabled people” creates the potential to disconnect the disability from the person or to suggest that the disability is of a second order nature to the person (Pothier and Devlin 2006).

In actual fact, the experience of disability, which is a consequence of the interactions between the person, their health and the environments they live in, vary greatly for individuals concerned (WHO 2011, p.7). Disabled people's priorities and needs, and their experiences of being more limited than other people in significant respects, need to be key phenomena informing the idea of 'disability' for disability theorists (Silvers 2010).

Criticisms of critical disability theory raise the concern that by emphasizing the breaking down of such polar opposites as ability and disability little is actually accomplished in the pursuit of justice for disabled people. It is claimed that critical disability theory does not engage fully with the key ethical and political issues confronting disabled people or examine how things ought to be. Furthermore, it is limiting in evidence of subjective wellbeing when inferring normative judgements about disabled people's well-being and lacks engagement with pertinent ethical issues related with the role of impairment and disability (Vehmas and Watson 2014).

In this research study, the author has chosen to predominantly use the term 'intellectual disabilities' to recognize the label most prominent in the Irish policy context. When discussing literature relevant to other countries the term most applicable will be utilised, for example, 'learning disabilities' in the United Kingdom. For the purpose of this research study, the significance of the experience of adults who are labelled with this term is axiomatic to research which focuses on such matters as their various physical, mental, intellectual and environmental challenges. The following presents the background and rationale for this research study.

1.3 Background and rationale for this research study

In Ireland, adults with intellectual disabilities are entitled to access service provision to identify and meet their individual needs and outcomes, and enable them to lead fulfilling lives. Current policy, legislation and social norms influence the prescribed guide for the service strategy, while effective implementation of the service strategy relies on a systematic approach to service provision which can provide high quality, safe and effective support to people of varying abilities. Ideally the service strategy strives to balance the need to protect those with intellectual disabilities with empowering them to lead fulfilling and independent lives. Additionally the service is challenged to provide a person-centred service within the context of a group- managed care facility, while being obligated to be as cost-effective as possible.

Bearing the label and experience of intellectual disability has ramifications for adults needing and accessing differing types and levels of support at different phases in their lives. As a consequence of

the inherent medical model which pre-supposes that those with intellectual disabilities have very limited choice-making capacity, and perhaps because society has traditionally limited their freedom to make choices, the current capability for many of these individuals to make choices has been adversely affected (Abbott and Marriott 2012; Small et al 2003).

In the current climate of choice frequently referenced in quality of life (O'Brien 1987), and rights (UN 2006) focused literature, the components have not been clearly described (Brown and Brown 2009). The relative lack of theory and research to support our understanding of choice itself has resulted in the lack of evidenced-based practical or effective methods to help people make choices (Harris 2003) and there is a dearth of research representing the experiential realities of how people with intellectual disabilities in Ireland make choices. Using data collected from adults in the actual setting to develop a theory which reflects their decision-making and what is actually happening in their lives as they currently make choices would ensure the presentation of a sound evidence base representing the relevant behaviour patterns. Additionally, this evidence base would better inform understanding of choice, including the presence and/or absence of choice, the factors which optimize and/or limit choice, and could pave the way for the development of more practical and effective methodologies. More than a mere analysis of the history and categorization of intellectual disability, undertaking this research study would add to the identification and explanation of the various ways empowerment, marginalization or oppression, are experienced by this group of people, which could ultimately assist in the pursuit of equality and social inclusion for such individuals.

1.4 Situating the researcher

The employment of reflexivity requires researchers to consider their position in relation to their research (Darawshe 2014). This is accomplished by the researcher reflecting on his/her: cultural background; thoughts; actions; emotions; assumptions; and unconscious responses, and considering how these factors may have influence on the research process and findings (Rolfe 2006). Researcher reflexivity is intermingled throughout this thesis as the researcher reflects on how she impacted on this research study and vice versa.

The following demonstrates the triggers and motives which influenced this research study. The researcher reflects on the realities of cultural influences, past experiences working in clinical practice, educational achievements, current knowledge on the emphasis of choice conceptualisations in the lives of people with intellectual disabilities, along with considering and questioning the process through which this researcher came up with the novel and pertinent research question.

The researcher grew up in Ireland, a country which at the time, while economically challenged had a strong Catholic identity both of which influenced decisions made by the Irish Government. Primary and secondary education accessed by the researcher was facilitated by Catholic Religious orders. And in the 1980's venturing on a career pathway in the area of intellectual disability nursing the researcher worked in education, health and social care service provision for people with intellectual disabilities in Ireland which continued to be almost exclusively dominated by Catholic Religious orders. Working in clinical practice as a registered intellectual disability nurse (RNID), the researcher had first-hand experience of how people with intellectual disabilities lived restricted lives, lacking opportunities to make choices. Over time as philosophies of service provision shifted focus from the medical model to the social model of care provision for people with intellectual disabilities the researcher was witness to the prominence gained in the value of choice which was subsequently perpetuated when the rights agenda for people with disabilities came to the fore.

Combined with years of experiential learning in clinical practice, completion of the BSc. Nursing Studies, MSc. Advanced Nursing and working as a lecturer in Nursing (Intellectual Disability) from 2004, led to more specific research interests for the researcher in areas of person centred planning, rights, inclusive research and choice. Specifically undertaking her MSc. research study the researcher aimed to describe and analyse structures and processes of person centred planning utilised in a residential service for people with intellectual disabilities. The findings from this research described the presence or absence of certain structures and processes which could be conducive to person centred planning. However, for the researcher, in the absence of the involvement of individuals with intellectual disabilities as research participants the MSc. study was limited in explaining person centeredness from the perspectives of these people as users of services. Therefore, when undertaking this PhD research study the researcher sought to fill the gap of understanding person centeredness from the perspectives and experiences of people with intellectual disabilities. At the time of commencing this PhD study, there was a widespread recognition that choice in the lives of people with intellectual disabilities was an important element of person centred care; nonetheless there was a dearth of literature written on their choice making practices. Therefore by explaining how adults with intellectual disabilities make choices derived from data embedded in their own perspectives and experiences would be an ideal foundation from which to work on to improve choice experiences for these individuals.

So, the motivation for this research was to really know what choice was about for adults with intellectual disabilities. How did it fit with notions of person-centred planning, empowerment, rights and inclusion? Was it about having freedom to choose and opportunities to make choices? Further deliberations by the researcher centred on how choice was incorporated into her own lecturing, which raised questions that if lectures delivered by the researcher did not promote meaningful choice in the lives of adults with intellectual disabilities then what exactly was she doing?

1.5 Layout of the thesis

Chapter 2 Choice policy and legislation for people with intellectual disabilities

Chapter 2 presents an overview of the paradigm shift in service provision, from institutionalisation to de-institutionalisation for people with intellectual disability in Ireland and makes comparisons internationally. These individuals are now being re-integrated back into their communities and as 'choice' has gained prominence in relevant policy and legislation, critical issues have arisen which are affecting their choice opportunities. How best to support these people are frequently debated issues of empowerment vs protection which are pivoted on the capacity people with intellectual disabilities to make decisions. Drawing on similarities and differences, this chapter provides a discussion of relevant policy and capacity legislation in United Kingdom, Ireland and Canada which internationally has been a lead country in policy development to promote re-integration. Specifically concepts of decision-making capacity, support structures and monitoring of decision-making are addressed.

Chapter 3 Research theory, methodology, methods and application

Chapter 3 introduces the purpose of this research study and the epistemological and ontological assumptions of the researcher to elucidate how the overall chosen design of the research study ensured congruency between the purpose, aim and objectives. The theoretical underpinnings of research theory, methodology, methods and ethics are explained and discussed as applied in this study. Research methodology approaches applicable to the research are examined leading to justification and explanation of classic grounded theory, as the chosen research approach for this research project which is substantiated and detailed as applied. The discourse employed throughout the chapter will be related to aspects of classic grounded theory methodology ultimately used as the approach of the current study.

Chapter 4 Fundamental choice issues

Chapter 4 is the first of two chapters explaining the emergent theory of aligning with the flow of control. This chapter introduces the reader to the research participants and initial efforts of the researcher in early coding and analysing the data. Early concepts explaining participant's domains and levels of functioning in physical health, psychological health, social health, occupational activity, cognitive intellectualising, materialistic malleability, aesthetic acceptance, pacing and aspirations are identified. Diverse in nature and extent these domains and levels of functioning lay the foundations of

the concept functional diversity which when combined with other concepts of support and engagement explains adult's actual doing, one of the main categories of the theory of aligning with the flow of control.

Chapter 5 Emergent theory – aligning with the flow of control

Chapter 5 introduces the emergent theory and offers a more focused elaboration on the classic grounded theory journey as experienced by the researcher as the relevant skills improved. An overview of the reflections of the researcher's journey using classic grounded theory adds to the explanations of how the theory emerged. The emergent theory of aligning with the flow of control is presented as adults are framing control, emotional connecting and adjusting compliance as they respond issues of control in the realities of their actual doing while being told what to do.

Chapter 6 Aligning with the flow of control and relevant literature

Chapter 6 commences with a scoping review of choice in intellectual disability literature followed by an overview of the tenets of rational choice theory as referenced in behavioural economics and sociological theory. The underpinnings of theories self-determination and control which are inextricably linked with choice behaviour are illuminated and specific discussion Glasser's (1998) choice theory is provided and comparisons are made with the theory of aligning with the flow of control, discussing its practical implications within the current contexts. Similar to evidence in the literature the emergent theory demonstrates that issues of choice, control, emotions and compliance behaviours are inextricably interlinked for this group of adults with intellectual disabilities.

Chapter 7 Summary and Conclusion

Chapter 7 summarizes the emergent theory and its contributions to knowledge. The credibility of this research study is addressed according to the classic grounded theory criteria of fit, work, relevance and modifiability. The contributions of this theory are condensed reflecting on its theoretical, methodological and practical implications. Limitations of the research study and opportunities for future developments are identified. Some possible recommendations for policy, research, education practice and researcher reflections are considered.

1.6 Conclusion

The promotion of choice in the lives of adults with intellectual disabilities has become a core objective of service providers. Due to the dearth of evidenced based information there is an onus on researchers to scrutinize the concept of choice in the lives of these adults as they access support and services. This is a timely research study as it occurs in the context of changing circumstances in the lives of adults with intellectual disabilities as they are accepted back into their communities which are now compelled to offer them more choice opportunities. Responses to supporting people with disabilities in general and more specifically intellectual disabilities are heavily influenced by how disability is defined as different definitions of what disability is and how it exists can result in variable consequences for what is viewed as appropriate and timely support. But it is only from the perceptions and experiences of individuals labelled with the term intellectual disability that an authentic explanation of the realities of choice can be generated.

2 Developments in legislative policy and service provision

2.1 Introduction

International and national policy agenda and subsequent positions of service providers persistently impact on the life choices of people with intellectual disabilities. The following chapter presents an overview of the paradigm shift in service provision, from institutionalisation to de-institutionalisation for people with intellectual disabilities in Ireland and makes comparisons internationally. As these individuals who traditionally have had limited choice experiences are now being re-integrated back into their communities they have their own aspirations and ideals of the choices they wish to make. Critical issues central to debates of empowerment vs protection are centred on the capacity people with intellectual disabilities to make decisions. Relevant capacity legislation in United Kingdom and Ireland are discussed and Canadian policy and legislation is considered as internationally Canada has been a lead country in developing policies promoting de-institutionalisation and re-integrating these people back into their communities.

2.2 Institutionalisation, de-institutionalisation and community re-integration

Throughout the 18th and 19th century's buildings called asylums, institutions or hospitals were built across Europe, Canada, America, Australia and New Zealand. Not only was this institutional era the operation of a series of large and segregated building compounds, but it was also reflective of a state of mind inherent in society's values and ways of thinking about how to best protect, educate and train the destitute in society, while providing services which were cost effective (Brown and Radford 2015). In Ireland, in the 20th century this continued era of institutionalisation paralleled Ireland's reliance on a combined collaboration between the Irish government and Catholic religious orders resulted in the delivery of service provision for people with intellectual disabilities moving gradually from government-managed complexes and district mental hospitals to the direction of religious orders (Linehan et al 2014). It is now widely accepted that individuals who accessed service provision during these times lived severely restricted lives limited in opportunities for choice and control.

Initial questionings of this institutionalisation epoch came from Goffman (1961) who began to establish disability as a social construct rather than an internal condition, damningly proclaiming that institutionalisation had a destructive effect on both inhabitant's and employees. Impetus to such

criticisms was added in the subsequent conceptualizations of “normalization” and “social role valorisation” (Wolfensberger 1972). And along with notions that individuals with disabilities were as valid a human being as anyone else, supporters of people with intellectual disabilities became enlightened as to the requirements for these individuals to live ordinary lives (O’Brien 1987). Policy makers and service providers were then driven by the tasks of closing institutions and re-integrating people into their communities, for example, O’Brien’s (1987) five service accomplishments incorporated; choice, respect, competence and community presence. Additionally, voluntary organisations such as the National Association of Mental Handicapped of Ireland, (now known as Inclusion Ireland) founded in 1961 and ‘Parent and Friends Associations’ worked tirelessly to advocate for the rights of people with intellectual disabilities.

Furthermore, the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD 2006) has been the international springboard to develop policies which facilitate those with disabilities to live in their communities and enjoy the same opportunities as the general population. The United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) (2006) is an international agreement which Ireland was one of the first signatories. However Ireland has yet to ratify the agreement in order to have it as part of Irish law. The Irish Government acknowledge that one of the barriers to the ratification of the agreement is the current Irish law governing decision making which are outdated and governed by the Lunacy Regulations Act (1871) and the Irish Ward of Court System. Specifically, the United Nations Convention (UNCRPD 2006) recognises the rights of all individuals including people with intellectual disabilities to equal recognition before the law, for example: they must be entitled to enjoy legal capacity on an equal basis with others and that they should have access to the supports required to enjoy their right to legal capacity (Equal Recognition Article 12); people with intellectual disabilities have the right to access justice including the right to accommodations as required (Access to Justice Article 13) and that persons with disabilities have the right to choose where they live and with whom they live (Living Independently Article 19) emphasizing the significance of support for community living. But while significant steps have been made in the promotion of deinstitutionalisation and community integration of people with intellectual disabilities, individual counties have varying reports in the degree of progress being made (Carrigan 2011).

In Ireland Time to Move on from Congregated Settings –A Strategy for Community Inclusion (HSE 2011) specifically recommended that institutions should be closed and individuals should be reintegrated into their communities. And reports Moving Ahead (Lenihan et al 2014; Tatlow -Golden et al 2014) examined the factors which contributed to the successful transfer of people with intellectual disabilities from congregated settings to community – based living arrangements. However, such anticipated progress in the move to community based settings has been slow and while still far from completion, deinstitutionalisation continues to be a central component of discourse

within Irish society. Indeed progress in developing, implementing and evaluating policies has varied across countries internationally with Canada taking the lead on closing institutions and developing policy frameworks so that individuals with can be successfully integrated into their communities. Reviewing and learning from the implementation of such policy developments in other countries, Irish policy makers have subsequently aligned Irish policy philosophies and developments with Canadian policy. The following presents an overview of policies in the United Kingdom, Ireland and Canada, who are all currently operating at variable levels of policy development and implementation.

2.3 'Choice' for people with intellectual disabilities in UK, Ireland and Canada

The United Nations Convention on the Rights of Persons with Disabilities (UNCRPD 2006) has been the international springboard to develop policies which facilitate those with disabilities to live in their communities and enjoy the same opportunities as the general population. Progress in developing, implementing and evaluating such policies has varied across countries. The following presents an overview of policies in the United Kingdom, Ireland and Canada, who are all currently operating at variable levels of policy development and implementation.

2.3.1 'Choice' in United Kingdom policies for people with learning disabilities

The four United Kingdom countries have devised individual policies on how the needs of people with learning disabilities are supported. However, the aims of the policies are similar in nature, reflected in the broad themes of 'having choices and making personal decisions', 'having equal rights', 'citizenship', 'social inclusion and empowerment', and subsequent to the implementation of such policies, the overall quality of life of people with learning disability continues to improve. The word 'choice' is amply represented in UK policy for people with learning disabilities as presented in Table 2-1:

Table 2-1 An overview of 'choice' in UK policy for people with learning disabilities

Scotland	Northern Ireland	Wales	England
The same as you? (Scottish Government 2000).	<i>Equal Lives: Review of Policy and Services for people with a Learning Disability in Northern Ireland</i> (Bamford 2005)	<i>Fulfilling the Promises</i> (Learning Disability Advisory Group 2001)	<i>Valuing People – A new strategy for Learning Disability for the 21st Century</i> (Department of Health 2001)
A review of services for people with learning disabilities. Principles that people: be valued, not treated differently from others, asked for their opinions, be involved in making choices, be supported to do everything they are able to; be able to use the same local services as everyone else, benefit from specialist social, health and educational services, have services which take account of their age, abilities and needs (14 references to choice)	A review of policy and services for people with learning disability – compilation of consultations, research and analysis. A wide range of proposals for improving the lives of people with a learning disability and their families based on the key values of: Citizenship, Social Inclusion, Empowerment, Working Together, Individual Support (17 references to choice)	A service framework prepared by the Learning Disability Advisory group setting out the vision and guidelines, principles, the policy context, priorities, performance indicators and an action plan to ensure the highest standards of service to people with learning disabilities (13 references to choice)	A Government strategy of which the main emphasis is that people with learning disabilities will live a full and independent lives as part of their local communities underpinned by key principles of rights independence, choice and inclusion (28 references to choice)
<i>The Keys to Life: improving life quality for people with learning disabilities</i> (Scottish Government 2013)		<i>Statement on Policy and Practice for Adults with a Learning Disability</i> (Welsh Assembly Government 2007)	<i>Valuing People Now: a new three-year strategy for people with learning disabilities Making it happen for everyone</i> (Department of Health 2009)
A ten year Government strategy of which the main emphasis is health. The majority of over 50 recommendations made are aimed mostly at health whereas others involve varying degrees of participation in working with other agencies and one recommendation is solely for local authorities (33 references to choice)		A Government statement on policy and practice for adults with learning disabilities reaffirms key rights: to an ordinary pattern of life; treated as individuals; the provision of additional support maximising potential. Aims for equality independent living and support to develop potential (12 references to choice)	A Government strategy restating commitment to so that people with learning disabilities access the same aspirations and life choices as other people driven by a human rights based approach aims to ensure that the Governments vision is made a reality (34 references to choice)

All of the above documents have been instrumental in contributing to more meaningful choice experiences, more specifically in providing guidance for people with learning disabilities and their

supporters. Other policies for people with general disabilities have similarly contributed to improving choice experiences for people with learning disabilities. For instance, the Improving the Life Chances of Disabled (Office of Deputy Prime Minister 2005) (UK Government's 2005 cross-departmental report), set a goal that by 2025:

"...disabled people in Britain should have full opportunities and choices to improve their quality of life and will be respected and included as equal members of society.."

(ODPM 2005, p.4)

And the basic principle of Independence, Well-being and Choice (Department of Health 2005) is that everyone would have a right to have control in their lives. The Office of Disability Issues (ODI) in England published the Government's cross-departmental Independent Living Strategy (ILS)(Office of Disability Issues 2008) aimed to fill the gap between national policy and people's real experiences by promoting the involvement of disabled people of all ages in the planning and delivery of services, thus ensuring that:

"...individuals are supported in the ways that they choose and barriers to access removed.."

(ODI 2008, p.3)

To enable people with disabilities to have greater choice and control over their care packages, pilot schemes, such as the "Right to Control Trailblazers" were introduced by means of the Disabled People's Right to Control Regulations 2010 (Pilot Schemes, England). The implementation of these pilot schemes aimed to ensure that people with disabilities were facilitated to combine available supports from different sources. The evaluation of these pilot schemes subsequently identified current issues for policy makers (Office for Disability Issues 2013). The development and implementation of such policy is shaped by current matters, such as demographic factors, ageing populations, economic climates, and the cost effectiveness of facilitating long term care provision while meeting the needs and aspirations of public (Rabiee and Glendinning 2010).

There is consensus in the literature that increased participation in society as equal citizens with emphasis on choice and self-determination ultimately improves the lives of those with learning disabilities (Lotan and Ells 2010, p.114). The policy frameworks of the United Kingdom reflect a governmental emphasis on providing people who have (learning) disabilities with more choice in and control over their lives and increasing participation in their communities. While the Scottish Government (2013) have mostly focused recommendations on the healthcare aspects of people with learning disabilities, the remit of the English Government (DOH 2009) and Welsh Assembly Government (2007) have been driven mostly by the rights-based agenda. Nonetheless, the drive for the implementation and evaluation of these new policy frameworks has energized agendas for the

reconfiguration of services for people with learning disabilities and idealistically, policy is a driving force for which enables those with learning disabilities to have choices and to control those choices, whether the focus is on rights to independence or health care. But evidence is limited in answering the question posed by Antaki et al (2009) as to what does everyday choice look like in actual practice?

2.3.2 Choice in Irish policies for people with intellectual disabilities

Ireland has made progress in generic disability strategies developed by organisations which promote the rights of Irish citizens (NDA 2012; NDA 2012a; NDA 2011). From a policy perspective, the United Nations (1993) standards on equality proved to be the inducement for Ireland to take action to improve the lives of people with disabilities. The subsequent establishment of the Commission on the Status of People with Disabilities (1996) resulted in the policy and legislation guiding principles of equity, choice, independence and participation. Service provision for people with intellectual disabilities was also restructured, underpinned by the introduction of policy changes which were monumental in ensuring access to mainstream services for people with disabilities, and so providing opportunities for them to participate in mainstream society.

Many subsequent legislative acts continued to generate greater choice opportunities for people with disabilities in the context of; health (DOHC 2001); education (EPSEN 2004); access (Disability Act 2005); information and advice (CIA 2007), and equality through the Equal Status Acts, 2000-2008 (Equality Authority 2011).

The Independent Living Strategic Plan (CIL 2013-2015) stipulates that people with disabilities should be facilitated to access the same choice opportunities as those without disabilities. Time to move on from Congregated Setting: a strategy for Community Inclusion (HSE 2011) asserts that people with disabilities should be able to exercise meaningful choices when deciding whom to live with and where to live. And aiming to achieve this ideal the National Housing Strategy for People with Disability 2011-2016 (DECLG 2011) prioritises the need for people with disabilities to enjoy choice and independence by having access to appropriate housing and supports.

Further initiatives and guidelines influential in promoting the choice agenda with and for people with disabilities have been published through the National Disability Authority (NDA 2012; NDA 2012a). Your Voice Your Choice (NDA 2012a) demonstrates that choice is closely aligned with independence by people with disabilities stressing concerns of equality, maximizing potential, and making meaningful contributions to community life.

Unfortunately, while the need for a strategy specifically for people living in Ireland with intellectual disabilities continues to be advocated for (NFVB 2009), Needs and Abilities (GOI 1990) was the most recent Irish policy document published to make such provisions. Support groups lobbying for people with disabilities, especially for those with intellectual disabilities, have long awaited improved standards and the auditing of such services which are finally being implemented under the auspices of the Health Act (2007), wherein The Health Information and Quality Authority (HIQA) have devised the ‘National Standards for Residential Services for Children and Adults with Disabilities’ (HIQA 2013). Auditing of such services is aimed at monitoring person-centred approaches to care where each person is supported to exercise choice and control in the daily realities of making choices in accordance with their stated preferences. However, in the absence of current specific intellectual disability policy and strategies, progress in Ireland in supporting people with intellectual disabilities to live lives as equal citizens in society continues to be slow.

2.3.3 ‘Choice’ in Canadian policies for people with intellectual disabilities

Canada has been progressive on developing and implementing generic disability policy frameworks and Canadian human rights laws and the Canadian Charter of Rights and Freedoms (CCRF) (1982) in accordance with equality rights, recognizes that every citizen is equal under and before the law and have the right to equal benefit and equal protection, without discrimination on the basis of mental, sex or physical disability (Kelly 2013). Specifically, the Charter insists that denying any individual access to facilities/services or differentiating on disability grounds, is a discriminatory practice. Examples of Canadian policy frameworks are presented below in Table 2-2:

Table 2-2 Overview of ‘choice’ in Canadian policy

Canada	
In Unison (Government of Canada 1998)	Sets a blueprint for promoting the integration of persons with disabilities in Canada. To make as inclusive as possible all domains of Canadian society (GOC 1998).
Advancing the Inclusion of People with Disabilities (Human Resources and Social Development Canada, 2009).	This report provides invaluable information to support all levels of government, associations, researchers and non-governmental organizations in designing and planning services to enable people with disabilities to participate fully in society.
Obstacles (HOC, 1981), Report of the Royal Commission on Equality in Employment (Abella, 1984), and Pathway to Integration (1993)(Federal/Provincial Territorial Review of Services Affecting Canadians with Disabilities (1993)	In combating discriminatory practices such reports as were influential in creating deinstitutionalization and furthering opportunities for integration.

Canada Health Act (CHA 1985)	Set the primary objective of Canadian health care policy <i>"to protect, promote and restore the physical and mental well-being of residents of Canada and to facilitate reasonable access to health services without financial or other barriers."</i> (CHA 1985, p.5).
Accessibility for Ontarians with Disabilities Act (Government of Ontario 2005)	Sets the objective that Ontario would be accessible for people with disabilities by 2025 (Government of Ontario 2005).
The Canadian Association for Community Living (CACL) (2007)	Adopted a ten-objective agenda to guide Canadians in achieving a more inclusive Canada and the vision of the priority area of closing institutions was that <i>'people live in homes of their choice, with appropriate supports'</i> (CACL 2007, p.4).
The Framework for Documenting Equality Rights (CHRC 2010) and the Report on Equality Rights of People with Disabilities (CHRC 2012)	Presented a national portrait of people with disabilities compared to people without disabilities based on seven dimensions of well-being, namely; health, economic well-being, education, employment, housing, justice and safety, and political and social inclusion (CHRC 2010; CHRC 2012)

However, in Canada, variations arise according to jurisdictions and provinces with regard to strategies and policies used to implement the national and international legislation. Table 2-3 presents an overview of policy in Nova Scotia:

Table 2-3 Overview of 'choice' in Nova Scotia policy

Canada Nova Scotia	
Putting People First Working Together to Support Independence and Dignity (Government of Nova Scotia 2013)	Considers that generally people take living independently for granted, including how they make daily choices, and acknowledges that there simply aren't enough choices being offered for individuals in need at all age levels, concluding that Nova Scotians <i>'deserve more options and choices'</i> (GONS 2013, p.2).
And Putting People First: What We Heard (Government of Nova Scotia 2013a)	proposals and possibilities for appropriate supports and conditions which would enable citizens to have <i>".... more choice, and stronger, more socially inclusive communities"</i> (GONS 2013a, p.5)
Choice Equality and Good Lives in Inclusive Communities A Roadmap for Transforming the Nova Scotia Services to Persons with Disabilities Program (Government of Nova Scotia 2013b)	laid out a 'Roadmap' for redesigning the program with Goal 1: <i>"Greater self-direction, choice and control"</i> (GONS 2013b, p.7).
Building Community and Affordability for Nova Scotia Families A Housing Strategy for Nova Scotia (Government of Nova Scotia 2013c)	aims to: <i>"ensure that Nova Scotians can find the housing choice that's right for them and their families, at a price they can afford, in a healthy, vibrant community that offers the services, supports and opportunities they need"</i> (GONS 2013c, p.13).

For individuals with intellectual disabilities, there is a recognized shift to a human rights framework in care provision in Canada (Boone 2013). For example, in addressing the special education needs of children the Education Amendment Act (1980), Bill 82, the Ministry of Education (2013) and Gallagher-Mackay and Kidder (2014) have been influential in promoting opportunities for inclusive education for children with disabilities. However, intellectual-disability specific policy linked mostly with social welfare policy has been fragmented in nature.

For example, in British Columbia, under the remit of the Community Living Authority Act (CLAA 2004) the British Columbia Community Living Action Group (BC-CLAG) has responsibility for overseeing the delivery of services to people with intellectual disabilities and in 2011 published *Reaching Out Weighing In. A Report on the Skills & (Dis)Abilities Meetings to Address the Community Living Crisis in B.C.* One of the recommendations of the report is to:

“Re-centre the community living support system.....by promoting choice in service options and inclusion in planning processes”

(BC-CLAG 2011, P.5)

Canadian social policy recognised inaccessible and inadequate healthcare services as a health disparity experienced by people with intellectual disabilities (Beiser and Stewart 2005). With the remit of accrediting healthcare and social services, Accreditation Canada in 2010 established a set of standards for people who provide services to people with intellectual disabilities. The Developmental Disability Primary Care Initiative in Canada (DDPCIC) subsequently developed a set of peer-reviewed guidelines and tools to guide healthcare delivery to people with intellectual disabilities (DDPCIC 2011). Interestingly, Ervin et al (2014) propose that standards of care for people with intellectual disabilities and their families need to be extended to accommodate the unique healthcare needs of people with intellectual disabilities. They further assert that these standards should integrate concepts of self-direction and self-determination, and reflect the need for and benefits of integration. To date, quality of life measurements have been widely accepted as a policy decision tool for governments to evaluate whether the needs of individuals with intellectual disabilities are currently being met (Schalock and Verdugo 2012; 2011; Townsend-White et al 2012). Yet, in the absence of evidence of Canadian rights-based experiences inclusive of people with intellectual disabilities, the extent to which the rights of this group of people are actually realized remain unclear. Nonetheless, legislation such as the Social Inclusion Act (2008) has also contributed to paving the way for more choice opportunities for adults with intellectual disabilities by facilitating access to services and supports.

2.3.3.1 Social Inclusion Act (2008)

Passed in Ontario, the Social Inclusion Act (2008) entitled *Services and Supports to Promote the Social Inclusion of Persons with Developmental Disabilities Act*, was intended to enable people with intellectual disabilities to exercise more independence, have greater decision-making power over their

day-to-day lives, and ultimately live as full citizens in communities of their choosing by shifting the developmental services sector away from institutionalized care and towards a system of services and supports (Joffe 2010, p.5). The Quality Assurance Measures (QAM) which accompany the act advocates for the “....promotion of social inclusion, individual choice, independence and rights..” (QAM 2011, p.2). Furthermore “About The Services and Supports to Promote the Social Inclusion of Persons with Developmental Disabilities Act (2008)” highlighted the provisions of “more independence and choice” (Ministry of Community and Social Services (MCSS) 2009, p.3).

While positive changes which enabled people with intellectual disabilities and their families to have more choice and control over the services they received were introduced, Joffe (2010) noted the absence in the legislation of rights with regard to services and supports for people with intellectual disabilities and the lack of robust mechanisms to enforce such rights. Joffe (2010) advocates that all citizens have ensured choice and control over the services they receive. Table 2-4 presents Joffe’s recommendations:

Table 2-4 Recommendations for services to enable 'choice' and 'control'

• Right to live free from discrimination, harassment, abuse and neglect • Right to be provided services and supports provided so that a person’s individuality is recognized and which is responsive to the person’s needs and preferences, including preferences based on familial, ethnic, spiritual, linguistic, gender and cultural factors • Freedom of choice regarding activities of daily living, choices about food, clothing, personal appearance and participation • Right to be informed in writing (or other accessible method) of programs and services and the laws, policies and complaint procedures that govern them. • Freedom to choose which services and supports to access • Right to enjoy personal privacy, such as the right to have private telephone conversations and to receive visitors of the person’s choosing. • Right to be free from confinement or restraint, except as provided for by the Act and regulations, and to have personal decisions respected. • Right to receive information about an individual’s rights in plain language and an accessible format. • Right to raise concerns, complain and/or recommend changes about services and supports without interference, fear of reprisal or retaliation. • Right to effective ways to enforce these rights, and a right to receive information about these enforcement mechanisms. • Right to access or be referred to advocacy support services or legal services for appropriate representation. (Joffe 2010)

Joffe (2010) highlights the necessity of the underlying principles of accountability, accessibility, participation and independence, and all-encompassing of respect for human dignity, as the foundational elements of a human rights based approach to enforcing service rights.

The above presented an overview of choice with regard to fundamental and service rights, relevant to people with disability. To date, the UK and Canada have been progressive in developing both generic and intellectual/learning disability specific policies. Ireland has been progressive in developing generic policies for people with disabilities emphasising human rights in social care provision (Inclusion Ireland 2013; NDA 2011a; 2012a,b), but unfortunately these policies are conspicuously silent in the context of making provisions specifically for people with intellectual disabilities (Carey and Griffiths 2014). Choice and decision making are also embedded in capacity legislative frameworks which have a profound impact on the choice-making agency of people with intellectual disabilities.

2.4 ‘Choice’ and decision making policy and legislation

The European Commission on Human Rights and the United Nations have been the main drivers for the development of decision making policy and legislation in promoting the rights of people whose mental capacity could be questioned, with the onus on individual countries to ensure that appropriate legislative frameworks are set in place. Such policy and legislation impacts immensely on how people are supported to make choices when their intellectual capacity might be questioned. And, how these approaches are interpreted and implemented will significantly influence choice opportunities and decision-making experiences of many people with intellectual disabilities. The following examines the capacity legislation in the United Kingdom, Ireland and Canada.

2.4.1 Capacity legislation in the United Kingdom

The following Table 2-5 presents an overview of capacity legislation in the United Kingdom.

Table 2-5 Overview of capacity legislation in the United Kingdom

Country	Bill/Act	Supporting documentation
England and Wales,	Mental Capacity Act (MCA) (2005)	Deprivation of Liberty Safeguards (Ministry of Justice, 2008) <i>Whose decision? Preparation for and implementation of the Mental Capacity Act in statutory and non-statutory services in England and Wales</i> (Myron et al 2008)
Scotland	Adults with Incapacity (Scotland) Act (2000) Mental Health (Care and Treatment) (Scotland) Act (2003) Adult Support and Protection (Scotland) Act (2007)	Adult Support and Protection (Scotland) Act (2007) Code of Practice (2014)
Northern Ireland	Mental Capacity Bill (MCB) (2014)	Guidance on Consent to Treatment (2003).

The legislative documents above set the United Kingdom agenda which influences how people are supported to make choices when their intellectual capacity might be questioned. While the legislation stipulates the fact that people with intellectual disabilities need support to make some decisions, there is agreement that the mental capacity of people with intellectual disabilities may prevent them from making other life decisions (Duffy 2011; Wong et al 2000, p.307). This implies that some decisions may need to be made for this group of people. The Mental Capacity Act (MCA) of 2005, applicable in England and Wales, emphasizes the need for every adult to make their own decisions, unless it is proved they have no mental capacity to do so (Werner 2012). Interestingly, Myron et al (2008 , p.6) indicate that should there be restraints on choices, these restraints should least infringe on the rights and freedoms of people without capacity. Arguably, in the context of people with learning disabilities, the issue drawing most debate is how best to support people in decision-making, while upholding their rights. All four countries in the UK have ratified the United Nations Convention. Ireland has not yet done so.

2.4.2 Capacity legislation in Ireland

European Convention on Human Rights Act (2003), coupled with the international perspective of the UNCRPD (2006) have been the main drivers for the development of capacity legislation in promoting the rights of people whose mental capacity could be questioned. These legislations stipulate that people with intellectual disabilities need support to make some decisions, with the primary focus being to support these people to exercise legal capacity. There is also agreement that the mental capacity of some people with intellectual disabilities, at certain times for certain choices, may challenge or prevent them from making other life decisions, again implying some decisions may need to be made for this group of people (Centre for Disability Law and Policy (CDLP) 2011).

On the 30th of March 2007 Ireland was amongst the first signatories of the UNCRPD (2006). However, Ireland has been greatly challenged to ratify the convention due to its out-dated laws governing decision making, namely the Lunacy Regulations Act (1871) and Ward of Court System, which primarily functioned to find lack capacity in people in order to remove all decision making rights from them (Doyle and Flynn 2013). In 2008 the Irish government proposed the Scheme of Mental Capacity Bill (2008), but this was highly criticised and rejected by groups campaigning for people with (intellectual) disabilities. In reconsidering the need to redress the deficits in the legislation, the Irish government responded with the introduction of the Assisted Decision-Making (Capacity) Bill (ADMB) (2013), (hereafter referred to as the Irish Bill) which introduces many important reforms, supporting people in making their own decisions, and which is paving the way for

Ireland to ratify the United Nations Convention on the Rights of People with Disabilities (UNC RPD 2006). While the primary focus of the UN convention (UNC RPD 2006) is that people with disabilities are supported to exercise their rights, there remains agreement that some people with intellectual disabilities need support to make some decisions, and others need some decisions made for them (CDLP 2011). While not without its detractors, there is a general consensus the Bill has been welcomed (CIB 2013; MHR 2014; Quinn 2013) as it is regarded as an improvement on the previous Scheme of Mental Capacity Bill (2008). While the Irish Bill (ADMB 2013) has been passed by the Irish Government, it has yet to be enacted, a step which will bring Ireland closer to being in a position to ratify the UN Convention (UNC RPD 2006).

2.4.3 Capacity legislation in Canada

Canadian human rights law reflects similar principles as those set out in the UNC RPD (2006), promoting opportunities for individuals to make life choices through ensuring respect for the inherent dignity of people with disabilities and facilitating full and effective participation in society, through opportunities for accessibility resulting in greater independence (Joffe 2010). Under Canadian human rights laws, which have no explicit emphasis on the need to have capacity to exercise human rights, most Canadian citizens routinely avail of choices to vote, get married, buy a house, set up a bank account, and so on. However, for Canadian citizens whose capacity maybe questioned, individual jurisdictions and provinces develop and maintain responsibility for their own capacity legislative frameworks. Thus the development, implementation and governing of these capacity legislative frameworks are therefore variable across Canadian jurisdictions, as typified by the Ontario, Substitute Decisions Act (1992), the British Columbia Representation Agreement Act (RAA 1996) and the Manitoba, Vulnerable Persons Living with a Mental Disability Act (VPLMDA 1993). Drawing on the above mentioned capacity legislative frameworks the following discussion considers the implications, support structures and monitoring of decision-making capacity for those with intellectual disabilities.

The capacity legislation in the United Kingdom has been active in progressing agendas which support people whose capacity could be questioned focusing on the assessment of capacity as the determining factor, whereas Canada and Ireland have focused on supported decision-making models. The central debate centres on the decision-making capacity of the person.

2.5 Decision making capacity

Debates regarding the interpretation of what capacity actually is, and whether or not capacity should be assessed are synonymous with discussions of capacity legislation, as those people who formulate, and implement capacity legislation are continually making judgements about others' abilities and capabilities to make decisions.

While acknowledging the need for presumption of capacity, the Irish Bill (ADMB 2013), interprets 'capacity' to mean 'mental capacity' and then specifies criteria for 'lack of capacity'. For example, a person lacks capacity to make a decision if s/he is unable to:

- (a) to understand the information relevant to the decision,*
- (b) to retain that information,*
- (c) to use or weigh that information as part of the process of making the decision, or*
- (d) to communicate his or her decision (whether by talking, writing, using sign language, assisted technology, or any other means) or, if the implementation of the decision requires the act of a third party, to communicate by any means with that third party*

(ADMB 2013, 3(2))

Similarly, in the UK, the England, Wales and Northern Ireland capacity legislation identify the terms 'capacity' and 'mental capacity' are also limiting in the provision of definitions, while the Scottish In(capacity) legislation, pioneering at the time of its introduction, uses terms of incapacity and incapable making no reference to 'capacity' or 'mental capacity'. For example while, the Irish and UK capacity legislation provide criteria for 'lack of capacity', significantly neither make reference to the terms 'presence of capacity' or 'capability', Canada capacity legislation identifies terms 'capacity' and 'mental capacity' but is limited the provision of definitions for the same, while the term 'legal capacity' is absent. With regard to the interpretation of legal capacity law in Canada, specific reference is made to a person's cognitive functioning. For example, in Ontario, aligned with the Substitute Decisions Act (1992), the 'Guidelines for Conducting Assessments of Capacity' (Ministry of the Attorney General 2005) defines capacity in the context of whether or not an individual demonstrates an understanding of information and an appreciation of reasonable consequences, which are associated with either making or not making a decision.

Traditionally, when questions have arisen regarding a person's capacity, assumptions of capacity have been based on the 'status approach' and the 'outcomes approach' which determine whether a person is regarded as being 'incapable' based a specific disability or action. More recently, the functional test

of mental capacity has been regarded as a more appropriate approach in the assessment of mental capacity. Interestingly, Quinn (2013) debates the wisdom of using a functional test to assess mental capacity as set out in Section 3 of the Irish Bill, rather believing that an assessment of current mental capacity should be utilised as the driver for stipulating support options to enable a person to exercise legal capacity.

In light of Quinn's misgivings as set out in the above, the promotion of the requirement for assessment and recording of capacity in the Northern Ireland capacity legislation could be regarded as being discriminatory in its nature and approach. While not stipulating the need for a capacity assessment at the outset, the capacity legislation in England and Wales does acknowledge that when a person's capacity is questioned, it is the balance of probabilities that leads to the defined outcome as to whether the person has or lacks capacity (MCA 2005, p.2). Paradoxically the absence of reference to capacity assessment from the Scottish capacity legislation could also be regarded as discriminatory in nature as the remit of the Act is embedded in the deficits model approach assuming that the person is 'incapable'.

Similarly capacity legislation in Canada is variable. For example, in Ontario, the Substitute Decisions Act (SDA 1992) initially provides criteria for incapacity to manage property determined when the person is unable to understand information relevant to the decision of managing his/her property, or is not able to appreciate the reasonably foreseeable consequences of a decision or lack of decision (SDA 1992, 6). In the same way, incapacity to make a decision regarding personal care is determined when a person is not able to understand information that is relevant to making a decision concerning his/her own healthcare, nutrition, shelter, clothing, hygiene or safety, or is not able to appreciate the reasonably foreseeable consequences of a decision or lack of decision (SDA 1992, 45). Conversely, the Act does provide criteria for 'capacity to give continuing power of attorney' for property (SDA 1992 8(1)), and for personal care (SDA 1992, 47(1)). For example, capacity criteria with regard to personal care, is fulfilled when the person demonstrates ability to understand whether the proposed attorney has a genuine concern for the person's welfare, and secondly, appreciates that the person may need to have the proposed attorney make decision for the person (SDA 1992, 47(1)).

In Manitoba, the Vulnerable Persons Living with a Mental Disability Act (VPLMDA 1993) indicates that unless demonstrated otherwise, vulnerable persons are presumed at the outset to have the capacity to make decisions affecting themselves, and that the persons support network should be encouraged to

assist the vulnerable person in making decisions so as to enhance his/her independence and self-determination. Incapable is taken to mean mentally incapable and incapacity is seen to have a corresponding meaning to being incapable. Similar to the Substitute Decisions Act (1992) criteria for incapacity with regard to personal care (VPLMDA 1993, 46) and management of property (VPLMDA 1993, 81) is applied to a person who is unable able to understand information or appreciate reasonably foreseeable consequences, or does not make a decision relevant to the choice available. While the Manitoba Act does not specifically mention any test/assessment (of capacity), it indicates that when a person is unable to make decisions by himself/herself or with support, substitute decision-making should be invoked as a last resort.

However, in British Columbia, the Representation Agreement Act (RAA 1996) aims firstly to allow adults to make advance arrangements about how, when, and who shall make decisions about their personal care or health, or routine financial affairs should they become incapable of making decisions independently (RAA 1996, 2(a)) and secondly, aims to avoid the need for the court to appoint someone to help adults make decisions, or someone to make decisions for adults when they are incapable of making decisions independently (RAA 1996, 2(b)). Importantly, there is an acknowledgement that it is not mandatory for all adults to have representation agreements, and once there is a presumption of capacity that the person can make the decision to appoint a representative, the adult does so. Considerations for capacity determination, are framed taking into consideration, firstly, whether the adult communicates a desire to have a representative (RAA, 1996 8, 2 (a)), secondly, whether the adult demonstrates choices and preferences and expressing feelings (RAA 1996, 8, 2 (b)), thirdly, whether the adult demonstrates awareness that he/she is giving power to the representative with regard to his/her decisions (RAA 1996, 8, 2 (c)), and fourthly, (d) whether the adult trusts the representative being appointed (RAA 1996, 8, 2 (d)). The standard provisions as set out in section 7 (RAA 1996,7,1) indicate that an adult may authorize his/her representative to help the with decisions, or to actually make decisions regarding personal care, routine management of financial affairs, major and minor health care decisions on behalf of the adult obtaining legal services. Decisions under section 9 Non-Standard Representation Agreements are relevant to choices of where and who the person lives, employment, education, vocational, and who the person has contact with, diet, dress or health. The need for a test to assess capacity arises with regard to Non-Standard Representation Agreements as set out in section (RAA 1996, 9, 1) where it is proposed that unless the adult is incapable of understanding the nature and consequences of the proposed agreement, an adult may authorize a representative to do any or all of the things referred to in section 9 (RAA 1996, 10).

People with intellectual disabilities often fall under the remit of ‘questionable capacity’ and therefore their right to exercise ‘legal capacity’ is often based on being subjected to a variety of tests, which determine the presence or absence of the pre-requisite of ‘mental capacity’. Arguably, for those who are found to lack the mental capacity to make a decision at a defined time and place, and are unable to make a choice, an assessment can be the first step in putting the necessary safeguards in place. Conversely however, there is a clear indication that the determination of whether or not a person has the capacity to make a defined decision at a set time and place sets the foundations for either enabling or disabling the person in having the freedom to choose. For example, should a person be found to be incapable of making a decision, s/he is often denied the right to exercise individual autonomy in the context of meaningful choices as capacity legislation can become enshrined in determining courses of action through guardianship implemented and based on principles of ‘best interest’ (SDA 1992; VPLMDA 1993).

The ratification of the UNCRPD, has forced Canadian citizens to re-think the philosophical underpinnings of the mental health laws which govern the country. The Canadian government is now challenged with ensuring maximization of a person’s legal capacity in the face of serious adverse effects as current adult protection and mental health laws in Canada do not effectively meet the needs of people with disabilities in promoting their full right to legal capacity, while at the same time, safeguarding people considered to be vulnerable (Bach and Kerzner 2010). Taking into consideration the definition of serious adverse effects as specified in Ontario’s Substitute Decisions Act (SDA 1992) and the need to enable a person to retain legal capacity, Bach and Kerzner (2010, p.133) suggest a revised definition of serious adverse effects as follows:

A situation of serious adverse effects occurs when a person, as a result of his/her actions or those of others:

- *experiences loss of a significant part of a person's property, or a person's failure to provide necessities of life for himself or herself or for dependants; or*
- *experiences serious illness or injury, and deprivation of liberty or personal security; or*
- *has threatened or attempted or is threatening or attempting to cause physical and/or psychological harm to himself or herself; or*
- *has behaved or is behaving violently towards another person or has caused or is causing another person to fear physical and/or psychological harm from him or her*

(Bach and Kerzner, 2010, p.133)

In re-evaluating Canadian adult protection and mental health laws in the context of the UNCRPD, Bach and Kerzner (2010) outline a definitional and institutional framework to address issues arising in

the context of serious adverse effects. Firstly, respect for personal choice, dignity and integrity must not be undermined, but rather balanced with a duty to ensure safety. Secondly, the paramount recognition that in situations of adverse effects access to appropriate supports and accommodations must be made available to the person enabling them to exercise their legal capacity. Thirdly, the assessment of serious adverse effects must not be applied in a discriminatory manner (Bach and Kerzner 2010).

In the Irish Bill (ADMB 2013), provisions are made for supportive decision-making where a person whose capacity is in question is enabled to nominate an assistant decision-maker and engage in an assistant decision making agreement (ADMB 2013). The Representation Agreement Act (1996) also creates provisions, which enable the person to enlist support to make decisions. On a finding of incapacity the Substitute Decisions Act (1992), provides for legislative approaches with the focus on substitute decision-making involving decisions being made by one person on behalf of another, either through the role of being a guardian (substitute decision-maker) or through establishing a power of attorney (planning document), and where, prior to a state of incapacity the person nominates person(s) to make decisions on his/her behalf. Nonetheless, while the Irish Bill (2013), has made immense strides in promoting the rights of those whose capacity may be questioned, Quinn (2013) presents a compelling argument that, in the continued absence of the term 'legal capacity', the ultimate implementation of the Irish Bill will not function in congruence with Article 12 of the UNCRPD (2006). Similarly, as a precondition of making a decision, Canadian laws generally require, that an individual possess a requisite level of decision-making ability. When the demonstrated level of decision-making ability does not meet the requirements, the law necessitates that a substitute decision-maker make decisions on behalf of the person.

As with the England and Wales, and Northern Ireland capacity legislation, Section 40 of the Irish Bill correspondingly permits individuals to create an enduring power of attorney, to take effect when persons are deemed either currently, or in the near future, to lack capacity. Quinn (2013) criticizes the conceptualization of this section as primarily adopting a deficits model approach of mental capacity which commences by portraying the person with deficits rather than rights (e.g. by stating that at a certain point when a person loses all decision-making skills, and these cannot be regained). In Quinn's opinion such a deficits model approach conflicts with Article 12 of the UNCRPD (2006) and requires change so that the section on enduring powers of attorney cannot commence based on a person lacking capacity (Quinn 2013). Nonetheless the Mental Health Reform (MRH 2014) have embedded their submissions in highlighting the deficit model approach to mental capacity to identify gaps in the legislation, by stipulating that the needs of 'incapacitated but compliant patients' (MHR 2014:11) are not adequately addressed in the Irish Bill.

Persons within the Wards of Court Scheme in Ireland may currently reside within approved centres, or social care settings, some with minimal family involvement or circles of support. With specific regard to Part 5 of the Irish Bill there is an urgent need to review need for urgency in having current Wards of Court cases and instantiate appropriate structures, to ensure that Wards of Court are supported to exit this scheme and exercise their legal capacity (Quinn 2013; CIB 2013; MHR 2014). Ensuring adequate support mechanisms for these people will inhibit the development of other forms of substitute decision-making (Quinn 2013; CIB 2013). Similarly the Mental Health Reform (2014) requests:

“an amendment of Part 5 of the Bill to ensure timely review of all wards of court and transition of persons from wardship to the decision-making structures of the Bill or full discharge from wardship as appropriate”

(MHR 2014, p.7)

Notably, whether or not people are under the remit of the Wards of Court Scheme, many people who access services in compliance with service expectations, may experience deprivation of liberty. Those with intellectual disability are particularly vulnerable, and may or may not be aware that their liberty is deprived and/or may have differing levels of knowledge with regard to their rights.

From a mental health perspective Part 9 of the Irish Bill covers detention orders and safeguards for persons either with a mental disorder (where the Mental Health Act, 2001 applies) and/or persons who are in institutions by order of a wardship court. In the context of detainment as referred to in the Irish Bill, Quinn (2013) recommends that changes in the legislation be made which reflect the extensiveness of the current realities of detainment as experienced by persons living in approved centres, along with those currently residing in social care settings, some against their will. According to Quinn (2013) an exact definition of deprivation of liberty, clear procedures for implementation of and monitoring of same, as well as opportunities for redress of detainment, all need to be inserted for compliance with the UNCRPD. While in cautioning with regard to the role of ‘informal decision-makers’ the Mental Health Reform (2014) goes further to specify ‘restraint’ and ‘potential overuse of medication’ as substantial issues which must be addressed within the context of the Irish Bill. The insertion of provisions for making decisions regarding deprivation of liberty will act as a protective and safety mechanisms both for people whose capacity may be questioned and informal decision-makers.

Interestingly, while both the UK and Ireland are grappling with how to incorporate mental health legislation with capacity legislation, Northern Ireland has initiated the development of a single legislative framework, namely the Mental Capacity Bill (MCB) (2014), which attempts to reform the existing mental health legislation while introducing mental capacity legislation.

As many countries are developing and implementing capacity legislation there is little doubt that law and policy makers, service providers, support persons and people with intellectual disabilities are trying to navigate the best way forward in the context of such a contentious issue as decision-making capacity. While the capacity legislation has greatly progressed, the agenda of protecting the rights of people whose capacity may be questioned, a primary challenge for law-makers is to present legislation which guarantees that provisions created to promote the capability of the person is first and foremost.

2.6 Support structures

Capacity legislative frameworks are tasked with ensuring that when capacity is in question, the person gets sufficient support to make a decision, while also ensuring that the person is enabled to have optimal control with regard to the choice being made. In Ireland and the UK, when a person's capacity is questioned, capacity legislation provides criteria for support persons and support structures.

In Ireland, the Irish Bill (ADMB 2013) identifies differing types of decision-making support persons, aligned with differing types of decision-making arrangements. Support persons can be informally appointed by the person with an intellectual disability or relevant others, and indicate differing levels of support required by the person when decisions are being made. Interestingly, the Irish Bill (ADMB 2013) identifies differing types of decision-making support persons, for example, informal decision-makers are people who fall within the remit of the person's circle of support, and are not formally appointed by the person or the courts and are not subject to monitoring by the Office of the Public Guardian. Assistant decision-makers are chosen by the person, and are people whom the person trusts to assist them with making one or more current and/or future decisions in relation to their properties, affairs or personal welfare. The Office of the Public Guardian must to be informed of the nature of the agreement but no court application is necessary. Co-decision makers are formally appointed by the person or by the courts and 'jointly make' decisions with the person. Co-decision making agreements need to be approved by the court and are legally effective. Decision-making representatives are regarded as 'substitute decision makers', and are appointed by the courts. The court can also appoint a 'court friend' for a person requiring assistance to present their case in court. Additionally, the person can create an instrument containing a statement of enduring powers of attorney to come into effect should the occasion arise that s/he lacks capacity to make decisions. As the Irish Bill (ADMB 2013) has only recently been introduced, evidence of the utilization of such

supports and their impact on how people with intellectual disabilities experience such support when making choices as recommended in the bill are not yet published.

Concerns regarding the inherent powers within the roles undertaken by those who support a person to make decisions are raised primarily in the context of 'informal decision-makers'. And while the supports that family members and relevant others provide for people whose capacity may be questioned are not in question, valid concerns are raised regarding the wide range of powers afforded to people who undertake the role of 'informal decision-makers' under the remit of the Bill (Part 7) (CIB 2013; Quinn 2013; MHR 2014). For this reason Part 7 of the Irish Bill should be amended to ensure that substitute decision-making by default does not continue to occur under the remit of 'informal decision-makers' (CIB 2013). It is possible that the absence of specific protocols, guidelines and role expectations may lead to those in such roles engaging in substitute decision making to the extent of being coercive (Quinn 2013). Clarity is also required regarding the legally binding nature of assisted decision-making agreements (CIB 2013). As such, further provisions should be inserted into the Irish Bill stipulating consequences for breach of duties of the assistant decision maker (Quinn 2013) and provisions placing obligations on third parties to respect decisions made (CIB 2013).

For the majority of people with intellectual disabilities a variety of staff and family members make the decisions, sometimes with, and sometimes for people with intellectual disabilities and therefore these are the people currently undertaking the roles of supportive decision-makers. While the Irish Bill has been forthcoming in stipulating the criteria set out for an unsupportive supportive decision-maker, further clarification is sought regarding the skill-set that supportive decision-makers will need. Furthermore, the Mental Health Reform (2014) contends that the list of persons who cannot undertake roles of co-decision makers and decision-making representatives should be extended to include staff of approved centres (as designated under the Mental Health Act 2001) at which a person is a patient.

In promoting an advocate to be the appropriate person to undertake a role in supportive decision-making the Citizens Information Board (CIB), (2013) highlights that when a person becomes subject to the Irish Bill, access to independent advocates is both a right and a crucial necessity, and that the role of advocacy should be recognised in all provisions of the Irish Bill. Furthermore, access to a skilled advocate is likely to enhance the full implementation of the principle to optimise the will and preferences of the person (CIB 2013). Currently, while HIQA (2013) includes provision for access to an advocate, many services do engage very positively with advocates, while for others there is still a lack of understanding of advocacy, and in some instances a level of resistance (CIB 2013a). The CIB (2013) also stipulates that section 60 of the Irish Bill allows the Public Guardian to appoint a court friend to assist a person to make an application to court and that accessing independent advocacy would ideally support and maximise the decision-making capacity of the individual. However, due to

the Irish budgetary circumstances, it has not been possible for the personal advocacy service to be fully implemented. Ultimately, there is a need for the full implementation of the Personal Advocacy Service provided for in the Citizens Information Act (CIA) (2007), which could facilitate an appropriate roll-out of the Irish Bill (CIB 2013).

In England and Wales the principle of 'best interests' is promoted and roles of support persons are referred to as 'donee' with reference to lasting power of attorney, as well as 'deputy', 'court visitor' and 'attorney'. Similarly in Northern Ireland the 'best interests' principle guides the roles of supporters, such as 'nominated' person, 'named person', 'attorney' and 'deputy'. The Scottish capacity legislation promotes roles for a 'guardian', 'continuing attorney' and 'welfare attorney', where supporters are allocated the power to act when a person is deemed as being incapable of making a decision. Notably, while the term 'advocate' is not present in the Irish Bill or in the Scottish capacity legislation, England and Wales and similarly the Northern Ireland capacity legislation acknowledge that Health and Social Care trusts can decide to enlist the services of an Independent Mental Capacity Advocate and provides criteria for the function of that position.

Canadian capacity legislation has been in existence since the 1990's, which is notably prior to the introduction of the United Nations Convention on the Rights of Persons with Disabilities (2006). Yet, there is a lack of clarity regarding the support structures (Kerzner 2011). Some of the Canadian legislative frameworks are similar to the Irish Bill. For example, in British Columbia, when a person's capacity is at question, the Representation Agreement Act (1996) makes provisions for the person to appoint a support person to assist the person in making decisions. The person and support person engage in a Representation Agreement, which is validated by the signatures of both. Section 7 Representation Agreements do not come with the tag of assessment of capacity, which is stipulated with regard to Section 9 Representation Agreements.

Much Canadian capacity legislation is similar to UK capacity legislation in that a guardian is appointed to make decisions in the 'best interest' of the person whose capacity is at question. For example, when a person is determined as being incapable of making a decision the Vulnerable Persons Living with a Mental Disability Act (1993) determines that the commissioner appoints a substitute decision maker, determines the areas of decision-making for which the person is incapable of making a decision, and grants the powers to the substitute decision maker to make relevant decisions in areas specified (VPLMDA 1993, 57(1), 92(1)). And on a finding of incapacity, the Substitute Decisions Act (1992) makes provisions for substitute decision making, which involves decisions being made by one person on behalf of another, either through the role of guardian (substitute decision-maker) where supporters are allocated the power to act or through establishing a power of attorney (planning document, whereby the person prior to a state of incapacity nominates person(s) to subsequently make decisions on his/her behalf). The Substitute Decisions Act (1992)

also makes provisions that the court shall not appoint a guardian if it is satisfied that the need for decisions can be met by alternative courses of action (SDA 1992, 3 (b)). Notably, the term ‘advocate’ is not present in the Irish Bill (ADMB 2013) or in the Canadian capacity legislation.

For the person with intellectual disability, the maximization of their capability to make decisions can hinge on the appropriateness of the distribution and implementation of the supports and accommodations provided. Life Planning Supports, Independent Advocacy, Communicational and Interpretive Supports, Representational Supports, Relationship-building Supports, Administrative Supports, should be aligned with the identified decision-making status of the person (Bach and Kerzner 2010). Acknowledging that a person’s ability to make a decision is not straightforward and attempting to define the scope of decision-making supports that are integral to constituting a person’s decision-making capability encompassed in Article 12(3) Bach and Kerzner (2010) summarize three main types of supports which can potentially impact on the person’s maximization of legal capacity:

Supports to assist in formulating one’s purposes, to explore the range of choices and to make a decision

Supports to engage in the decision-making process with other parties to make agreements that give effect to one’s decision, where one’s decisions requires this; and

Supports to act on the decisions that one has made, and to meet ones obligations under any agreements made for that purpose

(Bach and Kerzner 2010, p.73)

Additionally, selection from a wide variety of accommodations should be considered such as informal assistance from family and friends, plain language assistance, assisted/adaptive communication, visual aids and the use of interpreters (Bach and Kerzner 2010). There is a clear consensus that both people and mechanisms are required to support people when their capacity to make a decision is questioned. Moreover, it is widely acknowledged that such people require varying levels of support. The legal challenge is to ensure that the level of support provided is aligned with the requirements of the person to achieve optimal capability, and that for those people who are unable to make decisions for themselves; the necessary safeguards are in place.

Additionally, supports and accommodations are terms which are found in the capacity legislation and are often used interchangeably. Clearly defining such terms would create opportunities to ensure that the capability of the person is maximized when decisions are made. While having appropriate supports may arguably enhance the capability of some people, others may still be incapable of making a decision irrespective of the support provided. Nonetheless, Bach and Kerzner (2010) are of the opinion that the term ‘legal capacity’ is a critical issue with regard to the development and implementation of capacity legislation which will ideally maximize capability of the person through enabling the person to exercise their legal capacity. While most countries are grappling with Article

12 of the United Nations Convention on Rights of Persons with Disabilities (UNCRPD 2006), the act of denying or enabling a person to exercise his/her 'legal capacity' has become the international focal point of creating spaces for people with intellectual disabilities to achieve a sense of personhood, by living a life equal to other citizens (Bach and Kerzner, 2010).

In presenting a schema of decision-making ability Bach and Kerzner (2010) outline three types of decision-making statuses, where each of the three implies a particular combination of decision-making abilities and supports and accommodations, namely: 1) legally independent status, 2) supported decision-making status, 3) facilitated decision-making status. These authors advocate for recognition of the minimum threshold of legal independence whereby a person is enabled to retain legal capacity at all times, even though the status through which the person exercises their legal capacity may change.

All persons of majority age are presumed to be capable of acting legally independently, where this means the person has the ability, by him or herself or with assistance, to understand information that is relevant to making a decision; and to appreciate the reasonably foreseeable consequences of a decision page (Bach and Kerzner 2010, p.97).

People will move between status depending on the choice, the person's abilities and access to supports and accommodations. The overall combination of having a minimum threshold of legal independence, the nature of the person's decision-making ability, and the appropriateness of the allocation of supports and accommodations which the person receives, should enable them to exercise their legal capacity by scaffolding their decision-making ability into actual decision-making capability (Bach and Kerzner 2010). The challenge in ensuring the maximization of a person's ability is embedded in appropriate allocation of supports and accommodations and raises the question of distributive justice (Bach and Kerzner 2010). These authors suggest that combined with the recognition of disability as "functional diversity" if 'decision-making capability' were to be the concept used as the foundation for implementing legal capacity legislation, the recognition of the functional diversity of persons with an interpretation of the array of supports and accommodations a person might need to exercise their legal capacity would be conceptually assimilated. Where an approach to functional assessment is included, it is of the utmost importance that the assessment would focus on assessing how a person can be enabled to exercise their legal capacity, rather than determining whether or not a person possesses legal capacity (Bach and Kerzner 2010). This approach to assessment would oblige parties to concentrate on what accommodations and supports the individual requires to act out the process of decision-making in a way that is tailor-made to the unique decision-making abilities of the person and enables maximization of their legal capacity.

While the capacity legislation has made great advances the agenda of protecting the rights of people whose capacity may be questioned. The challenge for law makers then is to present legislation which

creates for provisions to be made which ensure that appropriate supports and accommodations maximize the decision-making capability of the person, and that regardless of the level of decision making capability achieved or not achieved, the person retains legal capacity. Necessary safeguards for persons whose capacity may be questioned need to be inserted into the Irish Bill clarifying the expected role and functions of support people in the context of decision-making (MHR 2014; CIB 2013; Quinn 2013). It is important to clarify the expectation of the role of the supportive decision-maker, the inherent powers within the role, and the necessary skills required to undertake the role. It is also necessary to ensure that appropriate standards and protocols are adhered to when selecting supportive decision-makers so that subsequent monitoring and evaluating of the process and the outcomes of decision-making may be less complicated.

2.7 Monitoring of decision making

Law makers are greatly challenged to create structures which ensure autonomy, empowerment, choice, independent living and wellbeing for a person, while operating in line with current capacity legislation. The capacity legislation relevant to Ireland and the UK provides accommodations for the monitoring of decision-making and the term Public Guardian is used by all to refer to the provisions as set out for mechanisms of monitoring. While the remit is similar in nature, Canadian capacity legislation is variable in the terms used for structures to monitor decision making.

Both the England and Wales the Mental Capacity Act (2005) and the Northern Ireland the Mental Capacity Bill (MCB) (2014) create provisions for monitoring decision-making which are similar in nature. The Public Guardian is to be an appointed officer, equipped with a team which functions to establish and maintain and supervise a register of lasting powers of attorney, enduring powers of attorney, and a register of orders appointing deputies (MCA 2005, p.33; MCB 2014, p.66) and appoints and instructs, when necessary Special Visitors, General Visitors, Court Visitors (MCA 2005, p.34; MCB 2014, p.69) and dealing with representations (including complaints) about the manner in which attorneys or deputies carry out their duties (Department for Constitutional Affairs 2007, p. 247). In Scotland under the Adults with Incapacity (Scotland) Act (2000) The Public Guardian functions to supervise any guardian or any person who is authorised under an intervention order (AIA, 2000, p.5).

Similarly, the Irish Bill (ADMB 2013) provides accommodations for the monitoring of decision-making processes through the Office of Public Guardian. In perceiving the term 'Public Guardian' to infer a substitution of decision-making, Quinn (2013) recommends that the title is replaced by: 'The Office of Legal Capacity and Support'. The Citizens Information Board (2013) request that

provisions be inserted in the Irish Bill for specific guidance and protocols regarding roles and responsibilities in the context of informal decision making, assisted decision-making, co-decision-making and representative decision-making to better facilitate the monitoring role of the Office of Public Guardian.

The Mental Health Reform (2014) seeks further clarification on how the provisions of the Irish Bill interact with the Mental Health Act (2001). Quinn (2013) highlights the need for the Irish Bill to clarify its interaction with existing agencies, recommending that a number of other measures be put in place. For example, in addition to the 'National Standards for Residential Services for Children and Adults with Disabilities' (HIQA 2013) identifies an urgent need for the introduction of a similar set of mandatory standards for community-based services (LRC 2011; CIB 2013). To this end the Law Reform Commission suggests that the regulation of home care for vulnerable adults should be taken into account (LRC 2011). This is particularly important in the context of the new provision for the protection of informal decision-maker in the Irish Bill.

As with Ireland and the UK, the Canadian Substitute Decisions Act (1992) the Office of the Public Guardian and Trustee may appoint private individuals as statutory guardians of property, investigating reports of serious abuse or neglect of incapable persons, act as a last resort decision-maker for medical treatment and related decisions for incapable people under the Health Care Consent Act (1996), and maintain a register of property or personal care guardianship in Ontario (Ministry of the Attorney General 2000). The Vulnerable Persons Living with a Mental Disability Act (1993 , 30) underscores the appointment of a commissioner to exercise powers and duties under the act to provide people whose capacity is questioned with information as to their rights, appoint substitute decision-makers, provide information to substitute decision-makers, mediate between substitute decision-makers, receive and investigate complaints regarding substitute decision-makers and exercise others powers as required by the minister. The Representation Agreement Act (1996) makes provisions for duties and powers of monitors in Section 20, where a monitor named by or appointed for an adult must: (1) make reasonable efforts to determine whether a representative of the adults is complying with section 16; (2) at any reasonable time, the monitor may visit and speak with the adult; (3) anyone having custody or control of the adult must not hinder the monitor from visiting or speaking with the adult; (4) guidance for when the monitor has reason to believe that a representative is not complying with section 16 of the act. Section 31(1) makes provisions for investigations by public guardian or trustee, where the public guardian and trustee may conduct an investigation without receiving a notice of objection. While the Canadian approach to monitoring the decision-making process for people whose capacity is at question was pioneering in its own time, more recently, Bach and Kerzner (2010) propose an institutional framework presented in Table 2-6 which aims to safeguard the integrity of the person's decision-making process and their right to exercise legal capacity:

Table 2-6 Framework to safeguard decision-making and legal capacity

Legal Capacity and Decision-making Supports	Ideally, a legislative framework overseeing the provision of accommodations and supports, and evaluate the nature of the relationship between the person and third party, ensuring reasonable efforts to support the person and the third party.
Legislated Duties and Liability of Representatives and Facilitators	Essential duties of representatives/facilitators include: Act diligently, honestly and in good faith; Act in accordance with all applicable legislation, orders and relevant agreements; Adhere to ethics of confidentiality; Document and record actions taken regarding aspects of identified role; Be inclusive of the persons network of support. In complying to the best of their ability with the requirements as set out it is acknowledged that representatives and facilitators would not be liable from actions they have taken in their role
Monitors	A monitor has the responsibility of ensuring that the rights of the person are protected by monitoring the work of the representative/facilitator, ensuring that the action taken is in compliance with the expectations of agreed duties. Should disputes arise the monitor has responsibility to resort to and monitor the directions of the Administrative Tribunal.
Community-based Resource Centre	Provides resources in the formats of information and assistance to the person whose decision-making capacity may be in question as well as third parties with whom they interact.
Legal Capacity and Support Office	Function in conjunction with appropriate input and direction from the Administrative Tribunal. Has a dual role of 1) investigating allegations of serious adverse effects, 2) act as a facilitator or monitor of last resort.
Administrative Tribunal with a Focus on Decision-Making	To have exclusive jurisdiction over decision-making cases focusing on 1) duty to accommodate 2) state provision of supports; 3) decision-making status, 4) appointment of supporters and facilitators; 5) the appointment of monitors; 6) applications to approve and recognize people wishing to act as supporters; 6) decisions fundamentally affecting people's personal integrity (for people in the supported status)
Legal Counsel	State funding must be available to hire a lawyer, should an individual be unable to pay.
Formal Advocate	Independent advocacy is an important support for an individual whose capacity may be questioned. Independent advocacy would: 1) Be a resource for people with regard to the different types of decision-making statuses; 2) Be a resource for people with regard to legal processes and options; 3) Be a support to a person who is the subject of a capacity proceeding by explaining the nature and implications and possible consequences.
(Bach and Kerzner 2010)	

2.8 Conclusion

There is consensus in the literature that paradigm shifts in service provision from institutionalisation to de-institutionalisation along with the rights agenda, advocacy movements, voluntary organisations and 'Parents and Friends Associations' have traditionally and continue to influence choice in the lives of people with intellectual disabilities. More recently, the introduction of decision making capacity legislation has made immense progress in promoting the rights of people with intellectual disabilities, by making the commitment to ensure that citizens with intellectual disabilities experience the same rights as others in society and are enabled to live as others without intellectual disabilities do within their communities. There is a need to understand the choice behaviour of adults with intellectual disabilities who in the past have been denied opportunities, and who are now ideally expected to make choices. And while being guided by policy and legislative frameworks, it is evident that current choice availability and decision-making processes aimed at supporting these adults still lacks several

decision- making elements. This has both practical and conceptual implications for the fundamental rights of people with intellectual disabilities. Far more needs to be done to improve the process of informal, supported and facilitated decision making for these adults as they require varying levels of support, guidance, protection, freedom and control when accessing choices and making decisions. Most importantly, all parties involved should take the appropriate measures to offer necessary support and accommodations to individuals so that they have opportunities to make meaningful choices in their lives.

3 Research theory, methodology, methods and application

3.1 Introduction

Research is a key factor in promoting health, combating disease, reducing disability and improving quality of care in all areas of strategic concern in the Irish health system (HSE 2013). It is a systematic, rigorous critical investigation, which has as its goal, describing, explaining, predicting, and/or controlling phenomena (LoBiondo-Wood and Haber 2014; Norwood 2009, p.26).

This chapter initially introduces the purpose of this research study and the epistemological and ontological assumptions of the researcher to elucidate how the overall chosen design of the research study ensured congruency between the purpose, aim and objectives. The theoretical underpinnings of research approaches, methodology, methods and research ethics are also explained. Classic grounded theory methodology as applied in this research study is also introduced, substantiated and detailed. The discourse employed throughout the chapter will be related to aspects of classic grounded theory methodology ultimately used as the approach of the current study.

3.2 Research purpose

Historically, care provision for people with intellectual disabilities resulted in the access to many life choices being either abolished or severely restricted, thereby greatly reducing the possibility for developing personal control for both minor and major life choices (Brown and Percy 2007). Wolfensberger (1972) argued the case for social care and integration in the community on the grounds that the life of a person with an intellectual disability should be comparable with that of the 'average citizen'. Subsequent models of care were guided by the person-centred planning writings of John O'Brien (O'Brien 1987), which placed the person at the centre of planning and focused care provision on how best to support the intellectually disabled to live the life they wanted. Human rights, international policy and legislation have been influential in driving the national agenda, and Ireland is currently on the cusp of being in a position to ratify the United Nations Convention for People with Intellectual Disabilities (UNCRPD 2006). In this way Ireland formally recognizes that this group of people have a right to be equal and active citizens in their own society, and entitled to access opportunities necessary to make their own choices. However, there is limited self-reported experiential evidence from adults with intellectual disabilities to evaluate their current choice circumstances.

3.3 Epistemological and ontological assumptions

Matthews and Ross (2010) highlight existing debates which are derived from divergent ontological and epistemological perspectives of researchers which impact on researchers in terms of the overall approaches to gathering data. In saying this, there are numerous assumptions about reality and knowledge, and how they are converged to form a relationship between the knower and the known (Hansen-Ketchum and Myrick 2008). Ontology is our understanding of existence of being in the world (Pesut and Johnson 2008). Epistemology is our set of beliefs about the nature of knowledge (Carter and Little 2007). Zwirn (2009) argues strongly for a need for researchers to provide clarity about their epistemological and ontological assumptions. The positivist paradigm is the basis of most empirical quantitative research guided by the ontological view that there is one reality (LoBiondo - Wood and Haber 2006). However, most researchers now accept that positivism in its purest form is untenable and adopt a more post-positivist perspective, which is a modified version of positivism (Lincoln and Guba 2000). A strong thread of radical opposition to the traditional objectivist epistemology of empiricism in the positivist paradigm is constructionism (LoBiondo-Wood and Haber 2006). While grounded theory has been widely associated with post-positivist critical realist assumptions (Chen and Boore 2009), Glaser rejects the neat divide between positivist, post-positivist and constructionist paradigms claiming that grounded theory is neutral. Glaser advocates that:

"No preoccupation is necessary regarding questions of ontology and epistemology or interpretation: Generation of concepts that are abstract of time, place and people will transcend these issues"
(Glaser 2001, p.199)

Classic grounded theory is a general methodology that can facilitate any philosophical perspective (Glaser 2008; Holton 2008). The ontological perspective that underpinned this research was congruent with the assumptions of critical realism. The researcher thought of the current practice of choice making by adults with intellectual disabilities as a reality that needed to be explored by combining the multiple accounts of participants. This resonated with assumptions of critical realism, in which reality exists independently of subjective values and beliefs and can be identified by the collective construction of a shared view from the multiple accounts of participants (Ritchie and Lewis 2007).

3.4 Research aim

The aim of this research project was twofold:

- To explain how adults with intellectual make choices and exercise autonomy in their lives
- To develop a substantive explanatory theory

3.5 Research objectives

- To explore how adults with intellectual disabilities agree and disagree in the context of their life choices
- To explain the main issue of concern for adults with intellectual disabilities as they agree and disagree in the context of their life choices
- To explain the latent pattern of behaviour which adults with intellectual disabilities engage in as they respond to their main issue of concern
- To develop a conceptual theory of how adults with intellectual disabilities agree and disagree in the context of their life choices

3.6 Research approaches

This section provides a synopsis of research in the field of intellectual disabilities; quantitative and qualitative research approaches used either individually or combined by researchers. As classic grounded theory was chosen as the most appropriate research design for the current study, a detailed account of the methodology is then provided.

3.6.1 Research in the field on intellectual disabilities

Involving people with intellectual disabilities in research about their lives is now widely endorsed (UNCRPD 2006; WHO 2011; Carey et al 2014; Salmon et al 2014; Salmon and Carey 2013; McDonald et al 2009; Andre-Barron et al 2008). While recognizing that research has the potential to uncover issues requiring attention, inform policy, evaluate programmes, service provision and to track how social and economic status affects the lives of people with intellectual disabilities, Irish support organizations specifically request researchers to develop projects which reinforce inclusive research (NFVB 2013; NFVB 2009,a,b; NDA 2009). In 2009 The Inclusive Research Network was established as a joint project between the National Federation of Voluntary Bodies and the National Institute for Intellectual Disability and with the purpose of promoting the research agenda for people with intellectual disabilities, aimed to counteract identified deficits in this sector (NFVB 2009). The Research Network sought meaningful inclusion of people with intellectual disabilities in research which represents their daily realities of life experiences, networking opportunities, and research education and training both for those with intellectual disabilities and other relevant parties engaged in intellectual disability research (NFVB 2009). While still in its infancy, progress has been made with regard to promoting the inclusive research agenda with people with intellectual disabilities (Bane et al 2012; Boland et al 2008; Johnson 2009; Tierney 2009).

But the term 'inclusive research' has not been easily defined. While the term was coined to denote research involving people with intellectual disabilities as 'more than just subjects or respondents' (Walmsley 2001, p.188), some critics have argued that there is little conceptual clarity about the nature of inclusive research to guide researchers (Nind and Vinha 2012), and others have demonstrated that making reasonable adjustments facilitated meaningful involvement of people with intellectual disabilities as members of research teams while ensuring ethical standards and upholding the requirements of ethics committees (Northway et al 2014). The most prominent research designs to emerge in the field of intellectual disabilities have been emancipatory and participatory action research (Nind and Vinha 2012) where the focus is on changing social relationships and empowering this group of people by ceding them partial or total control over the content and direction of the research study (Porter and Lacey 2005). More recently these research designs have been incorporated under the umbrella term of 'inclusive research', highlighting the diversity of approaches and forms of involvement of people with intellectual disabilities (García-Iriarte et al 2014; O'Brien 2014; Bigby et al 2014).

Parallel with the onset of diversity in inclusive research approaches the availability of unique research roles for people with intellectual disabilities has increased. The increase in such research roles are on a continuum ranging from engaging in one aspect of research, for example, as a participant interviewee (Beart et al 2004), acting as an adviser (Nind and Vinha 2012), identification of research questions and illustration of ideas through art (Garbutt et al 2009), data collection and analysis (Kramer et al 2011), reflection (Bigby and Frawley 2010), dissemination of research findings (Goodley and Moore 2000), being a member of an ethics committee (McDonald and Kidney 2012), and to contributing to all phases of the research process (Bigby and Frawley 2010; Tuffrey-Wijne and Butler 2010; Kramer et al 2011).

As the onus is now on researchers to undertake research inclusive of people with intellectual disabilities, opportunities to partake in research have amplified for many (Roberts et al 2011; Johnson 2009; Bane et al 2012). And subsequent accommodations and supports which are variable in nature and extent have emerged to facilitate meaningful inclusion, for example the advancement of high - technology devices and supports (McCleery 2015); digital story telling (Manning 2009) and video recording (Cannella-Malone et al 2013); digital technology as an art medium (Darewych et al 2015) and photo-voice as a participatory action research method (Akkerman et al 2014) as well as the relatively recent provision of research education and training (Carey et al 2014; Salmon et al 2014; Salmon and Carey 2013).

In light of the advancements in technology data protection is probably the biggest ethical concern for intellectual disability researchers of this era. Common to all ethical regulations and codes of ethics is the researcher's adherence to best ethical practice which guarantees that research participants' right to privacy, confidentiality and anonymity is respected (Maltby et al 2010). In Ireland according to the Data Protection Act (1988) and Data Protection (Amendment) Act (2003) an individual who collects stores or processes any data about living people on any type of computer or in a structured filing system is a data controller (Sheikh 2008) and data must be stored and retained with respect to the conditions laid out in these Acts. As a consequence of the current digital era data protection concerns revolve around the facts that: digital records can last forever; the speed of digital communications means that the chance of error can be increased; keeping pace with continual advances in hardware and software create challenges when testing particular interventions in a timely manner suitable to people with intellectual disabilities; digital data requires specialised security and complexities can arise across cultures and technology (Kennedy and Deshler 2010). Advanced digital technologies create new opportunities which can fundamentally change how people with intellectual disabilities are included in research, how intellectual disability researchers interpret sources of data and how readers

interact with those interpretations, adding complexities to existing ethical issues and creating new dilemmas for researchers who are now challenged to develop codes of ethics on how best to manage data in a digital era (Gubrium et al 2014; Carroll 2015).

Irrespective of current contentions and complexities, consensus exists that there is an onus on researchers to carry out research with (naturalistic paradigm) rather than on (positivistic paradigm) people with intellectual disabilities people, as inclusive research has contributed to how adults with intellectual disabilities are being reconceptualised as people who need to be taken seriously as competent decision-makers who can contribute to the construction of their lives and choices.

3.6.2 Quantitative research

The quantitative research approach is underpinned by a theoretical, philosophical and methodological perspective, developed and attributed to positivism (Matthews and Ross 2010). Quantitative researchers aim to understand, explain and analyse data in terms of universal laws and objective truths, by testing hypotheses and facilitating the generalizability of findings to larger populations (Bölte 2014; Norwood 2009). LoBiondo-Wood and Haber (2014) reflect on three major types of research designs, closely associated with quantitative research, namely experimental, quasi-experimental, and non-experimental.

3.6.3 Qualitative research

Qualitative research designs differ from quantitative research designs in that qualitative researchers assert that the discovery of meaning is the basis for knowledge (LoBiondo-Wood and Haber 2014). Qualitative approaches as a form of naturalistic inquiry have also become increasingly popular in exploring health care provision (Bölte 2014). Qualitative researchers endeavour to describe, explain, understand and interpret phenomena in relation to the meanings people bring to them to elude a deeper understanding of certain processes in humans (Bölte 2014; Silverman, 2013; Burns and Grove 2011). Qualitative approaches to research have particular relevance when undertaking research with people with intellectual disabilities. Qualitative research can be regarded as a broad term which incorporates several different methodologies that share many similarities, ultimately leading to a better understanding of phenomenon (Topping 2007). Qualitative research is usually conducted in

natural settings, relies on analysing 'textual data' based on 'extensive interaction', while undertaking a 'flexible plan of inquiry' with the individuals being studied in order to gain understanding (LoBiondo-Wood and Haber 2014, p.8). Qualitative research can be broken down into several research paradigms, all of which have their own philosophical underpinning (Norwood 2009). The most commonly used approaches are identified as ethnography, phenomenology, and grounded theory.

3.6.4 Ethnography

Ethnographic research is the immersive experience, attentive observation and systematic documentation of a social group in order to establish knowledge (Skaggs 2010). Ethnographic approaches are based on the principle that cultural groups can be understood by observing what people do and say (Desai 2010). Ethnography is distinct from other qualitative research approaches in that it focuses on cultural and anthropological origins (Holloway and LesT odres 2007). In doing so it focuses on elaborate descriptions of a social group based on recorded observations of and interaction with individuals and their environments (Kelly and Gibbons 2008). Ethnographic methodology could arguably be considered an appropriate methodology to adopt for the purpose of this proposed study as it aims to promote an understanding of why people behave as they do (Wolcott 1999). However, the ethnographic approach is not a theory generating process (Cirgin and Beausang 2002). Also, as ethnography is concerned with a group of people sharing a similar culture, it is in -depth and focuses on a single, but complex social system. Findings are atypical and are not independent of time, place or situation, and therefore cannot be generalised. Furthermore, for the purpose of this research study the day service where the participants were away from their natural lived environment was the main centre of focus. Consequently for the purpose of the present study the ethnographic approach was deemed inappropriate not appropriate.

3.6.5 Phenomenology

Phenomenology has its roots in philosophy (Sloan and Bowe 2014; Jasper 1994) and phenomenological researchers focus on embodied meanings as experienced by the individual (Finlay 2009) with the aim to uncover fresh, complex, rich descriptions of a phenomenon as it is concretely lived (Wertz 2005) and as such researchers contend that only those people who experience phenomena can fully communicate them (Connelly 2010). Phenomenology focuses on revealing

meaning rather than on arguing a point or developing abstract theory (Flood 2010). Consequently a researcher's empirical observations are limited in understanding people's perceptions (Reiter et al 2011; Parahoo 2006). Hypothetically, the examination of the lived experience, for example, the question of choice, would be well supported by the use of a phenomenological approach which revealed how people verbalise their lived experience and the meanings attached (Karp 1996). However, the approach "does not explain, predict or generate theory" (Sorrell and Redmond 1995, p.1120) and this study intends to go beyond the examination of lived experience per se. Rather, this study is designed to develop advanced practice theory or new knowledge within the context of Irish service provision for adults with intellectual disabilities.

3.7 Grounded theory

Grounded theory has perhaps been the predominant contributor in accepting the legitimacy of qualitative methods in applied social research (Hays and Wood 2011). Classic grounded theory is a systematic, inductive approach used in developing a conceptual theory to explain people's behavioural patterns (Glaser 1978, 1998). But, it should be emphasized that one such pattern of behaviour does not represent the participants entire being or doing (Glaser 2001). Two basic kinds of theory can be developed through the use of grounded theory; substantive, which is developed in order to understand the activity in a particular area of investigation for a substantive area of examination; and formal, which is developed to explain occurrences in a conceptual area of investigation (Glaser and Strauss 1967a). The credibility of the theory developed resides not in terms of validity of findings as applicable to qualitative methods, but rather in the fit, relevance, workability and modifiability (Glaser and Strauss 1967a).

3.7.1 The power of grounded theory for the generation of conceptual theory

Classic grounded theory researchers have successfully generated conceptual theories in many disciplines and particularly from nursing perspectives. For instance Higgins (2007) 'veiling sexualities' explained how psychiatric nurses respond to issues of sexuality in a clinical practice context; Berthelsen and Frederiksen (2014) 'safeguarding self-governance' explained how older patients' respond to their relatives' involvement in fast-track programs during total joint replacement whereby they maintained their autonomy through four strategies of actions: embracing, shielding,

distancing, and masking, and Sandgren et al (2010) 'living on hold' explained patterns of behaviour of palliative cancer patients and their relatives in the context of home care. Toner et al (2006) developed a grounded theory of 'Living in Chaos and Striving for Control: How adults with Attention Deficit Hyperactivity Disorder (ADHD) deal with their disorder'. The main issue of concern for these adults emerged as 'Chaos' and 'The Double Life' and explained the basic social-psychological process employed by the research participants to deal with their issue of concern. Toner et al (2006) explains how adults with ADHD live in a state of chaos (Category 1), while striving for control (Category 2). When they achieve a state of control (Category 3) it is never permanent, and loss of control (Category 4) is inevitable so they are constantly cycling through chaos and control, which results in their leading a "double life" (Category 5).

3.7.2 The roots of classic grounded theory

Barney Glaser's educational experiences at Columbia University and University of Paris where he was inspired by Paul F. Lazarsfeld for the systematic processes of quantitative methodology and qualitative maths, and Robert Merton for the study of 'explication de text', combined with working with Anselm Strauss for the introduction to symbolic interactionism, have all contributed to the development of the methodology classic grounded theory (Glaser 1998).

3.7.3 The inception of Strauss and Corbin grounded theory

Strauss branched away from the Glaser and Strauss' (1967a) classic grounded theory approach to qualitative research, and began working with Corbin (Hernandez 2008). In 1990 Strauss and Corbin published 'The Basics of Qualitative Research Grounded Theory'. The book diverged quite significantly from the classic grounded theory method. Hernandez (2008) highlights the difference between the original classic grounded theory and that presented by Strauss and Corbin 1990, 1998 in Table 3-1:

Table 3-1 Philosophical differences in classic and Strauss and Corbin grounded theory

Classic grounded theory	Strauss and Corbin/Post-classic
Grounded theory is an inductive theory generation method (Glaser and Strauss 1967a, p.114) Where conceptual categories and their conceptual properties are generated (Glaser and Strauss 1967a, p.35). This inductive method develops theory that is “more trustworthy than logical-deductive theory for the simple reason that the latter often requires forcing of data into categories of dubious relevance to the data’s meaning” (Glaser and Strauss 1967a, p.98) Verification was repeatedly condemned by as “stifling to the creative energies required for discovering theory” (Glaser and Strauss (1967a, p.7) Grounded theory uses qualitative or quantitative data generated from interviews, observation, or written sources or some combination thereof (Glaser and Strauss 1967a)	Strauss and Corbin make description mandatory as they view the purpose of the theory to specify the conditions that give rise to specific sets of action/interaction pertaining to a phenomenon and the resulting consequences (Strauss and Corbin 1990, p.251) The theory is mainly deductive with minimal induction and can be summed up by their statement of “verifying inductively what we proposed deductively” (Strauss and Corbin 1990:111) Strauss and Corbin believe that it is the purposeful grounding or verification process that makes this mode of theory building different from many other modes of theory building (Strauss and Corbin 1990, p.12) Strauss and Corbin advocate that the literature be reviewed and that the concepts of the researcher may to be brought into the study rather than emerging from the data (Strauss and Corbin 1990, p.7). This forces the development of the theory (Strauss and Corbin 1990, 1998; Hernandez 2008, adapted)

Table 3-1 identifies many similarities in the evolving process of grounded theory. The starting point of both approaches is similar; they are based within the context of lived experience, social and psychological processes: responsiveness to emergent themes and data analysis. The main differences that emerge relate to how the theory is applied in practice; data generation (emergent or compelled), coding techniques, and descriptions of how to engage in this process. The differing processes are therefore inextricably linked to data analysis, which will now be examined.

3.7.4 Differences in grounded theory data analysis

Glaser and Strauss (1967), and Strauss and Corbin (1990, 1998) identified their respective processes for examining the data obtained within a grounded theory research process which is summarised in Table 3-2:

Table 3-2 Differences in Glaser and Strauss and Strauss and Corbin data analysis processes

	Glaser and Strauss (1967)	Strauss and Corbin (1990, 1998)
Researcher preconceptions	Held in abeyance	Influences the stance taken to the study and what is looked for in the data (Strauss and Corbin 1998, p.50). Preconceptions drive the study
Problem definition	Problem emerges from the data	Problem is specified a priori by the researcher
Summary of method	Open coding: the researcher begins by asking questions What is the data a study of? What is actually happening in the data? What category does this incident indicate? The identified codes lead to further theoretical sampling and through the identification of properties and dimensions codes accumulate to form concepts, which in turn form categories. These categories in turn become subcategories to the core category Selective Coding :begins when the core category has been found and data collection is now limited to the core and its related categories Theoretical coding: emergence of the relationships among the core and other categories and their properties by the sorting of theoretical memos Write up: sorting memos into piles- the focus is on the write up of the sorted memos with illustrations where necessary	Open coding: use of imagination through strategies such as the flip-flop technique (1990); theoretical sampling is directed by the literature or ones previous experience Axial coding – one by one each category is saturated through the use of the conditional and consequential coding paradigm. The literature is used to identify properties or dimensions which are sought in the data. Process and interaction are built into the theory. Selective coding – the five step approach in 1990, and 3 step approach in 1998 when the term ‘core’ has been replaced by ‘central’ category: 1) discover the central category (using help from outside individuals, like colleagues), 2) use techniques to aid integration (story line, diagrams, review and sort memos); and 3) refine the theory

Charmaz (1990, 2000, 2006) subsequently declared a constructivist grounded theory approach which was based on the relativism of multiple social realities and the assumption that knowledge was mutually created by the researcher and the researched by interpretive understanding of subjects’ meanings giving rise to cognitive constructionism or constructivism/social constructionism. Later, along with Strauss, Charmez was influential in the development of Adele Clarke’s (2005) situational analysis approach to grounded theory.

3.7.5 Variations in presentations of grounded theory studies

There is consensus in the literature that since its inception in 1965 there have been many remodels and adaptations of the theory which has led to confusion for the novice under taking grounded theory

research (Glaser 2009). The following Table 3-3 presents some examples of how versions of the grounded theory are presented:

Table 3-3 Variations in the presentation of grounded theory studies

Many researchers who present grounded theory studies inaccurately demonstrate:
• how their studies were led by preconceived ideas (Jeon 2004) • that grounded theory is a qualitative research method (Norwood 2009; Mitchell and McCusker 2008) • that symbolic interactionism is the philosophical underpinning of grounded theory methodology (Kushner and Morrow 2003; Jeon 2004; Hernandez 2008; Pilot and Beck 2006; Holloway and Todres 2007; Chang and Schneider 2010) • a focus on description rather than conceptualisation, for example, Starr (2007) shows the classic signs of qualitative description and data overwhelm as she appears to embark on a reflective journey of her own experiences rather than memoing on identified concepts • to have used grounded theory methods without presenting substantive or formal theories (Hallberg and Klingberg 2007; Mitchell and McCusker 2008; Mills et al 2007) • classic grounded theory to represent just one coding family: that of a basic social process (Skeat and Perry 2008)

The variations presented in Table 3-3 add to the confusion of exactly defining grounded theory which can be especially daunting for novice grounded theory researchers.

3.7.6 Rationale for the chosen research design of classic grounded theory

The aim of this research project to develop an explanatory theory from self-reported experiences of how adults with intellectual disabilities make choices coincides with the remit of the naturalistic paradigm. However the all-embracing emancipatory and participatory action research designs where those with intellectual disabilities have more influence in leading and controlling the direction of the research were found to be less congruent with the aim of this research study, which was to explain how adults with intellectual disabilities make choices and to develop an explanatory theory. Further scrutiny of qualitative research approaches identified limitations in the use of ethnography and phenomenology to develop an explanatory theory. The researcher further examined grounded theory research approaches as identified by Glaser and Strauss (1967), Strauss and Corbin (1998), Charmez (2000; 2006) who identified a number of similarities and differences of the theoretical constructs supporting data analysis within grounded theory methodology. Application of such approaches necessitated a critical examination of how the data is collected and analysed. Each of these grounded

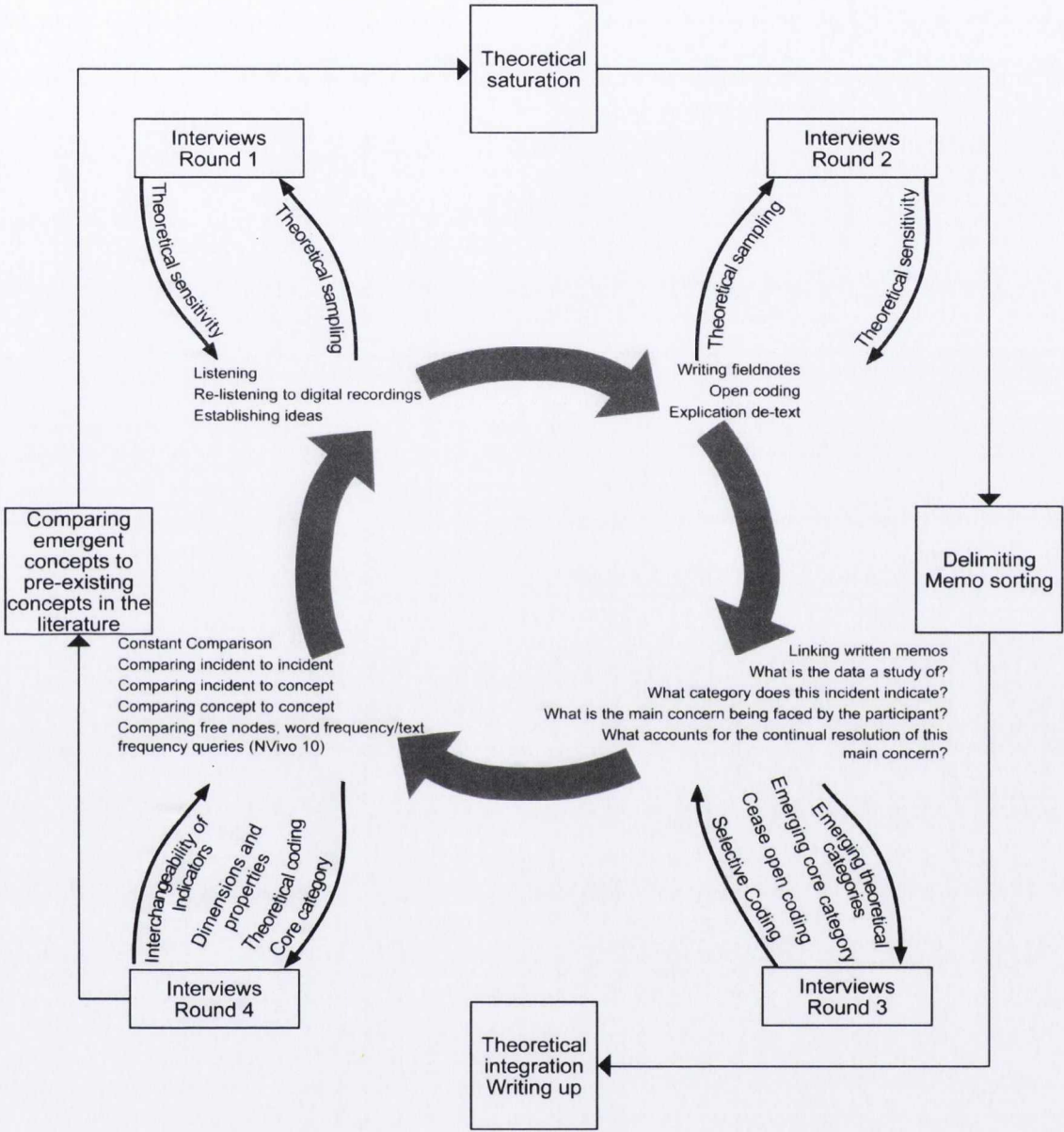
theorist approaches to data analysis identified a guiding framework in which the researcher can examine data in a responsive and adaptive manner (Knox et al 2000).

Classic grounded theory a predominant contributor in legitimising qualitative research methods (Hays and Wood 2011), is a systematic, inductive methodology founded on the premise that the problem emerges from and is guided by data collection to develop a conceptual theory (Glaser 1978, 1998). It relies on abstract conceptualizations and conceptual relationships while avoiding contextual descriptions and descriptive interpretations of the empirical data, whereas other qualitative research approaches focus on in-depth descriptions (Carey 2010) or are overly reliant on literature to the detriment of developing a conceptual theory grounded in data from the substantive area. To reiterate, research which is inclusive of people with intellectual disabilities is still in its infancy. Classic grounded theory is a methodology most suitable for use in areas where scant research has been undertaken. Additionally, classic grounded theory is particularly suited to observing rarely explored phenomenon where extant theory would not be appropriate, and its methodology is therefore congruent with the aim of explaining how adults with intellectual disabilities agree and disagree to choices. A classic grounded theory building approach is more likely to generate new and accurate insights into the phenomenon under study than reliance on either past research or office-bound thought experiment (Glaser and Strauss 1967). When undertaking a research study the researcher needs to ensure that the chosen research approach is consistent with the researcher's epistemological and ontological beliefs and with the purpose of the study (LoBiondo-Wood and Haber 2014; Sahu 2013; Maltby et al 2010). Having compared the different approaches the researcher opted for the classic grounded theory study design as the best possible approach to present an explanatory theory which would be derived from the embedded and self-reported experiences of the research participants. Classic grounded theory was chosen to explain 'choice' from the perceptions and experiences of people with intellectual disabilities, and to develop an explanatory theory of the patterns of behaviour with which they engage when responding to their main issue of concern. The following discusses the application of classic grounded theory methodology in this research study.

3.8 Classic grounded theory and application in this research study

The use of systematic processes in the analysis of qualitative data has generated much debate (Roberts and Woods 2000; Creswell 1998). Table 3-4 provides an overview of the application of classic grounded theory in this research study and the fundamental aspects of the classic grounded theory data analysis process and application are addressed.

Table 3-4 Overview of application of classic grounded theory in this research study



3.8.1 Coding, field notes and memo writing

Classic grounded theory methodology involves a core process of coding which comprises two types; substantive coding, which includes both open and selective coding, and theoretical coding, whereby researchers are advised to code from field notes and memos (Glaser 1978; Holton 2010). Field notes are written throughout the process, to capture immediate researcher reflections and thoughts both during and post interview activity. Completion of field notes or a reflective diary, during the

fieldwork period generates additional data that may otherwise be missed (Sheldon 1998). Throughout the entire data analysis process, memos are concurrently written to interpret in-vivo data, articulate metaphors, examine relationships amongst coded categories, explain major code categories, explain methodological issues and generate theory (Eaves 2001). And the use of 'explication de text' ensures that when coding and memo writing, researchers diligently read line-by-line, attentively establishing exactly what the participant is saying without misrepresentations (Glaser 1998). The researcher needs to memo from the initial data collection stages as memos focus on clarifying concepts, identifying categories and their properties, and help guide the researcher on aspects of theoretical sampling (Glaser 1978; Holton 2007). The four basic goals in memoing are to theoretically develop ideas (codes, with complete freedom into a memo fund that is highly sortable (Glaser 1978). Writing memos is the foundation of working papers which explain the integrative complexities of an emerging theory (Glaser 2013).

3.8.1.1 Substantive coding- open coding

Initially, in substantive coding through open coding, the researcher works with the data directly fracturing and analysing it, and identifying ideas emerging from the data which reflect the underlying pattern of what is happening in the data (McCann and Clark 2004). Glaser (1992) argues that at this stage of open coding, the researcher should compare all codes by posing the key questions of the data: What is this data a study of? What category does this incident indicate? What is the main concern being faced by the participant? What accounts of the continual resolution of this concern? (Glaser 1992, p.140). Incorporated in substantive coding are in-vivo concepts inherent to action scene e.g. milkman's "coffee stop" (Simmons 1993). It is through the process of constantly questioning during open coding that the identification of categories occurs and the process moves from description to conceptualization. Concept development means theorising about what the researcher views is occurring in the area under study (Glaser and Strauss 1967a). Such data as analysed facilitates identification of conceptual categories or their properties. Codes become concepts and concepts become properties of categories. A property is a conceptual element of a category. A category is a conceptual element of a theory. Both properties and categories are concepts that emerged from the data but have a life apart from the evidence that gives rise to them. Both lower and higher level concepts emerge from the data. The former emerges rather quickly, whilst the latter tends to come later through theoretical sampling, and the writing of field notes and memos. As the theory emerges the original list of concepts developed is reduced and all of this work, in turn contributes to the emergence of a core category and its properties (Glaser and Strauss 1967a).

3.8.1.2 Substantive coding – selective coding

As analysis proceeds and the understanding of the researcher deepens concepts will be merged, open coding will cease, and selective coding for a core category begins (Glaser 1978; McCann and Clark 2004). The core category explains the behaviour of the participants in resolving their main concern. Once the core variable is identified, focus should be placed on selectively coding data with the core guiding the coding, while the researcher ignores concepts with little importance to the core and its sub-cores (Glaser 1998). This in turn means that theoretical memos become focused on aspects of the core category and theoretical sampling becomes guided by these aspects. The researcher will review and selectively code old field-notes and memos, as well as selectively sampling and coding new data with the core in mind. In this way theoretical sampling will delimit the study and allow for rapid progress of the theory regarded as a deductive part of grounded theory (Glaser 1978).

3.8.1.3 Substantive coding as applied to this research study

In the context of substantive coding the researcher focused on two simple analytic procedures aimed at creating categories and their properties; coding the data in every possible way, and making comparisons.

According to Glaser (1978, p.56), open coding is “coding the data in every way possible ...running the data open”. To code the data in every possible way the researcher engaged in manual audio-coding of digitally recorded interviews, coding of field-notes and coding of memos. In seeking to run the data open the researcher firstly emerged herself in listening and re-listening to the audio-recordings, making note of open codes. Traditionally, researchers have depended on verbatim transcripts of audio-recorded interviews in order to apply rigorous and systematic analyses, but now that software programs such as NVivo have been developed some researchers view transcription as no longer being a necessity (Wainwright and Russell 2010). The challenge for the researcher was to stay close to data collected while not becoming engrossed in detailed description of transcripts, and to ensure an audit trail for data collection and analysis while not becoming distracted by the complexities of an NVivo program. Therefore, the researcher typed field notes which centred on the open codes identified in the audio-recordings. For each open code identified, the researcher typed field notes and memos under specific Microsoft Word headings (so that when imported into NVivo, would facilitate the making of comparisons).

Field note headings incorporated a Microsoft Word heading title (presence of phenomena) which would later facilitate constant comparison in NVivo 10 (open code). Glaser (2011) acknowledges that there is no one set format in the design of field-notes and that they may change in format as the research develops. The field-notes facilitated the incorporation of the researcher's own explanations and reflections as to what was happening in the realities of participants' choices. The field notes were typed by the researcher herself in Microsoft Word. As the researcher coded and typed each entry was awarded a reference code and initially typed into selected folders in a Microsoft Word programme. For example: FNID01.02.12.P8.1.13.9:50 represented (FNID) (Field Note, Interview, Date), followed by 01.02.12 (Actual Date), P8 (Participant No. 8), 1(Interview 1), 13 (Field note No. 13), 9:50 (Time on digital recording).

Similarly, memo headings also incorporated Microsoft Word heading titles which would later enable comparisons to be made in NVivo 10, asking Glaser's key questions of the data: What is this data a study of? What category does this incident indicate? What is the main concern being faced by the participant? What accounts of the continual resolution of this concern? (Glaser 1992, p.140). As recommended by Glaser (1978, p.57) the researcher examined the data by writing and typing memos which linked to the open codes. For example: M13.05.11.12.rules.FNID01.02.12.P8.1.13.9:50 represented M (memo), 13 (number), 05.11.12 (date), rules (memo name), FNID01.02.12.P8.1.13.9:50 (Linked Field Note).

All individual field notes and memos were imported into NVivo 9 which was later upgraded to NVivo 10, (hereafter referred to as NVivo 10), which allowed for storage and managing of the data. Under the heading 'sources', in the Internals folder the researcher set up individual folders for each participant. The researcher then created subfolders for 'Field notes', 'Memos' and 'Recordings' in the individual folders of each participant and imported these accordingly. In the Nodes folder the researcher created subfolders for 'case nodes', 'questions of field-notes' and 'questions of memos'. The 'case node' was created to store demographic data of each participant. The 'questions of field notes node' was created to elicit information on the 'presence of phenomena'. Whereas, the 'questions of memos node' enabled the researcher to ensure openness to emergent theory by eliciting information based on Glaser's (1992, p.140) key questions of the data.

In maintaining the need to fracture the data the researcher initially immersed herself in open coding of the data in NVivo 10 through line-by-line analysis of field notes and memos.

Interestingly the Free Node term in NVivo 10 refers to the Open Code term of the classic grounded theory methodology. The researcher fractured the data line-by-line and named open codes (FreeNodes) in the NVivo program. Simultaneously, the researcher wrote and typed further memos and subsequently grouped open codes together naming concepts and their properties leading to further development of categories. The associated terms in the NVivo program are parent and child nodes.

The researcher was able to compare incident with incidents of similar codes, which enabled the identification of properties and development of categories. As when comparing incidents with other incidents the researcher was able to explain properties and develop categories. This was facilitated by the writing and typing of memos and when two categories or properties appeared in the same memo the relationship between the two categories facilitated the typing of further memos and further categorization of categories and their properties which documented the ideas of the researcher as the coding proceeded.

3.8.1.4 Theoretical memos as applied to this research study

The main aim of memos was to record ideas. The starting point of memo writing and typing was to get out the first idea that occurred to the researcher about her data. Memoing allowed the researcher the freedom to express the idea in whatever way that made sense at the time. The initial memos were descriptive in nature as the researcher felt obliged to describe when where things were happening, and who and how many were involved, rather than focusing on what the main issue of concern for participants might be and how they managed this main issue of concern. The researcher kept a notebook and pen at her bedside to capture ideas as they emerged. As the researcher gained more experience, she began to write and type probability statements that linked emerging concepts to concepts and this helped explain how these might relate to each other.

Each memo was introduced by a title or caption, which was the category or property that the memo was about. Any other code, property or category that appeared in the memo was linked to the other relevant memo, and this memo was sorted for this concept. If two categories or their properties appeared in the memo, the relationship between the two was subsequently memoed and categorized so that it could be also be sorted.

Memos were maintained separately from field notes but all memos were referenced to the sources from which they emerged so that the researcher could check grounding and draw illustrations when needed. NVivo 10 facilitated opportunities managing and sorting of the data, enabling easy retrieval of and linkage with either field notes or memos which were separately stored. It was also possible to print off all codes, concepts and memos to facilitate sorting and grouping manually and yet retain original copies. Theoretical memos were sorted by manually arranging a considerable accumulation of memos into groups of similarities, connections and conceptual orderings which became the the ory outline.

3.8.2 Theoretical sampling

There is consensus in the literature that theoretical sampling is an integral part of classic grounded theory and in distinguishing it from other forms of sampling the fundamental strength of this analytic approach is ensuring that data is collected and analysed with the expressed intention of developing theory (Glaser 1967; Glaser 1978; Glaser and Strauss 1967; Strauss and Corbin 1998; Charmez 2006; Clarke and Friese 2007; Charmez 2006).

As soon as the researcher starts to code and comparatively analyse the data on the first day, the initial codes, no matter how primitive, guide the researcher in identifying theoretical leads and theoretical sampling. Assessing the relevance of these concepts to the emerging theory becomes a question of further analysis (Glaser 1998). Glaser (1998) advises that the classic grounded theorist researcher should leave the field after 3-4 hours, record field-notes, code them and start analysing them for direction for the next day. Most frequently the problem is to slow down conceptualisation while theoretical sampling corrects for fit, work and relevance (Glaser 1978). The researcher in this mode does not have to know beforehand but rather has to believe his data and theoretically sample for it (Glaser 1998).

Theoretical purpose and relevance is the decisive factor for the sampling process criteria and they are applied in the simultaneous collection and analysis of data based on emergent findings. Theoretical purpose relates to the rationale for having particular participants or areas of study included in the sampling process which is advancing the emerging theoretical constructs. Groups may be used in the generation of comparison data based on their theoretical relevance for advancing the development of emerging categories (Glaser and Strauss 1967a). Theoretical sensitivity requires researchers to follow the developmental trail by allowing their sampling to be driven by what they are seeing, hearing and feeling, relative to the data and the emergent constructs.

Grounded theory sampling is used for incidents that when compared, extend conceptual categories by adding properties to them (Glaser 2001). Firstly, the researcher compares incident to incident with the purpose of establishing the underlying uniformity and its varying conditions (Glaser 1998), as both the uniformity and the conditions become the generated concepts and hypotheses. Secondly, s/he compares the concept to more incidents to generate new theoretical properties of the concept and more hypotheses. This comparison of concept to further incidents has the purpose of theoretical elaboration, saturation, and verification of the concepts, densification of the concepts by developing their properties, and the generation of yet further concepts (Glaser 1998). Continuing the processes of constant comparative method combined with further theoretical sampling, more in-depth data collection is based on the emerging findings and guides where, when, and how further data is

generated. The researcher continually takes the lead from the data at hand and its emergent findings. The emerging theory suggests the future direction of the sampling and data generation process (Glaser and Strauss 1967).

Depth refers to the amount of data collected on a category through the process of theoretical sampling. When the main categories of a theory are emerging in the initial stages of research, comprehensive coverage of the subject area or group may be required. This process occurs relatively quickly. Focus is then placed on collecting data on categories for the generation of properties and subsequent hypotheses. There are no limits to the manner in which slices of data are collected or used (Glaser and Strauss 1967a). The continuous evaluation of data collected by the researcher is crucial to guiding the emerging theory.

3.8.2.1 Theoretical sampling as applied to this research study

Theoretical sampling emerged as an issue of concern for the researcher in the early stages of seeking ethical approval. The ethics committee required a protocol for informed consent which ensures potential participants are informed of the nature and extent of the research. The challenge to the classic grounded theorist researcher was balancing the need to provide specific, accessible and timely information regarding the nature and procedures associated with the research study to potential participants about what would be expected and to remain neutral and be guided by emerging data. All the researcher could do was to inform potential participants what would definitely be happening at the outset of the research study, e.g. giving information about the study, signing up for the research study and meeting with the researcher. However the researcher was not able to provide information regarding how many times she would return to the participants and what exactly she would want to know, as this would be driven by the data being collected from the research participants. In meeting the requirements of the ethics committees the researcher incorporated the recommendations set out by Glaser (1978), on how to meet the requirements of ethics committees while enlisting a grounded theory study. Using the six C's the researcher informed the ethics committee that the researcher sought to explain the presence of phenomena, causes, contexts, contingencies, consequences, co-variances and conditions. Additionally, for the purpose of gaining informed consent from each participant, the researcher informed each individual that s/he would have the option to talk about what was important to him/her in the context of making choices and provided examples of what these might be. In directing the nature and extent of theoretical sampling the researcher refined emerging concepts through 'explication de text', facilitated by the use of online and manual thesaurus and online synonym word classification. The researcher continuously focused on being theoretically sensitive to the data, while remaining open to emergent theory and being scrupulous in not forcing the data.

3.8.3 The constant comparative method

Classic grounded theory is in a large measure rooted in quantitative methodology and qualitative math as the researcher affirming a latent pattern of behaviour uses the qualitative math embedded in probability statements (Glaser 1998). Constant comparative analysis used concurrently with theoretical sampling is the method by which every element of data is compared with every other element of the emergent data (Glaser and Strauss 1967). Glaser adhered to the importance of initially comparing each incident to incident in order to develop a concept. Comparing incidents means that the researcher begins with coding each incident in the data into as many categories for analysis as possible. The researcher must constantly compare each incident with every other incident coded in the process of category development. By comparing each incident to a concept and finally comparing concept to concept, a far richer meaning from concepts and relationships between them would be derived (Glaser 1992; Holton 2008).

Many researchers have interpreted the constant comparative method as the constant comparison of incidents, but constant comparison is just one dimension of this method (Glaser 1998). Constant comparative analysis is the core simultaneous and circular process of data collection, coding, categorising, memo-writing and theorising, which are all central to the grounded theory research process where only evidence from data collected is used to establish suggestions (Glaser and Strauss 1967a, 1966). Hypotheses are generated through the comparison of differences and similarities among groups and the identification of relations among them. Further hypotheses could seem unrelated but as categories and properties emerge, develop, and become related, their accumulating interrelations form an integrated and central theoretical framework which becomes the theoretical guide to the further collection and analysis of data (Glaser and Strauss 1967a, 1966).

The use of the constant comparative method forces the researcher to confront similarities, differences and degrees in consistency of meaning between indicators, to generate an underlying uniformity which contributes to the development of properties, while from the comparisons of further incidents to conceptual codes categories are sharpened to achieve best fit while further properties are generated until categories are verified and saturated (Holton 2008).

3.8.3.1 The constant comparative method as applied in this research study

The researcher focused on the making of comparisons, by examining the data through the constant comparative method. With the use of NVivo 10 the researcher made comparisons with what was

emerging from the results of Open Codes, which was attributed the term of Free Nodes in NVivo 10 with the Node Codes as set up by the researcher in NVivo 10. The emergent Open Codes were compared with the Word Frequency and Text Frequency queries range of the Node Codes in NVivo 10.

In identifying the most common words arising in the NVivo queries, the researcher was able to compare these with her memos and identify the most common concepts arising, and explain their similarities and differences leading to further theoretical sampling and memo-writing about the conceptual and theoretical ideas that were emerging during the course of analysis. The researcher typed further memos to constantly compare incident and responses of participants to possible issues of concern. Memos were typed comparing incident to incident, incident to concept and concept to concept. When comparing incidents in the data, the researcher sought to establish the properties of each category. The typing of possible answers to these questions in memos enabled the researcher to transcend the descriptive detail of the data and abstract the incidents within as indicators of the latent patterns of social behaviour. Every aspect of the data was compared with every other aspect in the data. The constant comparison process built and substantiated the emerging categories by defining their properties and dimensions. Emergent codes were grouped which led to the development of categories. And by the constant comparison of incidents in the data discovering patterns of activity with which adult research participants engaged when choices were made the sub-core category was derived.

Combining the above procedures with additional memos documenting the researcher's ideas as the coding proceeded, as well as theoretical sorting which facilitated the organization of the data and the memos illuminated the underpinnings of Glaser's method. Furthermore, 'explication de text' was ensured through the use of a dictionary and online thesaurus, which were continually used to check the definitions and synonyms of words used so as to ensure that the words reflected the experience of the participant. Interestingly, NVivo 10 facilitated the movement of codes into groups and eased retrieval of linked memos. Coding of the categories (then re-organized under broader themes) into subcategories where memos provided a more in-depth understanding of the meaning embedded therein. In keeping with the tenets of classical grounded theory, constant comparative analysis of data occurred and substantive material emerged for conceptualization, learning and theoretical hypotheses. Re-organizing, renaming, merging, distilling, grouping and clustering of codes according to their relatedness as directed by analytical memos, led to the emergence of a tentative core category and the researcher began selective coding for the tentative core category.

3.8.3.2 Interchangeability of indicators as applied in this research study

The researcher engaged in memo writing/typing which became more focused on similarities, differences and degrees in consistency of meaning between the emerging concepts. Only evidence from the data collected was used to establish suggestions. Such constant comparison facilitated the generation of theoretical properties by challenging the researcher to consider the diversity in the data. Comparing each incident with other incidents or with the properties of categories, the researcher focused on consistency analysis and then demonstrated instances where core indices yielded the same significance for each relationship when related separately to a meaningful set of indicators by cross tabulations. This led to the conceptual naming of emergent patterns and subsequently the verifiability of the theory.

By continually comparing new incidents and thereby generating new properties of a code categories were fully developed and the saturation of ideas was reached through the inter-changeability of indicators. Subsequently data was delimited, contributing to conceptualisation and theory development. Some hypotheses made initially based on similarities and differences seemed unrelated but as categories and properties emerged and developed it became clearer where the unrelated became related. The accumulating interrelations formed an integrated, central theoretical framework. This framework became the theoretical guide to the further collection and analysis of data.

3.8.4 Reaching theoretical saturation and writing up the theory

Establishing readiness and moment to write a conceptual theory is part of the methodology of classic grounded theory (Glaser 2012). The following considerations were taken by the researcher when writing up the theory.

3.8.4.1 Theoretical saturation

Theoretical saturation means that based on the widest possible range of data the process of theoretical sampling continues until no additional new data is being found and gaps in the emerging theory are filled (Glaser and Strauss 1967, 1966). According to Glaser and Strauss (1967) “theoretical saturation” is the criterion used to judge when to stop collecting data. Strauss and Corbin (1990) state that theoretical saturation can occur at three junctures in the research: when new data reveals no new categories; when each category is richly and densely described with all of its properties revealed; when the relationships between categories are well established and validated by data. The challenge

facing the researcher is early closure of the data collection process and Glaser (2012) advises that when the saturation of indicators within the data set has generated concepts, further data collection is not necessary.

3.8.4.2 Delimiting the theory

Delimiting the theory means that throughout the theory development process, the researcher applies a number of theory delimiting measures to ensure a working and workable process. Delimiting occurs in two areas, namely; theory solidification, where major changes become fewer and fewer; and reduction, where core consistencies in the original set of categories or their properties are discovered, thus facilitating the development of the theory with a smaller set of higher -level generalised concepts (Glaser and Strauss 1967).

3.8.4.3 Memo sorting and theoretical codes

A highly sortable memo fund is the source of all writings from the grounded theory study (Glaser 1978). The actual process of sorting the memos stimulates the researcher to write further memos which facilitates the development of the properties of each category and begins to define operational and present hypothetical explanations of connections between categories and/or properties (Glaser 2012). Connections with clusters of other categories are integrated to generate the theory and the researcher begins to compare the emerging theory with other theories with potentially more or less relevance. Drawing out the theoretical properties of the code eventually saturates the code by helping define boundaries of it, the empirical criteria on which the code rests the conditions under which it emerges or is evident, and its theoretically coded connections and significance to the data and the major theoretical themes in the data.

Glaser (1992) points out that theoretical sorting is the key to formulating the theory. It is the act of arranging a vast accumulation of memos into an integrated theory, in what Glaser labels as the epitome of the theory generation process (Glaser 1998). As the research heads toward theoretical saturation and the emergence of a core category, theoretical memos are sorted by similarities, connections and conceptual orderings (Glaser 1978). This becomes the theory outline Glaser describes as “parsimonious set of integrated concepts” (Glaser 1978, p.120). The central theme of any grounded theory methodology is that the pattern by which how categories relate to one another should emerge from the data.

Theoretical codes are abstract models that integrate categories and their properties into a theory (Glaser 2013, p. 4). According to Glaser (1978), theoretical coding generates meaning and scope to the emergent theory and involves conceptualizing the relationship between categories. Glaser further states that researchers must be sensitive to “the myriad of implicit integrative possibilities in the data” and accordingly sets out a range of coding families of theoretical codes to assist in the process (Glaser 1978, pp.73-82). The coding families incorporate, for example, the six C’s: causes, contexts, consequences, contingences, co-variances, conditions (Glaser 1978, 2013). But it is imperative for the researcher to stay open to the emergence of all the codes that fit with relevance when generating a theory. The full power of grounded theory is contextualised by the sorting of mature memos into theoretical codes for writing up (Glaser 2013). Glaser further stresses that whichever coding family is adopted during the process of theoretical coding, it is vital to allow the data to determine which coding family best fits the data (Charmez 2011). It was on the basis of the failings of some of Merton’s students when attempting to test theory which had not been grounded in empirical data, that Glaser developed the conviction which he still holds strongly today that theory has to be grounded in the data collected, and that grounded theory sticks only to what is actually happening in the substantive area (Glaser 1998). Glaser (2001) is critical of researchers who import coding concepts from other theories without their having earned their way into the theory.

3.8.4.4 Parsimony and scope

Parsimony and scope involves reducing the amount of terminology and developing higher level concepts. Parsimony is engaged in through reducing the number of codes, categories and theorising which result in the development of an overarching grounded theory (Glaser and Strauss 1967a, 1966).

3.8.4.5 Dense and integration

In analysing and sorting concepts, the analyst must ensure that they are both dense and integrated. Being dense refers to the proliferation of the concepts, the development of the sub-properties, causes, consequences and so forth, of a particular concept. Integration relates to the process of identifying the relationship between the various concepts and categories, thus demonstrating how they relate to one another in a systematic and organised manner (Bigus et al 1979).

3.8.4.6 Writing up

Theory writing occurs when the researcher is satisfied that the emergent and reasoned framework forms a substantive theory which is understandable and useable by others (Glaser and Strauss 1967a, 1966).

Applying the rigour of the systematic approach of classic grounded theory facilitated the emergency of the theory. Having diligently recorded memos from the outset of the research study, the researcher printed off memos and placed them in piles for sorting. Further memos were written on relationships between the memos and when the researcher found that new information consistently dovetailed with the current categories and was satisfied that categories were sufficiently explained, and with relationships between categories well established that it was time to write up the theory. Theoretical codes were challenging to understand but the practical aspect of looking at piles of memos and thinking about and writing about relationships facilitated the researchers understanding of the theoretical codes, ultimately facilitating the write-up of the theory.

3.8.5 Audit trail

An audit trail is comprised of documentation and materials (including interview transcripts, field notes, personal notes from the analysis process) that could be independently analysed by another researcher to confirm findings (Norwood 2009). Bowen (2009) found that an audit trail can serve as a means of holding, the methodological theoretical and analytical decisions made by the researcher throughout the research process up to scrutiny. Such a process facilitates understanding of how a particular research study was conceived and undertaken. Conversely, Cutcliffe and McKenna (2004) argue that regardless of the specificity of the trail, the unique interpretative and conceptualising eye of one researcher is going to see the world in a different way than that of another. Furthermore, the changing nature of life itself is such that the world in which studies are completed change (Glaser 1965). Therefore, any emergent theory would be open to modification in light of such changes (Glaser 2010).

3.8.5.1 Justification for use of software programmes in classic grounded theory

When comparing incidents, the researcher coded each incident in the data into as many categories for analysis as possible. Initially, the researcher focused on writing and typing memos in Microsoft Word, and accumulating and formatting data while trying to maintain an audit trail proved to be challenging for the researcher. The most challenging dimension was the management of data as the writing of memos increased and became multivariate; for example, when a memo related to more than one incident and/or concept. While each concept in the memo was highlighted, the researcher found it increasingly complex to retrace concepts recorded in the files of other concepts. It was at this juncture that the researcher had the opportunity to attend an NVivo Qualitative Data analysis workshop. Following the workshop it was decided that the researcher would enlist a qualitative data analysis package for the management and storage of data in the main study. Despite Glaser's reservations that the use of a qualitative data analysis package impinges on the capability of the researcher to write ideas and memos freely as they present, or indeed to go through the process of

manually sorting written memos so as to stimulate the intellect to writing theory, the researcher found the use of NVivo 10 to be imperative to ease of storage and retrieval of such ideas so as to free intellect to focus on establishing relationships of links between and boundaries of emerging concepts without having to physically retrieve a handwritten memo. An overview of the application of NVivo is presented in Appendix 9.

3.8.5.2 Software programmes as applied in this research study

The use of qualitative data analysis programs have become widely used in qualitative research (Bazeley 2009; Bergin 2011). NVivo computer assisted software package was used in the organisation and presentation of this study. NVivo version 9 updated to version 10 qualitative data analysis package was used to archive all data, codes and related memos. While using the software package to store, group and identify commonalities in the data collected, the researcher was also enabled to focus her efforts on using grounded theory's conceptual memoing, which, while grounded in data, is abstract of the data itself. Combined with the use of NVivo 10 as the memoing progressed and accumulated, the researcher used classic grounded theory methods preconscious processing (Glaser 1978, p.30; 1998, pp.51-52) and hand sorting approaches to integrate and develop the theory (Glaser 1998, pp.187-192).

3.8.6 Researcher reflexivity on use of classic grounded theory methodology

Undertaking this PhD the researcher broadly sought to explain person centredness from the perspectives and experiences of people with intellectual disabilities. And according to O'Brien's (1987) service accomplishments choice was recognised as one of the fundamental aspects for service providers so as to facilitate person centred planning in services provided. Initially the researcher had thought of exploring how adults with intellectual disabilities make choices in the context of the process of informed consent. Reviewing the literature on research design and attending some workshops, the researcher attended a classic grounded theory workshop where she had the opportunity to present her research question. The following is an excerpt from her reflections:

Presenting my research question at my first classic grounded theory workshop, Dr. Barney Glaser informed me that it was full of preconceived ideas. 'Cognitive Stripping' was what I was subjected to and while at the time I found the experience embarrassing, the words rolled off my lips I loved the use of conceptual abstraction. Comfortingly Dr. Glaser informed me that while I was full of preconceived ideas I was a conceptual thinker. I came away from the classic grounded theory workshop with mixed feelings. I was dismayed that my research question was full of preconceived ideas but the idea of entering the research field with a 'blank page' appealed to me. I felt that to enter the substantive area with adults with intellectual disabilities with a "blank page" approach to how they actually make choices would ensure that I focused on their perceptions and experiences and would be less influenced by myself or other external experiences.

Engaging with the classic grounded theory methodology was challenging, frustrating, exciting and rewarding. Having previously enjoyed making large puzzles the researcher often wondered if such a skill could be a pre-requisite for using the methodology. Engaging with the methodology the researcher found herself continually wanting to see the bigger picture and from the outset was confronted with her own insistence of automatically adding a question to Glaser's', that being: What theory does this incident indicate? Being aware that this exercise was in fact forcing the data the researcher was continually challenged to curtail her use of this questioning in the early stages of theory development when using the methodology.

Another challenging aspect of using the methodology was the use of theoretical codes. While in Glaser (1978) provides a list of codes and brief description of such, the researcher found it impossible to develop a full understanding of the totality of such coding. And for a novice classic grounded theorist seeking such information from reading classic grounded theory studies an explicit template is not available as the theoretical codes are implicit in the theory. A benefit for novice classic grounded theorists would be a simplistic dictionary of theoretical codes comprising of definitions and examples. Interestingly Dr. Glaser himself is at variance with the use of diagrams to represent classic grounded theories.

Nonetheless, irrelevant of the elements of frustration encountered by the researcher in developing and explaining a complex theory in a simplistic manner, using the methodology from the outset has been exciting and as relationships have become clearer and the new and unique theory has emerged the experience has been especially rewarding.

3.9 Research ethics

Codes of ethics ensure that research is conducted ethically and legally, by setting regulatory requirements for researchers who include humans as research participants (LoBiondo-Wood and Haber 2014). Opportunities for socially valued contributions and the reduction of persistent health, economic and social disparities are acknowledged as important social and scientific benefits to including adults with intellectual disabilities in research (McDonald and Kidney 2012). However, ethical issues have been found to challenge researchers who include individuals with intellectual disabilities in research projects (Parley 2010; Liamputtong 2007). While there are numerous philosophical debates continue around the nature and extent of research ethics applicable for people with intellectual disabilities (Feudtner and Brosco 2011), no single theory or principle can be adopted as a guiding philosophy for researchers or research ethics committees (Biggs 2010).

3.9.1 International perspectives on ethics in research

The Nuremberg Code (1949) protects the rights of people from research abuse. Examples of such abuse of rights were the Nazi Experiments (1939-1945), Human Radiation Research (1944-1974) and, Deception Research (Stanley Milgram's studies of obedience in the early 1960s'). Specifically involving people with intellectual disabilities were the studies carried out at the Willowbrook State School, a New York State institution from 1963 until 1966. These studies were designed to gain an understanding of the natural history of infectious hepatitis. The subjects, who were all children with intellectual disabilities, were deliberately infected with the hepatitis virus. Some children were fed extracts of stools from infected individuals, while others were administered injections of more purified virus preparations. The central declaration of the Nuremberg Code (1949) mandated that the voluntary consent of every human subject would be obtained prior to research being undertaken (Beauchamp et al 2008). In light of such atrocities early history of research ethics policy focused more specifically on preventing subjects from being exposed to unacceptable or exploitive levels of risk, which resulted in many individuals being excluded from research (Fadan and Beauchamp 1986). Later The Belmont Report (1978) outlined the three most important ethical principles that should govern the conduct of research with human beings are respect for persons, beneficence and justice. The 1994 National Institute of Health (NIH 1994) guidelines ensured that research inclusion gained momentum over research exclusion. More recently, the United Nations Convention on the Rights of Persons with Disabilities (UNCPRD 2006) requires researchers include representative populations of minority groups unless there are special reasons for excluding them.

3.9.2 National and local perspectives on ethics in research

In 2002 the Irish Government set up The Irish Council for Bioethics, which published guidelines for Research Ethics Committees (REC) (ICB 2004). The National Disability Authority (NDA 2005, 2009) and the National Federation of Voluntary Bodies (NFVB) (2009a, 2009b) have driven the research agenda for people with intellectual disabilities. Conversely, Morgan (2007) advocates the need for more specific disability-sensitive guidance for researchers undertaking research involving people with intellectual disabilities. At the present time in Ireland there is no central office for research ethics committees governing research for people with intellectual disabilities (Carey 2010). As a consequence, many services for people with intellectual disabilities have established their own ethics committees. The function of ethics committees is to guide researchers on best ethical practice and to monitor ethical standards ensuring researchers act in accordance with professional expectations for researchers within the jurisdiction (McCallin 2010).

3.9.3 Ethical considerations in this research study

The following discusses theory and application of ethical considerations in this research study with regard to ethical approval and access to sites, sampling, justice and fair treatment, beneficence and non-maleficence, privacy, confidentiality and anonymity and autonomy and informed consent.

3.9.3.1 Ethical approval and site access

Understandably ethical regulation of social research has increased considerably in the past few years (Wiles 2013). Specifically, Iacono (2006) describes the dilemma between the intentions of an ethical committee of protecting people with intellectual disabilities from potential harm when participating in research while guaranteeing them the autonomy to make their own decisions as they participate in research. These people regarded to be some of the most vulnerable or marginalized in society are entitled to participate in research while having their interests safeguarded by ethics committees' (Smith 2008). Ethical approval was obtained from the Faculty of Health Sciences Ethics Committee (Appendix 1) in Trinity College Dublin in April 2010 and from the Service Ethics Committee in Site 1. Ethical approval was obtained from the Service Ethics Committee of Site 2 (Appendix 2) in May 2010.

3.9.3.1.1 Accessing site one – pilot study

Having obtained ethical approval from the Faculty of Health Science Ethics Committee (TCD) and from the Service Ethics Committee in Site 1, the pilot study took place from June 2010 to September 2010. During this time informal discussions, individual interviews and observations were undertaken. However, unforeseen challenges arose which obstructed the completion of the pilot study in Site 1. In line with the methodology in the initial stages of a classic grounded theory, the researcher is not in a position to know exactly what information she is going to require, or from whom or where. Contact with the gatekeeper was initialled and identification of the sample and consent process was initiated. At the outset of this research study a purposive sample of participants was identified and recruited. In line with classic grounded theory methodology, the researcher declared that theoretical sampling would influence the direction of the study. The researcher initially stated broad topics for discussion supplemented by a similarly broad request to access documentation and meetings. These requests of access were initially agreed between the researcher, ethics committees, gatekeeper, and research participants. Once consent was obtained the researcher accessed the site on an ongoing basis until September. Data was collected, transcribed and analysed from informal discussions, observations and interviews with the participants. Difficulties arose in September during which researcher access to some meetings was impeded. This was initiated by the gatekeeper preventing the researcher from attending some meetings and accessing certain documentation. Despite attempting to address the arising issues and meetings with the director of the organisation to discuss information needs for the research study, it was decided that the study could no longer be undertaken at the site. The researcher

exited the site and ethical approval was rescinded. The researcher sent letters to the participants thanking them for their time and explaining that it was no longer possible to continue the study. The researcher shredded all hard copy documentation and erased all digital recordings from the computer. The development of the explanatory theory is conditional on and informed by the data being collected which explains what is currently happening in the lives of the participants. Establishing clarification of what will be accessible or not accessible to the researcher from the outset of the research study would ultimately enhance the process of facilitating the undertaking of a classic grounded theory study in an area where previously there has been little research undertaken. Furthermore, explanation of the use of classic grounded theory as a general methodology, which transcends time, place and people, could alleviate staff concerns and help to neutralize relationships between the researcher and staff within the substantive area being studied.

3.9.3.1.2 Accessing site two – main study

The researcher sought access to the research site (Appendix 3), and met with the Service Administrator to discuss the nature of and procedures associated with the research study in April 2011. Critically the researcher reflections and learning from Site 1 impacted on her approaches to gatekeepers in Site 2. On meeting with the Service Administrator in Site 2 past experiences of the researcher in clinical practice and familiarity with the research site, while open to the criticisms of being research bias, facilitated an atmosphere of communication and trust as the researcher presence impacted on the lives of the Service Administrator, formal and informal gatekeepers and research participants. While explaining the nature and procedures associated with the research study to the gatekeeper, the researcher provided examples so as to ensure understanding and to afford the gatekeeper the opportunity to voice any concerns. The researcher also had invested time in anticipating any objections the gatekeepers might have and had responses ready. The researcher made guarantees to the gatekeeper emphasising that my research would not disrupt the operational issues in the setting; that in minimizing disruption to the activities of the participants meetings would be organised at coffee breaks and at lunch times. Additionally, the researcher informed formal and informal gatekeepers that her interest was focused on the reported experiences of the adults with intellectual disabilities and not on individual staff members taking consideration of Glaser's words that theory is abstract of time, place and people. Seeking to minimize the impact of researcher presence on the relevant informal gatekeepers who worked in roles mainly of day-service staff, it was important for the researcher to introduce herself and explain her role. In the day services, the researcher met with each group facilitator individually and explained the nature and procedures associated with the research study. The researcher was also vigilant of the need to continually be observant that these informal gatekeepers were comfortable with researcher presence as the study progressed. The following Table 3-5 provides an overview of the timeline of the research study in site 2.

Table 3-5: Accessing site two – main study

University Ethical Approval	April 2010
Ethical Approval Site 1	April 2010
Access to Site 1	May –September 2010
Ethical Approval Site 2	26 May 2010
Access to Site 2 Met with Service administrator Service Administrator nominated 1 st gatekeeper Met with first Gatekeeper	April 2011
1 st Gatekeeper met with managers of two day services	April – July 2011
1 st Gatekeeper nominated 2 nd gatekeeper	July 2011
Researcher met with 2 nd gatekeeper Researcher met with staff in two day services	July 2011
Gatekeeper provided information session to potential participants Researcher met with staff in two day services Gatekeeper informed researcher that 14 potential participants interested in going to the information session regarding the research study	September – November 2011
Researcher provided information session to 14 potential participants/support persons	December 8th 2011
Potential participants were given seven days to think about the study and to discuss participating in the study support persons, and/or gatekeepers. Moreover, the researcher was available to answer any questions at a set time each day.	7 days December 8 th to 15 th
12 participants opted to proceed with the study. Informed consent meetings with 12 participants	December 2011 (15 th to 19 th)
Interviews in coffee shops/day services	January – March 2012
Community residential house visits/day services/coffee shops	February – September 2012
Interviews in coffee shops/day services/community residential house visits	September 2012 –September 2013

As seen from Table 3-5 ethical approval and access to site and participants occurred over a period of time. While ethical approval was granted relatively quickly access to site and participants proved to be a lengthy wait. Gatekeepers were polite when speaking to the researcher and welcoming of the research. But progress of the research was slow as the researcher while getting access to Site 2 in April 2011 did not meet with the research participants until December 2011. Other than some minor operationalising issues there were no definitive reasons afforded to the researcher as to the slow progress of accessing the site and participants and the researcher had no option but to wait as decisions being made were outside her control.

3.9.3.2 Identifying a qualitative research sample

Sampling as a research process concerns how and why research participants are identified. The identification of the most appropriate sample for any given study is the key activity in the conduct of research (Matthews and Ross 2010) and there is wide-ranging debate in relation to sampling processes. Such debates add to the confusion experienced by novice researchers and lends to further criticism of methods (Mason 2010). Samples are derived from the population under study (Portney and Watkins 2009). A purposive sample has been described in which the researcher chooses subjects on the basis of specific criteria and must exercise fair judgement to make this process meaningful (Portney and Watkins 2009). A central tenet of classic grounded theory is theoretical sampling (Breckenridge and Jones 2009). The theoretical sampling in classic grounded theory begins with data collection and analysis (Glaser 1978). In the early stages of a grounded theory study there are no limits to numbers of participants, interviewees or data sources (Cutcliffe 2000). Indeed, Strauss and Corbin (1998) have described theoretical sampling as a means to “maximise opportunities to discover variations among concepts and to densify categories in terms of their properties and dimensions”. When the core category is saturated, considered sufficiently dense, and data collection no longer generates new leads theoretical sampling ceases (Glaser and Strauss 1967).

3.9.3.3 Purposive sampling as applied in this research study

Sampling involves the process of selecting representatives of the population as a whole with a view to making determinations about that population (Beck and Polit 2012). Each of the two day service facilities catered for the needs of approximately forty adults with intellectual disabilities. Qualitative research studies are often criticised for the smaller sample sizes in comparison to quantitative research but there are no specific criteria pertaining to sample size for a qualitative study (Nieswiadomy 2008). Based on the qualitative research design there are no specific rules in relation to study sample size with 6-10 participants best utilised in describing a populations experiences (Goodman and Moule 2008). An initial purposive sample of ten adults was presented in the ethics form with a request for further theoretical sampling if required. The researcher is required to develop inclusion and exclusion criteria to identify a target population with generally smaller sample sizes being utilized in order to obtain rich, in-depth and detailed data (Taylor 2014). While not a requirement of the university ethics committee the service ethics committee required that adults who choose to participate in the research study were to be ‘deemed to be in generally good mental and physical health by an appropriate healthcare professional’. The following Table 3-6 outlines the criteria for inclusion and exclusion:

Table 3-6 Inclusion and exclusion criteria

Inclusion criteria	Exclusion criteria
Aged 18 to 65 years inclusive Currently receiving a community based day service for adults with intellectual disabilities in Ireland Deemed to be in generally good mental and physical health by appropriate healthcare professional. Have experience of agreeing and disagreeing in the context of life choices. Wish to participate in the study.	Aged under 18 and over 65 years of age Not currently accessing a community based day service for people with intellectual disabilities in Ireland. Deemed by appropriate healthcare professional to be currently in a mental and or physical health state which renders him/her unsuitable to participate in the study Does not have experience of agreeing and disagreeing in the context of life choices. Does not wish to participate in the study.

While it could be argued whether or not it was discriminatory practice that each individual who indicated interest in the research study had to be deemed to be in good mental and physical health, and that as a consequence some individuals may be unfairly excluded from participating. It could also be counter argued that ensuring a person is generally in good health ensures principles of beneficence and non-maleficence. Nonetheless this inclusion criteria had its own knock-on effects as the Service Administrator and the Gatekeeper appeared to be at variance as to who would be the appropriate healthcare professional to deem potential research participants to be in good physical and mental health. And additionally the lack of resources of psychologists, psychiatrists and general practitioners further delayed the commencement of the research study.

3.9.3.4 Research participant right to justice and fair treatment

The right to justice and fair treatment is concerned with who is recruited and enrolled in a study and how they are treated during their participation (Norwood 2009). Recruiting people with intellectual disabilities as participants in research is increasingly recognised as important by people with intellectual disabilities themselves as well as by academics (McDonald and Kidney 2012; Walmsley 2004; Owen 2001).

3.9.3.4.1 Complexities of justice and fair treatment

Gilbert (2004) discusses the groups of people involved when undertaking research in the field of intellectual disabilities and the influences they may have. These include the attitudes of professionals, the diversity and complexity of lay groups, along with knowledge and power relationships. For

example, managers are often nominated by organisations as gatekeepers for the duration of research projects. Gerrish and Lacey (2007) claim that gatekeepers are those people who control access to either participants or data. Enlisting managers as gatekeepers can facilitate the research process and promote the best communication practices between the researcher, the participants and where necessary, families, about the nature and procedures associated with the research (Carey 2010). But power issues may also impact on the research when people undertake dual roles of manager and gatekeeper. Gatekeepers are people who can help or hinder research depending upon their personal thoughts (McDonald and Kidney 2012). Lee (1993) found that in some research, frequent attempts were made by gatekeepers to frustrate and circumscribe the studies, while in others; gatekeepers had preconceived expectations of the appropriate methodology and refused access to the study population.

3.9.3.4.2 Application of principles of justice and fair treatment

The Service Administrator nominated a gatekeeper and the researcher met with the gatekeeper in April 2011 to explain the nature of and procedures associated with the researcher study. The gatekeeper was very open and forthcoming with suggestions to create variation in the data to be collected by proposing it to be inclusive of individuals which would maximize differences. The gatekeepers' reasons for doing so were to yield the best possible outcome from the research study. This also facilitated the researcher's ability to make comparisons between the data collected. Following a meeting with the researcher the gatekeeper met with two managers of day services and discussed the proposed study. In July 2011 the researcher received formal notification from the first gatekeeper to access a second nominated gatekeeper who had the responsibility of managing two day services. The researcher subsequently met with the second gatekeeper and discussed the perceived role of the gatekeeper and responsibilities of the researcher in the context of requirements of the study and sought information on how best to support potential participants. The second gatekeeper then introduced the researcher to the relevant staff in the day services. The researcher explained the nature of the research study to the staff, answered any questions, and sought further information on how best to support potential participants. Having had the experience of being a clinician in practice, the researcher appreciated the need for managers/gatekeepers/staff to be apprised of certain information regarding the research study in order to: a) fulfil their responsibilities as an employee in an organisation providing a service for this particular group of people, b) facilitate the running of the normal operational activities of the service and, c) to fulfil their role as gatekeeper/facilitator for research purposes.

Ensuring justice and fair treatment for potential research participants was beyond my control in the getting access to potential research participants. While the gatekeeper was amicable and welcoming of

the research, the researcher was also very much aware that she would only get access to the site when deemed suitable by the gatekeeper and that she would only have the opportunity to recruit from those potential participants recommended by the gatekeeper. The researcher duly waited until July when she got official notification to contact the second gatekeeper. Similarly, the second gatekeeper was welcoming and supportive of the research study, it was disappointing that at this time the day-service was due to close for summer holidays so it was mutually decided that recruitment of potential research participants would commence in September, 2011. While it can be debated that the rights of people with intellectual disabilities are to be upheld in research, in the reality of this research study in the initial stages pace and progress was dependent on the gatekeepers. Nonetheless the actual process of gaining access to the setting and potential research participants lent insights into how people related to each other and how they processed others. While researcher notes at this time concentrated on the experience of meeting with the Administrator and different gatekeepers, the structure and hierarchy of the organisation and often competing levels of competitiveness within and between this hierarchical relationships these notes also assisted me also in developing insight into how she was viewed by the organisation and how she could alleviate concerns or anticipated fears to promote trustful relationships with gatekeepers while optimising opportunities for adults with intellectual disabilities to engage in this research study. Overall gatekeepers appeared supportive of the need for research, for adults to be involved in research, but somewhat apprehensive in anticipating the outcomes of how these adults perceive how they are supported within the context of accessing service provision.

3.9.3.5 Participant right to beneficence and non-maleficence

Beneficence aims to promote the best interests of the research participants (Parahoo 2006). People with intellectual disabilities have become increasingly seen as reliable informants who hold valid opinions and have the right to express them (Johnson 2009; Ramcharan and Grant 2001; Vallenga et al 2007; Atkinson 2004; Johnson 2009; Stalker 1998). Establishing and maintaining respectful and mutually beneficial relationships with research participants with intellectual disabilities is paramount for researchers (McDonald and Kidney 2012). Non-maleficence recognises that the person must not be harmed physically or psychologically by the research (Parahoo 2006). Researchers have a duty to protect their participants from harm (ABA 2007). McDonald and Kidney (2012) highlight concerns that adults with intellectual disabilities may be systematically excluded from research, subjected to harmful research, or over-researched.

3.9.3.5.1 Complexities of beneficence and non-maleficence

Ethical regulation of social research has increased considerably in the past few years (Wiles 2013; Hammersley 2009). Specifically in relation to people with intellectual disabilities, Horan et al (2002) describe the dilemma between the intentions of an ethical committee of protecting people with intellectual disabilities from potential harm by research and guaranteeing the autonomy of people with intellectual disabilities so that they can decide for themselves if they wish to participate. Horan et al (2002) state that the ethics committee who perceive their role as that of protection for people with intellectual disabilities may also initiate the unintentional side effect of weakening the position of persons with disability in society. Similarly, Hammersley (2009) argues that increased regulation by ethics committees will not raise the ethical standard of social science but instead may worsen the quality of what it produces. Interestingly, Wiles and Boddy (2013) contend that more research is required to explore the realities of undertaking research with groups regarded as 'vulnerable' in order to facilitate how these realities can be ethically managed.

3.9.3.5.2 Application of principles of beneficence and non-maleficence

To ensure ethical accountability the researcher availed of the ethics advisory group of the School of Nursing and Midwifery, then sought and obtained ethical approval from the Faculty Ethics Committee, Trinity College Dublin, prior to seeking and obtaining approval from the Service Ethics Committees. Both receiving advice and adhering to the requirements of relevant ethics committees enhanced the principles of beneficence for the participants in the study. Additionally, the researcher met again with relevant staff, explained the nature of the research, answered any questions so as to alleviate any concerns, and sought relevant information which would support potential participants. Furthermore, each potential participant was afforded the opportunity to have a support person if desired. The Data Protection Acts 1998/2003 advises a nominated support person to be a close blood relative of the research participant. The service had a policy whereby families were informed if an adult attending the service was involved in research. Taking the service policy into consideration, it was agreed between gatekeeper, staff and service user, that an option was available to the service user to have or not have a staff member support person, available prior to, and during the informed consent interview, and accessible to the person for the duration of the study. Including people with intellectual disabilities in this research study was of benefit to them as it gave them a voice. Furthermore, the ultimate benefits of developing a conceptual theory regarding the main issue of concern for people with intellectual disabilities and how they resolve this main issue of concern would have the potential to immensely benefit the lives of people with intellectual disabilities and outweigh the possibilities of any risk which could be defined as minimal.

3.9.3.6 Participant right to privacy, confidentiality and anonymity

Common to all ethical regulations and codes is the researcher's adherence to best ethical practice which guarantee that the research participants' right to privacy, confidentiality and anonymity is respected (Maltby et al 2010; Giordano et al 2007). The Irish Council for Bioethics (ICB 2004) comment on the significance of privacy and confidentiality.

The concept of privacy pertains to the control, which a person has over himself or herself. Therefore the person has a right to control information about themselves, including the collection, use, and disclosure of that information. Confidentiality is the researcher's obligation to protect that information which a research participant entrusts to the researcher on the expectation that it will be kept confidential and that the researcher will maintain its secrecy, not misuse or wrongfully disclose it (Hawkes 2007).

Discussing confidentiality at the outset of research is necessary for acquiring informed consent and for building trust with participants (Crow et al 2006). However, Kaiser (2010) emphasizes that these discussions occur without knowledge of the specific information which will be subsequently shared by the respondent with the researcher.

Anonymity affords assurance to an individual who participates in a research project of being unidentifiable (Svalastog and Eriksson 2010). Researchers are obligated to protect the identity of their research participants (Ryen 2004) and ensure that the parameters of such protection are fully explained before the research begins (Giordano et al 2007). According to the Data Protection Act (1988) and Data Protection (Amendment) Act (2003) an individual who collects stores or processes any data about living people on any type of computer or in a structured filing system is a data controller (Sheikh 2008).

3.9.3.6.1 Complexities of privacy, confidentiality and anonymity

The Data Protection Acts 1988/2003 oblige all data controllers to adopt 'appropriate' security measures to safeguard personal data which has been entrusted to them (Hawkes 2009). The basic tension between data access and data confidentiality in the social science context is well understood (Doyle et al 2001). The core challenge for the researcher is to balance the risk of re-identification

with the utility associated with data collection, storage analysis and dissemination. An Bord Altranais (2007) rule that consent must be obtained from the participant before any confidentiality can be breached. Conversely, Giordano et al (2007) have argued that research participants have an autonomous choice to waive their right to confidentiality. He further argues that if such a choice were to be requested by the research participant, it should be seriously considered, with careful examination of the reasons as to why the participant may be refused such a choice as well as the implications of allowing it. This can be problematic, particularly if assumptions are to be made by researchers about participant anonymity and confidentiality.

3.9.3.6.2 Application of the principles of privacy, confidentiality and anonymity

The protection of an individual's privacy and confidentiality is central to successful data protection practice in healthcare, medical research and public health (Sheikh 2008, p.34). For the purpose of this research study written identities of participants appeared only on the informed consent forms. All documents bearing participants' personal information were stored in locked cabinets in an office with access strictly restricted to researcher. All recordings, transcripts and computerized information, collected and transferred to hardcopy format, were locked in a filing cabinet in a locked office with access strictly restricted to the researcher only. These were stored separately from the consent forms and anonymity was maintained by using identity codes for the participants. The identity of others mentioned in transcripts was protected by using filters to block out names. Data was stored in a password-protected file on a password-protected computer accessible only to the researcher and encrypted as per the Data Protection Act 1988/2003. The researcher transcribed field notes and maintained primary control over data generated by the study. Only the research supervisors and the researcher had access to data collected. The researcher took full responsibility for the project and was the designated person with access to the data generated by the research. While the study involved two community-based day service facilities for adults with intellectual disabilities in one geographical location, the title of the study was generically presented as adults living in Ireland engaging in day services. All data collected for the purpose of this study will be securely stored in the researcher's office for 5 years following completion of the study.

What was challenging in this research study was upholding the principles of confidentiality and anonymity as so many gatekeepers needed to be informed of the research study and the adults who were participating. While the researcher could uphold principles of confidentiality to each individual she had no control over what each individual said to each other. Additionally, a challenging situation arose when one individual told the researcher that 'things are not good for me' and 'I'm going to throw myself out of the window'. In treating the issue ethically and sensitively the researcher told the

participant that she would inform the gatekeeper how upset the participant was and the participant was agreeable to this. The researcher met with the 1st gatekeeper and voiced her concerns. On a subsequent meeting with the research participant told the researcher that she was on medication for a thyroid health concern. As the research participant had recently transferred to residential services accessing the on-site General Practitioner services it was difficult to discern whether the health concern had just emerged; had not detected by the participants community General Practitioner; had routinely been detected in health checks by the on-site General Practitioner or detected as a consequence of concerns raised by the researcher.

3.9.3.7 Participant right to autonomy and informed consent

There is a presumption that every adult, including those with intellectual disabilities, has the capacity to make decisions and be supported to exercise this right (ADMB 2013; MCA 2005). Such decision-making encompasses the concept of consent, that is, individuals giving their agreement to a decision and its consequences. Dye et al (2007) identified the three main components of consent as, (1) possessing sufficient information relevant to the decision to be made, (2) having the capacity to make a decision and to understand the consequences of the decision, and (3) making the decision voluntarily and free from coercion. 'Seeking Consent: Working with people with learning disabilities' (Department of Health, Social Services and Public Safety 2003) describes seeking consent as a 'respectful relationship', and as a 'process' rather than a one-off event and advocates for facilitating resources to enhance the process. Gaining consent from people with intellectual disabilities is often an on-going process, rather than a single event.

An additional consideration for classic grounded theory researchers is balancing the human subject's requirement for informed consent with facilitation of theoretical sampling in classic grounded theory which both focuses on and drives emergence to develop theory (Glaser 2001). Understandably a participant's requirement for informed consent is the foremost priority of an ethics committee's decision to grant ethical approval to undertake research people with intellectual disabilities. But at the outset in a classic grounded theory study it is impossible to generate answers to the requirements of ethics committees as to the specific plan relating to the research design, the specific processes involved and the number of people or groups to be examined (Glaser and Strauss 1967).

Breckenridge and Jones (2009) encourage novice classic grounded theorists to be mindful that the methodology should not be subject to generic 'qualitative' guidelines. Having expertise of classic grounded theorists as members on ethics committees could ensure research is carried out ethically while supporting research studies amenable to classic grounded theory methodology (Carey 2010).

3.9.3.7.1 Complexities of autonomy and informed consent

The hallmark of ethical research lies with the researcher ensuring that decisions taken by research participants are informed and voluntary, and in the daily realities of making choices about research participation, these are the very issues of most concern for adults with intellectual disabilities (McDonald and Kidney 2012). In facilitating autonomy and gaining consent from adults with intellectual disabilities to participate in a research study, the following addresses complexities of facilitating autonomy while obtaining consent, in the context of accessible information, capacity and obtaining informed consent.

Firstly, researchers clearly need to provide sufficient accessible information in conjunction with oral information to enable participants to make informed decisions (Dye et al 2007; Alderson 2004). For most research a considerable amount of information needs to be given to ensure informed consent and this can often result in long and sometimes complex statements in the consent documents and associated information sheets (Scott et al 2006). While Alderson (2004) stresses the importance of not overwhelming study participants with information and of making information sheets friendly and attractive, Truman (2003) concedes that various forms of ethical regulation appear to be constraining researchers' ability to do this, particularly in health care settings.

Secondly, while researchers have placed more focus on determining the individual's capacity to consent to research studies (Dye et al 2007, Fisher et al 2006), there are no empirically-based guidelines to help researchers evaluate research consent capacity in people with intellectual disabilities (Fisher 2003). Conversely, when capacity assessments are carried out, some adults with intellectual disabilities are excluded from research projects (Morton et al 2009). One could argue that it is an act of discrimination to assess one's competence to participate in research, due to the fact of the person having an intellectual disability. In a recent critique of the Irish Bill (ADMB 2013), the College of Psychiatrists of Ireland (CPI), make recommendations for the need to introduce explicit measures to govern research (CPI 2014), while adults with intellectual disabilities have expressed their concerns about what happens when professionals incorrectly assess capacity (IRN 2013). McDonald and Kidney (2012) conclude that although scholars are challenging traditional framings of consent, identifying acceptable solutions to the issue of capacity to consent will be critical to encouraging research inclusive of adults with intellectual disabilities.

Thirdly, Biggs (2010) avers that the nature of the research project proposed may dictate that fully informed consent from potential participants is in many respects an impossible ideal, as the outcomes are not known. Emanuel et al (2008) reports that there is no consensus about what constitutes adequate informed consent for any research, let alone research with those deemed to be vulnerable. McDonald and Kidney (2012) underscore the challenges for people with intellectual disabilities, such

as the amount of information individuals must grasp, their ability to weigh risks and benefits and to fully understand the processes and consequences of participating in research. Andre-Barron et al, (2008) examined the definition of “appropriately informed” when reporting on a qualitative project including people with intellectual disabilities in research while Biggs (2010) warned that issues can arise when a researcher elicits a broad consent rather than an explicit informed consent. Nonetheless, consent is widely regarded as the legal expression of autonomy, but the ability of consent to protect the interests and safety of research participants continues to be highly contingent (Biggs 2010).

3.9.3.7.2 Application of principles of autonomy and informed consent

The challenge to the classic grounded theorist is balancing the need to provide specific and accessible information to the person about expectations of him/her in the study with the requirement remain open and to be guided by what is emerging from the data. For this study the researcher was challenged with striking a balance between presenting an overview of a complex study with many components with providing sufficient accessible and timely information enabling a person to make a particular decision at a particular time. From the outset, the researcher sought to involve people with intellectual disabilities in a meaningful way in this research study through genuine and well-planned processes of collaboration and consultation with them and relevant others. Prior to undertaking this research the researcher reviewed current guidelines pertaining to research and people with intellectual disabilities (NDA 2005, 2009, 2005b). In addition, sources such as Change Organisation United Kingdom and Mencap were utilised in order to use appropriate and accessible means of communication. About the Study sheets (Appendix 5A, 5B) and ‘Informed Consent’ forms (Appendix 6A, 6B) were reviewed by adults with intellectual disabilities in Inclusion Ireland and recommendations for changes were made. The researcher also sought background information regarding needs of the potential participants from the second gatekeeper and relevant staff and acted on same.

The second gatekeeper introduced the study to potential participants and offered them the choice of attending an information session. This verbal invitation to attend the information session was accompanied by a written invitation (Appendix 4). The gatekeeper also offered potential participants the choice to have a support person to accompany them to the information session and to be present for the consent meeting. Fourteen adults volunteered to attend an information session facilitated by the researcher regarding the nature and procedures associated with the research study. The researcher made two types of ‘About the Study’ sheets available (Appendix 5A, 5B). The research participant had an option of choosing whether or not to have less text with pictures or more text without pictures.

Interestingly, actions of the potential research participants during this time made the researcher more aware of her influence on the research process. In preparing accessible literacy the researcher had presumed that potential participants who had difficulty reading and writing would avail of the option to have more pictures and less text and that those whom had less difficulty in reading would take the option of more text without pictures. All potential participants opted for less text with pictures.

The researcher then ran the information session for potential participants and relevant support persons. During the information session the researcher went through the 'About the Study' sheets (Appendix 5A, 5B) in detail with the research participants, supplementing the documentation with a verbal explanation of the proposed study, discussion of possible vignettes, and demonstrating the use of the digital voice recorder. The researcher provided information regarding issues of privacy, confidentiality, anonymity, storage and publication of data. The participants were also informed of the possibility that they may experience distress or discomfort when relaying information to the researcher about their experiences, and that if, during the research they should disclose events of an untoward, unethical or criminal nature in relation to misconduct, discriminating practices or malpractice as stipulated in the practice guidelines of the site and An Bord Altranais (ABA 2007), the researcher would have an obligation to report this to her supervisors. Potential participants were given seven days to think about the study and to discuss participating in the study support persons, and/or gatekeepers. Moreover, the researcher was available to answer any questions at a set time each day. For potential participants, the issue, which required most clarity during this time was the query as to whether partaking in the research study would bring about immediate change for some of their current choices. The researcher advised that while participating in the research would create a voice for the participants, and that research outcomes would inform management, policy and practice, no immediate change would take place with regard to their circumstances. Two potential participants opted not to continue and ultimately twelve participants expressed interest in participating in the research study.

Following discussion with the second gatekeeper, and only when potential participants had decided that they would like to participate in the study did the researcher approach the participant to arrange a meeting for the purpose of obtaining informed consent (Appendix 6A, 6B). When obtaining informed consent from the participants the researcher met with each participant and, again communicated with, and informed the participant of the purpose and procedures of the study in a way which was meaningful to the person. Consent interviews took place from the 15th to the 19th of December 2011 inclusive. Five adults opted to have a support person present at the informed consent meeting and seven adults opted not to have a support person present. While making the choice not to have a support person present, two individuals requested that they both attend the same informed consent meeting. The researcher facilitated the request which proved to be quite beneficial as both individuals engaged in dialogue regarding the nature and procedures associated with the research study. The

researcher was vigilant for signs of assent or dissent from the participants as she provided examples with regard to how the topic of choice would be approached in the research. The researcher sought clarification of appreciation and understanding by asking each individual question's, about the nature and consequences of the study. Once the researcher was satisfied that the potential participants had answered questions in a way that demonstrated appreciation and understanding of the nature of and procedures associated with being in, not wanting to be in, or wanting to opt out of the research study, consent was obtained.

Whether or not participants had opted for a support person, service requirements ensured that each informed consent form was signed. The second gatekeeper signed these informed consent forms. Twelve participants provided informed consent to participate in the research study. All participants opted for a written format of the informed consent form. As well as receiving the written format six participants opted to have the meeting recorded. This recording was made accessible to the participants. One of the participants availed of this option. The study proceeded with those who understood the nature of the study, who voluntarily agreed to participate in the study; who knew that they could withdraw at any time from the study. All research participants reported that this was their first time being involved in a research project. The process of consent was ongoing, as the researcher was constantly vigilant of the verbal and non-verbal communication responses of each participant, and also sought clarification with terms most familiar to the participants. For example, with regard to interviewing, the researcher used questions such as e.g. 'Is it ok with you if I meet you again.....?'

In matters of ethics then researchers must counterbalance their multiple responsibilities to their profession, their university or institutional affiliation, the pursuit of knowledge, the society, their informants, and ultimately, themselves. Ethics committees set restrictions on research but they cannot make ethical decisions for researchers. Just because an ethics committee has approved a study does not make it ethical. Additionally, the researcher was acutely aware that although she had obtained ethical approval and access to the site that other staff working in services may resent her presence. The researcher ensured that she was as unobtrusive as possible to the daily activities of the individuals while be vigilant of any issues or concerns which staff may have.

3.10 Interviews as a method of data collection

Interviews are one of the most common forms of collecting both qualitative and quantitative data from participants and have probably been used by social researchers throughout the history of research (Sullivan-Bolyai and Bova 2014; Matthews and Ross 2010; Myers and Newman 2007). The qualitative research interview attempts to understand the world from the subject's points of view and

to unfold the meaning of their experiences (Rowley 2012; Maltby et al 2010; Kvale and Brinkman 2009). Interviewing is a dynamic interactional process enabling the interviewer to elicit information, feelings, and opinions from the interviewee using questions and interactive dialogue (Matthews and Ross 2010). Research interviewing involves a cultivation of conversational skills that most adult human beings already possess by virtue of being able to ask questions (Kvale and Brinkman 2009).

3.10.1 Types of interview

Structured, semi-structured and unstructured interviews are the three most common type of research interview found in the literature. Matthews and Ross (2010) present the structure and standardisation of research interviews as a continuum rather than three discrete types. Structured interviews are designed to ensure that the interviewer covers the same general areas with each interviewee and is primarily used to gather factual information, give information to patients/service users, or to motivate the patient to do something (Maltby et al 2010). Stewart and Cash (2008) refer to a structured interview as a thoroughly planned, highly structured, scheduled and standardized interview. All questions and answer options are expressed in identical words to each interviewee who then selects answers from the options provided. These interviews are the easiest to conduct, record, tabulate, and replicate, and therefore even novice interviewers can handle them. However, the breadth of information is restricted and probing into answers, explaining questions, and adapting to the needs of different interviewees is not permitted.

3.10.1.1 Semi-structured interviews

A semi-structured interview consists of a set of open-ended questions that allow for spontaneous and in-depth responses (Ryan et al 2009). This is a more flexible way of approaching the interaction between interviewer and interviewee. In this case the interview is a social interaction, and therefore the researcher needs to foster an atmosphere which solicits active participation (Baumbusch 2010). Semi-structured interviewing involves the use of an interview guide comprising a list of open-ended questions which can direct conversation without pressuring the interviewee to select pre-established responses (Stewart and Cash 2008; Loftland et al 2006). Control and direction of interviews of this nature still lies with the researcher but the capacity to be responsive to the interviewee's agenda and views is also built-in (Gerrish and Lacey 2007). The use of a semi-structured interview is suitable to classic grounded theory methodology, as a less rigid approach to interviewing is recommended when

the research purpose is to explore and generate theory of a phenomenon about which little is known (Gerrish and Lacey 2007). Interviews in grounded theory are characterized by encouraging participants to say what is relevant and pertinent to them in relation to the research topic say in their own words (Engward and Davis 2015). Wimpenny and Gass (2000) notably argued that there is no typical grounded theory interview.

3.10.1.2 Non-standardized interviews

According to Matthews and Ross (2010) non-standardized interviews can vary along a continuum, from the researcher being in control of the interview through to the participant being substantially in control of the interview and being enabled by the researcher to tell their own story, in their own way. Ultimately, the skill of the researcher determines the best place on the continuum to engage the interviewee, while simultaneously collecting rich data. The art of interviewing requires researchers to be proficient in a range of techniques such as use of probes, verbal and non-verbal communication, sensitive interviewing, as well as an awareness of the limitations of interviews which are reviewed in the following section.

3.10.2 Use of probes in interviews

The collection of data requires a repertoire of skills, tactics and techniques to ensure that comprehensive accounts of lived experience are collected during the interview process (Norwood 2009). Stelter (2010) recommends that the qualitative interview support temporal interaction, typically by helping to form some sort of story-line, viewing the concept of meaning for the person through actual experiences where the data is collected through the concept of first-person accounts, and through social negotiation and narratives that describe the participants' thoughts, feelings and reflections on their life practices. The success of the interview largely depends on the personal and professional qualities of the individual interviewer (Richie and Lewis 2007). Gaining insights into peoples' lived experience through asking questions can provide a rich source of narrative data, but only if the right questions are asked (Kvale and Brinkmann 2009) and asked sensitively (Henry et al 2013; Price 2002). Researchers have to be attuned to the experiences deemed important by the participants without overly influencing such accounts (Norton 1999). Equally, researchers have to be skilled in reading between the words and within the silences, as well as listening to what is said (Kvale and Brinkmann 2009). The researcher should pose questions such as: 'You mentioned...could

you tell me more about that?’ And for things not mentioned.... ‘Did this happen?’ or ‘would you consider?’ Such questions are called probes. Where the focus of the interview is on conceptual clarification, the questions will explore the meaning and the conceptual dimensions of central terms, as well as their positions and links within a conceptual network (Kvale and Brinkman 2009). When researchers use interviewing as a data generating process they utilize non-verbal and verbal skills simultaneously, and not separately or discretely (Stewart and Cash 2008).

3.10.3 Verbal communication in interviews

Stewart and Cash (2008) describe a process of different levels of communication interactions to facilitate questioning which may occur during interviews. It affords the researcher a framework, through which to obtain information, detect feelings, attain self-disclosure, discover insights, sensitively and responsively explore the participant experience (Stewart and Cash 2008). For level 1 communication interactions questions are posed simply and unambiguously. Questions of action are those inviting description of action, considered less invasive and used in greater quantity at the start and end of an interview. Level 2 communication interactions are employed when the interviewee shows signs of relaxing with, and engaging in the developing discourse. These questions are more invasive as they risk interviewees discovering that they did not know something, which they felt they should have known. They concern attitudes, values, beliefs, motives and deep-seated feelings, which are considered to be central to a person’s identity. Such questions relate to who we are how we think, feel, perceive and interact with our internal and external world. Responses tend to be half safe and half revealing, as parties seek to cooperate without revealing too much. Level 3 communication interaction questions deal with intimate and controversial areas of inquiry. Normally trust levels are high between researcher and participant and there is full disclosure. This ladderred questioning technique of communication interactions does not assume that all data is gathered in one interview. An evolving developmental and incremental process based on mutual respect and trust between participant and researcher facilitates the sharing of sensitive and personal data.

3.10.3.1 Non-verbal communication in interviews

The interactive nature of the interview depends upon non-verbal signals to regulate the flow of communication and turn-taking (Stewart and Cash 2008). Research confirms that people rely on non-verbal cues to express themselves and interpret the expressions of others (Stewart and Cash 2008). Non-verbal communication may convey hidden meaning and needs to be taken into account during any person-to-person encounter.

3.10.4 Challenges in interviewing

Eliciting personal and private information requires skill, sensitivity and integrity (Rakimeelmir et al 2011). Participants could have any number of anxieties about discussing their experiences. Sensitive responsive interviewing facilitates the sharing of such personal information (Price 2001). The ability to develop relationships of trust is a necessity (Beauchamp and Childress 1994). Furthermore, concluding an interview requires researcher sensitivity and openness to the possibility of participants requiring time to talk about the experience of engaging in the interview itself (Åstedt -Kurki et al 2001).

3.10.4.1 Limitations of interviewing

Interviewing, as a human person-to-person interactive process inheres a number of practical limitations. Table 3-7 presents potential difficulties, problems and pitfalls:

Table 3-7 Problems and pitfalls with interviewing

Artificiality	The qualitative interview involves interrogating someone who is a complete stranger; it involves asking subjects to give or create opinions under time pressure
Lack of trust	As the interviewer is a complete stranger, there is likely to be a concern on the part of the interviewee with regard to how much the interviewer can be trusted. This means that the interviewee may choose not to divulge information that he or she considers to be “sensitive”. If this is potentially important information for the research, the data gathering remains incomplete
Lack of time	The lack of time for the interview may mean that the data gathering is incomplete. However, it can also lead to the opposite problem – of subjects creating opinions under time pressure (when these opinions were never really held strongly to start with). In this case more data are gathered but the data gathered are not entirely reliable
Level of entry	The level at which the researcher enters the organization is crucial, e.g., if a researcher enters at a lower level, it may prove difficult to interview senior managers.
Elite bias	A researcher may interview only certain people of high status (key informants) and therefore fail to gain an understanding of the broader situation. Elite bias concerns overweighing data from articulate, well-informed, usually high-status informants and conversely, under-representing data from intractable, less articulate, lower-status ones.
Hawthorne effects	Qualitative interviews are intrusive and can potentially change the situation. The interviewer is not an invisible, neutral entity; rather, the interviewer is part of the interactions they seek to study and influences those interactions
Constructing knowledge	Naïve interviewers may think that they are like sponges, simply soaking up data that is already there. They may not realize that, as well as gathering data they are also actively constructing knowledge. In response to an interviewer, interviewees construct their stories – they are reflecting on issues that they may have never considered so explicitly before. Interviewees usually want to appear knowledgeable and rational, hence the need to construct a story that is logical and consistent.
Ambiguity of language	The meaning of our words is often ambiguous, and it is not always clear that subjects fully understand the questions the spoken or written word has always a residue of ambiguity, examples: words with multiple meanings, similar sounding words may lead to confusion, connotations, use of jargon, slang words, substituting better sounding words for common ones, use of labeling words and the order of words in a sentence.
Adapted from Stewart and Cash (2008) Myers and Newman (2007), Hesiskanen and Newman, (1997), Fontana and Frey (2000), Hermanns (2004), Appleton (1995), Reed and Payton (1997)	

3.10.5 Interviewing people with intellectual disabilities

Interviewing people with intellectual disabilities provides the opportunity for inclusive approaches to research, and progress has been made with regard to enlisting people with intellectual disabilities as valid interviewees (Pert et al 2013; Strnadova and Evans 2012; Owens 2007). However, Owens (2007) provides an account of the well-documented challenges involved in interviewing people with intellectual disabilities, some of which include inarticulateness, unresponsiveness, lacking a concrete frame of reference (particularly in generalizing from experience), and problems with time. Owens claims that the interviewer becomes speaker, listener, and interpreter at the same time. The interviewer speculates and speaks aloud what she thinks the participants want to say, while constantly checking for accuracy of the understandings and interpretations. Atkinson et al (2003, p.7) recognize the role of the researcher as:

"...the ghost writer, or scribe, or interviewer- has two jobs to do: facilitate the telling of the story and to listen attentively to its telling (to be its 'audience'); and, later, to be its compiler and its writer (though not its owner)."

(Atkinson et al 2003, p.7)

The tendency for people with disabilities to acquiesce has also been considered as a barrier in traditional research, although Owens (2007) contends the use of narrative methods to be successful in interviewing people with intellectual disabilities. In recognizing the problems that may arise when undertaking research with this group of people researchers have also suggested the use of methods such as pictorial aids and other visual adjuncts to assist in making research more inclusive (Aldridge 2007).

3.10.6 Rationalization for the choice of interview used in this research study

Matthews and Ross (2010) found the explanatory nature of the semi-structured interview combines well with the classic grounded theory methodology used to gather data and helps the researcher explain how research participants experience or understand a social phenomenon. However, the use of semi-structured interview frameworks in grounded theory research has been questioned in the context of adverting to pre-conceived themes and thereby influencing data (Smith and Biley 1997). Conversely, Wimpenny and Gass (2000) argued that there is no typical grounded theory interview. Interviews in grounded theory are characterized by allowing participants say in their own words what is relevant and pertinent to them in relation to the research topic (Engward and Davis 2015). This form of dialogue allows researchers to become aware of and make sense of the perceptions, feelings and attitudes of research participants (Crotty 1998). Taylor et al (2015) reported from their research that an interview guide served best not as a structured schedule or protocol but rather a list to remind

the researcher to ask each research participant about specific topics and it was in each interview situation that the researcher decided how to phrase questions and when to ask them. This type of semi-structured interview was suitable to the classic grounded theory approach as it afforded the opportunity for the researcher to focus on theoretical sampling while at the same time allowing for the generation of new concepts.

3.10.7 Application of interviewing as applied to this research study

Data collection in this research study involved a total of forty-six interviews comprised of four rounds of interviewing which occurred over a period between January 2012 and September 2013 (Table 3-8). Seated interviews lasted from thirty minutes to one hour and thirty-five minutes and times varied from morning to afternoon to evening. Interviews were held in venues at the discretion of the participant, in quiet locations in either of two day-services, in community settings e.g. coffee shops, in community residential settings and one adult was interviewed in the apartment in which she resided. Interviews were conducted as meetings and varied in nature and extent as the researcher and research participant grew more familiar with each other. Furthermore the researcher spent time with research participants chatting in day service, community residential house or walking to and from coffee shops which was as intriguing as the seated interviews.

At the outset of each round of interviews the researcher reminded research participants of the associated nature and procedures of the research study. The researcher allowed the participant’s time to consider the option and to discuss with others and ensured that participants were satisfied to continue. Prior to the interview the researcher recorded information connected to each interview, such as date, location, and name in the interview file on the digital recorder to ease the process of organizing the interview data. Table 3-8 provides an overview of interviews as applied in this research study:

Table 3-8 Interviews as a data collection method

	Interviews Round 1						Interviews Round 2			Interviews Round 3						Interviews Round 4			
	Day service 1			Day service 2			Community Residential Service			Day Service 1		Day Service 2		Day Service 1		Day Service 2			
	in	out	out	in	out		in	out	Day service	in	out	in	out	in	out	in	out		
P1		23.01.12	27.01.12				10.02.12					06.07.12				24.09.13			
P2		19.01.12					16.02.12					07.07.12							
P3		18.01.12					02.02.12					28.06.12				25.09.13			
P4		05.01.12					03.02.12	15.02.12				28.06.12							
P5		09.01.12					01.02.12					28.06.12							
P6		13.01.12					08.02.12					27.06.12							
P7				09.01.07					30.01.12								N/A		
P8		13.01.12			11.06.12	08.02.12								26.06.12			25.09.13		
P9		12.01.12						23.02.12				28.06.12				26.09.13			
P10		11.01.12						08.02.12				25.06.12				26.09.13			
P11		27.01.12					03.02.12					12.07.12				25.09.13			
P12		06.01.12			08.02.12	02.02.12								05.07.12			23.09.13		

3.10.7.1 Interviews round 1

These interviews occurred in the morning time and the researcher met with participants at their day-service. Eleven participants opted to go to local coffee shops of their choosing and one participant opted to have the meeting in the day service.

At the initial stages of interviewing a wide range of topics were covered. The topics changed over time as interesting concepts evolved and as new ideas were memoed in breaks between and during interviews. The process of constant comparison, writing memos, and generating concepts and categories, changed the focus of the interviews during the course of the fieldwork. At the initial stages of interviewing a wide range of topics were covered, but as the interviews continued, the researcher gradually narrowed down the topics using the techniques of writing memos and comparison to gauge what issues were most important to the respondents. Interviews became more focused as the researcher theoretically sampled, for example: "A lot of people feel that they are 'not allowed' to make choices; would you agree with this? Can you give me examples of choices that you are 'not allowed' to make? And are there choices you 'are allowed' to make? At this time evidence was emerging others were reporting experiences of being 'allowed' to make choices. The researcher sought to understand similarities and differences of 'allowed' versus 'not allowed' in the context of choices and while being mindful of the need to remain open adopted a technique of listening intently to topics that were brought up by the participants. After returning from the fieldwork, the researcher prepared field-notes and interviews for analysis and wrote memos. Emerging codes from round one of interviews were accompanied by memos with the same headings. Memo titles were printed and grouped so as to facilitate the emergence of early concepts centred on 'regulation', 'current state of being', 'mind-sets', 'choice enhancers', 'choice impiders', 'control', 'being told what to do' and 'going with the flow'.

3.10.7.2 Interviews round 2

From the initial set of interviews it emerged that all participants highlighted choice issues concerning what was happening in their residences. Following discussion with and clarification from the gatekeeper the focus of the second set of interviews was to afford the research participants the option to meet with the researcher in their residences. The gatekeeper informed the houseparent's in relevant community residential houses of the research project and that the participants maybe inviting the researcher to meet them in their houses. As family members were already aware of the research project the researcher linked directly with research participants who lived at home.

Ultimately, nine participants were interviewed in their community residences in the evenings, eight of which were interviewed in community residential houses in a room which ensured privacy and one in

her apartment. The father of one participant who lived at home was gravely ill at this time, and following consultation with the participant the interview was conducted in the day-service. One participant who lived in a community residential house and another participant who lived at home both declined the offer of an interview at their residence and opted to go to a coffee shop. Of these nine participants, two sets of two individuals who lived in the same community residential house opted to engage in the one interview. One participant became physically ill on the arranged day for the interview. Unknowingly, the researcher had called to the community house and met with the participant. The meeting was brief and once the participant had returned to day service and was feeling better an alternative date was arranged.

As the researcher and participants became more familiar, the researcher understood more the nature of how they made choices. For example those who were stressed with regard to recent choices made brought their stressed thoughts, feelings and emotions and sustained them throughout the interview and vice versa.

Interviews became more focused as the researcher theoretically sampled, for example: “A lot of people feel that they are being told what to do; would you agree with this? In what ways do you feel that you are being told what to do?” The researcher was also mindful to open broadly and adopt a technique of listening intently to topics that were brought up by the participants while continuing with the preparation of field-notes and memo writing.

3.10.7.3 Interviews round 3

These interviews were held in the afternoon with the researcher meeting the participants at lunch time. Similar to interviews in round 1 eleven of the twelve research participants opted to go to local coffee shops in the community, while one participant opted to have the interview in the day service. These interviews comprised of meeting in coffee shops and engaging in various community activities, such as a walk to the market, local shops or uptown.

Prior to round 3 of the interviews continuous coding explication de text, and memos had facilitated the topics changed over time as interesting categories evolved and as new ideas were memoed. The process of constant comparison, writing memos, and generating concepts and categories, changed the focus of the interviews during the course of the fieldwork. As the interviews continued, the researcher gradually narrowed down the topics using the techniques of writing memos and comparison to gauge what issues were most important to the respondents. Some of the initial codes became categories e.g. ‘being told’ and ‘going with the flow’ and as the researcher sought for similarities and differences in properties and dimensions these categories and related others were explicated.

3.10.7.4 Interviews round 4

Prior to undertaking the fourth round of interviews the researcher again met with and reminded the participants of the nature and procedures associated with the research study and clarified that they were agreeable to meet with the researcher again. The fourth set of interviews comprised of shorter focused interviews held with nine of the twelve participants. All nine choose to meet in coffee shops. Prior to entering the research field for the fourth round of interviews the researcher was cautiously confident of the core category, the sub core category and other related categories. Even though data saturation had been reached the researcher returned to the research site for two reasons: to be fully confident in the theory and to formulate closure for the research participants and for the researcher herself. Undertaking interviews the researcher was fully certain that no new concepts were emerging, the researcher met with each individual participant to ensure closure of the research.

3.10.7.5 Interview considerations

The main considerations arising in this research study for the researcher were relations with participants and gatekeepers and managing the interview situation.

3.10.7.5.1 Relations with participants and gatekeepers

From the outset of the interviews, the researcher developed an awareness of the need for flexibility, reminders, comfort zones and vigilance of research participants and of gatekeepers.

In adapting to the needs of the individual participants the researcher ensured flexibility in the duration of interviews. For example, one participant would ask the researcher if she were free for a short chat when she was on site meeting another participant, while others preferred to keep to themselves, abiding by the agreed meeting time and date.

The need for reminders was highlighted in the early stages of interviewing for the researcher when one of the participants muddled the interview time and date so the researcher met the participant for a short time at the first interview and a longer time at the second interview. Thereafter, in addition to telling the participants she hoped to meet with people the week before meetings and affording choice to research participants in where and when meetings occurred, the researcher contacted the participant by mobile phone the evening before the arranged meeting day to ascertain the meeting was still going ahead.

In recognizing and establishing comfort zones the researcher sought to establish a trusting relationship with research participants by informing and reminding them of the nature and procedures associated with participating in interview's while listening attentively and responding appropriately and time to their needs and aspirations. The organisation of interviews was tailored to meet the needs of research participants while being guided by emerging theory. Following the informed consent interview the researcher informed participants that she hoped to arrange meetings for the following week. This created the opportunity for observing for signs of assent and dissent while affording research participants to consider the choice to meet with the researcher. On arriving at the day service the following week some participants immediately initiated arrangements for meetings, and as this process evolved other participants were appropriately informed that meetings were now being arranged. Additionally, it was important to ensure opportunities for research participants to gain familiarity with the researcher in an environment that was comfortable for them. Research participants were afforded the options to have the interview in the day-service or in quiet locations e.g. coffee shops of their choosing outside of the day service.

It was important to afford time for participants to process and assimilate information regarding the nature and procedures associated with the research study. At the informed consent interview, one participant had opted not to have interviews recorded and this participants' request was respected. Subsequent to signing the informed consent form remaining participants demonstrated a variety of responses to the actual use of the digital recorder when the researcher sought consent to use it during the interviews. While one participant was excited about being recorded, another viewed the opportunity as a liberating experience and six participants agreed to the recording without expressing any specific opinion regarding the recording. Four of the participants sought clarification about who might actually hear the recording. The researcher explained again the nature and procedures regarding the interview recordings, and afforded these participants the option to have the interview recorded or not recorded. Three of these participants then agreed to have the interviews recorded. One participant, again asked who would be listening to the recording, and acknowledging this as a sign of dissent the researcher therefore enquired if she would feel more comfortable if the interview was not recorded and the participant opted to go ahead with the interview without a recording. In respect of this participant's wishes no further interviews were recorded. Instead, the researcher wrote field notes and entered her own verbal explanation of the interview into the recorder after the interview.

The requirements of the ethics committees sought templates of the specific interview schedule to be used (Appendix 7). Such templates provided the options of more text and fewer pictures, or more pictures and less text. In keeping with the classic grounded theory approach the researcher stipulated that the interview topic guide was kept general and open as grounded theory interviews rely on the emergent data to stimulate and generate discussion on the topic as relevant and important to

participant. The opening questions of the interview schedule included: 'Tell me about yourself? How is your day going?' With more specific questions relating to what happens when a person agrees and disagrees in the context of a life choices. For example, 'Do you feel that you have control over the choices you make?' But it was the content of interviews and the topics for discussion which revealed themselves that directed the process of data collection. The researcher listened and spoke aloud at times, offering clarifications of what the participant wanted to say, while also checking understanding. For example, 'So what you're saying is that it is the nurse that arranges your appointments with the doctor in the community?' 'And so tell me, where in the community do you go to the doctor?' Rather than viewing some participants reported confusion about choice arrangements as a challenge to undertaking research with this group of people, the researcher embraced these reports of confusion and wrote field notes and memos about how such confusion affected their choices. For example, to the question 'How long are you here?' one participants reported, 'I'm here a while', while another relayed exact time frames of her lifetime placements in the centre. Such replies provided rich data for comparing similarities and differences in choices.

When the researcher, in round two of the interviews, invited participants to meet in the evening in their residences she was vigilant of signs of assent or dissent. Participant responses varied from: 'Yes you would be very welcome, I will say it to the houseparent' to 'That's okay with me but I will have to say it to the girls in the house' and to 'I don't know, you see xxx (researchers name), they won't be there'. Of those that were enthusiastic and welcoming the researcher commenced meeting with these research participants in their houses. Concern arose again with regard to one participant who repeated 'I don't think we will be there'. The challenge for the researcher was to understand if this was a sign of dissent or if the research participant was concerned that they would be at other activities in the evening if the researcher were to call. Reflecting on the interview held with the participant the researcher was aware that the participant had been forthcoming and engaging in her initial interview and had reported contentious issues in the context of how she made choices. Therefore, the researcher offered to phone the houseparent's to establish when they would be there. To this offer the participant replied 'no they won't be there'. Immediately, the researcher took this as a sign of dissent, did not pursue the request but rather afforded the participant the opportunity to meet in a coffee shop. Reflecting on the response of the participant the researcher made the assumption that the participant felt safer talking about choice issues in an environment which was separate to the location of her community residential service. The participant agreed and met with the participant in a coffee shop. Another participant, who lived in the community with her family did not make any comment when the researcher indicated that she hoped to visit individuals in their houses. Based on information already collected in an individual meeting with the participant the researcher immediately took this participant's as a sign of dissent and reminded the participant of the option to meet in a coffee shop to which the participant agreed.

The researcher was aware that her presence in the research site would have an impact on staff and sought to ensure that the research study would have least disruption for day-service activities. Interviews were held at break times and the meeting area for the researcher and participant was in the day-service canteen. In addition, time spent with the adults in their everyday settings was at breaks in the canteen and sometimes going to their working group areas at break time to see some of the work they did.

While affording research participants the opportunity to go out to a coffee shop the researcher was aware of the ethical implications of such an offer in light of the “cutbacks” being experienced by the research participants where such opportunities previously enjoyed were now restricted due to lack of funding. Furthermore, as the researcher arrived at the day-service for the first meeting with the research participant, the researcher was consciously aware that staff raised questioning eyebrows when the issue of money arose as to who was going to or should pay for coffee. Taking the initiative the researcher stated that it was her treat, in doing so felt that this diffused any issue with regard to how monies of research participants were spent and lessened the operational challenges of asking for and getting money to go for coffee for some adults. It was important to relate to research participants as people and not as sources of data.

Overall the joy of past years working in clinical placement made it easy to create an atmosphere conducive to interviewing as the researcher felt very fit for purpose in listening and reporting on the experiences of these adults. It was important to create an atmosphere in which adults were likely to talk freely. The researcher valued the time spent with the research participants, and at the end of the data collection period in finalising the interviews and the research study bought and wrapped a small box of maltesers, signed a thankyou card, met with each individual and personally thanked them for participating in the research study.

3.10.7.5.2 Managing the interview situation

The researcher sought to relate to adult participants on a personal level in a respectful way so as to develop meaningful trustful relationships and to create an atmosphere in which adults felt comfortable talking openly about themselves. To ensure the conversation was relaxed the researcher sought to construct interview situations resembling those in which people naturally talk to each other about important things.

The conversation was understood to be private and confidential and while the researcher shared personal information the focus of the interest was on the participant’s views and experiences. For the

most part the researcher held back from expressing her own views on the accounts of the research participants but at times this proved challenging as some participants in some situations sought advice and answers to their issues of concern and at other times the researcher was unable to contain her expressions or offers of advice. Furthermore the researcher was challenged to curtail responses influenced by perspectives from her clinical practice experiences as a healthcare worker. Rather the researcher made conscious efforts to focus on her current role as a researcher seeking to represent the realities of choice for these individuals.

Since participants were expected to share private aspects of their lives during interviews, the researcher found it fair to exchange some information in terms of what she relayed about herself. Surprisingly to the researcher in the initial stages of the first interview with P6, this participant asked more questions of the researcher than the researcher asked of the participant. Later in the interview P6 informed the researcher that in the past when some staff had asked her about her private business, she has responded by asking personal questions of these staff as she said to the researcher; “what’s good for the goose is good for the gander”. While the researcher hadn’t realised it at the time but this participant in her own way, had checked out the researcher and drawn her own conclusions.

Another important consideration were the differing levels of willingness and ability of research participant’s to provide detailed accounts of their choice experiences and articulate their emotions. Participant 10 was elusive from the outset. At the initial meeting P10 started to say something several times but then said nothing at all. After affording such opportunities, the researcher began to talk about herself and as the atmosphere lightened asked the participant a question about herself to which she replied “no personal questions”. In dealing with the situation the researcher initially thought she might say to the participant that it is important to talk about her experiences and family issues but at the time the researcher gauged the situation, the personality of the participant and offered the participant the option to choose what to talk about.

Several thoughts occurred to the researcher as she reflected on this analysis:

‘I found myself to be uncharacteristically redundant for something to say. There was a shift in the power systems as P10 held the power as to which way the interview was going to sway? Was she going to engage? My intuitive was ticking striving to enlighten me that there was a wealth of rich data to be obtained from this research participant, if only I could press the right buttons. Yet I was at sea as to how to proceed! I could only take the lead from the research participant! While she had opted to engage in the study and meet with me, interviews became games of ‘what if’s’ and I entered this game with her. She asked me what if she met with a psychologist and told the psychologist that her sister had taken her to the bank, got her to take her own money out of the account and took her money from her – could she trust the psychologist not to tell anyone else? What if the psychologist told someone else? Should she be mad! What would she do! What would I do? It was challenging to undertake the interview in light of knowing whether we were talking about hypothetical situations or reality, while trying to engage Participant 10 without upsetting her. It was only after deriving an understanding of what was going on in her life that I better understood why she was so desperate and so distrustful’

By virtue of being interviewed, some participants demonstrated lack of awareness of how they presented in choice situations while others developed new insight and understanding with regard to their experiences. For example P9 engaged in flirting extrovert behaviour with most males she met in the street when walking to the coffee shops with the researcher. Yet this activity had little to do with how the adult viewed herself as she could not understand why she was not allowed to live on her own. Conversely, P3 when relaying that she had been uncomfortable about the work she was being asked to do by a houseparent, and when talking it out at the interview said 'that's not right, it's not right for the houseparent to ask me to hang out clothes' (in another community residential house). At a subsequent meeting this participant had reported this to her houseparent and was no longer hanging out clothes in another community residential house.

At other times the researcher felt an immense need to reassure research participants that their behaviour was understandable in her eyes, especially after they revealed something personal, which was embarrassing or discrediting. For example P2 informed the researcher that she had told the manager in the place she worked that she was now employed there ten years, for the manager to correct her and tell her that she was only there eight years. P2 was ashamed at having presented incorrect information, and telling the researcher her voice dropped to a whisper and she repeatedly said that she was sure she had been right. In reply the researcher communicated with her empathically saying that that sometimes she herself had made mistakes in dates and timeframes. And P2 had run away in the past and when relaying the information about the scenario demonstrated that she now felt guilty. It was significantly important to the researcher to let P2 talk, to listen attentively to what she had to say and to nod in agreement when P2 stated that she shouldn't have run away.

In other instances, some participants did not think about or report on events which were of interest to the researcher, and for those that did some were interpreting things a bit differently each time. Nonetheless, it was still important for the researcher to listen politely and attentively. Rather the researcher concentrated on being open to seeing perspectives of the research participants in new and different ways. Furthermore when probing for information it was important to gauge sensitively when and how to use open ended questions, descriptive questions about general topic listen and let adults talk throughout the interviewing. The researcher followed up on topics raised by some participants by asking specific questions and encouraging the participant to provide more details for clarification. For example, the coping mechanisms of P6 were so good the researcher felt it was important to know how she came about to have these mechanisms, while being sensitive to the fact that the participant felt she coped so well that she was more aligned with normal individuals rather than having an intellectual disability. P6 replied that she had received counselling. The researcher was sensitively aware that P6 would have preferred not to have admitted that she had received counselling, but rather convey that she was as 'abled' as the general population.

While some adults provided different accounts of the same scenario the researcher cross-checked individual stories across participants and examined statements for consistency between different factual accounts of the same event or experience, and in some instances the researcher raised the issue directly with the research participant asking him/her to explain something they had said. The researcher was not as concerned about finding out which account was the most truthful but rather each individual's perspective of that account and his/her personal narrative so as to present a more or less honest rendering of how participants actually viewed themselves and their experiences. Some of the questions while not meaning to did challenge the identity of the person; "So what do you think that you need to live independently in the community?" and became an uncomfortable situation for P1 who wanted this ideal so much but also realised that for her it might never be fully achievable. And some questions did elicit painful memories and feelings in research participants. P9 who was distressed over a certain choice issue, repeatedly returned to the actual stress. Gentle probing of her understanding of the stressful situation was to no avail, rather than trying to understand the situation she repeatedly revisited the stress. In seeking to support P9 the researcher offered to change the subject or to stop the interview which the participant declined. The participant was using the interview to offload her cumulative stressing with her choice situation.

As researcher awareness of her presence and impact on the interviews developed it became obvious that past experience as an intellectual disability nurse and as an academic could have impacted on the researcher efforts to remain as open and non-judgemental as possible. The researcher continually challenged herself to take off her healthcare worker and academic hats and put on her researchers hat, so as to ensure that the purpose of the research study was being met, that being to explain the realities of choice from the perspectives of the research participants.

3.11 Rigor

Glaser (2001) and Charmez (2000) write of the rigor required in grounded theory, an area that has prompted much debate over many years. However, it is important that readers are able to assess how well studies represent the reality of the participant's experiences and the phenomena examined (Charmez 2000). A number of areas have been identified for researchers to contemplate when considering the trustworthiness of a qualitative research study, namely; nature of research question and initial thoughts of the researcher; philosophical base of study; sampling process; data collection and sources; authentication or confirming process analysis and report development. Researcher reflexivity has been melded throughout this thesis.

Consultant backup in the form of research supervisors, advanced classic grounded theorist fellows, attendance at classic grounded theory workshops, and the support of a qualitative data analysis consultant for the duration of the research study, all enhanced the rigor and trustworthiness of the research project. Glaser (1978, pp.4-6) attributes the credibility of a grounded theory to the fit, work, grab, relevance and modifiability of the emergent theory. The evaluation of the credibility of the emergent theory is explained in detail in Chapter 7 section 7.3.

3.12 Conclusion

Research approaches and methodologies are necessarily wide and varied as researchers need to choose the most appropriate for the study in question. Further, the approach must correspond with the philosophical viewpoint of the researcher in order to support authentic application in practice. Views vary as to the most appropriate way to capture the world of experience and being. A study of a sensitive nature, such as that of examining the experiences of adults with intellectual disabilities in the context of the life choices they make adds further complexity. The current study required application of a research process that was open to the examination of life experiences as they occurred.

Permission to engage in the study required examination of a range of access and consent issues which were addressed within an ethical approach to research practice. The study was designed to capture a picture of the grounded realities of people with intellectual disabilities when they agree and disagree to choices. Recruiting and obtaining informed consent twelve adults with intellectual disabilities in research this classic grounded theory research study required a tenacious and proactive and patient approach. Supporting twelve adults with intellectual disabilities to exercise their choice to participate in research and provide informed consent were considered within frameworks for ethical decision-making and classic grounded theory methodology. Opportunities of identifying a purposeful sample when initially enlisting classic grounded theory methodology, seeking advice from such experts as people with intellectual disabilities themselves and those who support them on ways to make research literacy accessible, ways to promote successful relationships with gatekeepers and how to support the consent process of adults with intellectual disabilities in research. Challenges were identified with regard to the competing detailed requirements of ethics committees and rigor of remaining open to emergence in classic grounded theory methodology and negotiation of access and bureaucracy of services.

There is consensus in the literature that the involvement of people with intellectual disabilities in research requires a strong focus from researchers, academics and the individuals themselves. Specifically when undertaking classic grounded theory research in an ethical manner intellectual

disability researchers must counterbalance their multiple responsibilities to their profession, their university or institutional affiliation, the pursuit of knowledge, the society, ethics committees, research participants, and ultimately, themselves. This research contributes to literature on ethical and methodological considerations for researchers undertaking inclusive research with people with intellectual disabilities.

Data collection comprised the use of interviews which required sensitive and skilled application. Initial purposive sampling was to identify concepts, and later theoretical sampling was used to capture more focused experiences. The grounded theory interview is one that is responsive to the person being interviewed, taking the lead from their voice and their experience. Grounded theory provides an opportunity to explore the world of adult experiences of making choices as encountered in a manner that is responsive and adaptive to that world. It allows for the generation of theory based on the analysis of what occurs. Classic grounded theory therefore provides a solid platform to engage in the current study of examining the phenomenon of how a person agrees and disagrees in the context of life choices. The specifics of the grounded theory methodology have been articulated in previous works (Glaser 1978, 1998; Glaser and Holton 2004; Glaser and Strauss 1967). An in-depth elucidation of classic grounded theory, the approach used in the current study was provided. Data capture and analysis was a simultaneous process which was applied, both manually and through use of a computer software package NVivo 10. The use of the constant comparative method and interchangeably of indicators provided conduits through which to complete all activities in a manner that was guided and directed by the data collected. In the final analysis it was the continual memoing which facilitated the development of the emergent theory, and the subsequent theoretical coding facilitated its explanation.

This chapter contributed to an understanding of how to apply for ethical approval, negotiate access to potential participants, enlist reasonable accommodations and obtain informed consent in the context of the methodological strictures of classic grounded theory methodology. Research projects need to be carefully planned making space for the development of empathic relationships with both the potential participants and also with the structures and services supports.

4 Functional diversity a fundamental choice issue

4.1 Introduction

The previous chapter elucidated the classic grounded theory methodology and its application in this research study. Chapter 4 is the first of two chapters which delineate the emergent theory of aligning with the flow of control for twelve adult participants who access day-service provision from one service provider in the republic of Ireland. For the purpose of this research study the eleven female and one male participant are referred to as adults and ‘agency’ when not otherwise defined is used to refer to those in power positions, such as, service employees, family members, advocates and relevant others, with the main focus in this research study being service employees.

The purpose of this chapter is twofold, the reader is introduced to the research participants and initial efforts of the researcher at analysing data are presented. Early coding and emergent concepts discovered that domains and levels of adult functioning in physical health, psychological health, social health, occupational activity, cognitive intellectualising, materialistic malleability, aesthetic acceptance, pacing and aspiration’s impact on how they make choices. Diverse in nature and extent these domains and levels of functioning lay the foundations of adult functional diversity which when combined with other concepts of support and engagement explained the category of adult’s actual doing. Chapter 5 introduces the emergent theory, offers an elaboration of the classic grounded theory journey as experienced by the researcher as her research skills improved, outlines how the theory emerged and presents an explanation of the emergent theory of aligning with the flow of control.

4.2 Research participants

This research study was undertaken in a service for people with intellectual disabilities facilitated in the Republic of Ireland. Service provision incorporated a comprehensive range of residential, community residential and day services for individuals with a wide variety of needs. At the time service providers were striving to create some opportunities for individuals to integrate with and access mainstream services and supports. Twelve adults with intellectual disabilities participated in this research study. They ranged in age from 28 years to 47 years old and all attended day service provision. Table 4-1 provides an overview of the adult participants in this research study:

Table 4-1 Research participant profile

P1 was a 38yr old female who lived in the service for as long as she could remember and was a ward of court. She had tried to make contact with her mother through a social worker but was unsuccessful. She had no home contact but was in a steady relationship with her boyfriend and enjoyed the company of his family, specifically his mother. P1 had moved to the community and lived independently for a while, but then moved into a supervised community residential house. P1 frequently suffered from headaches, psoriasis, earaches, which subsequently rendered her too sick to attend day service. P1 did not have paid employment or engage in voluntary work. P1 had a bank account but did not manage her own money. P1 had difficulty with remembering some appointments. P1 despised disability and being treated like a child. She wanted to be treated like an adult.
P2 was a 40yr old female who previously attended another service and moved to this service about 20 years ago. P2's mum was alive but her father had died. P2 went home on special occasions, such as anniversaries, Christmas and for short holidays. She had one lifelong friend who was a nun. P2 suffered from high blood pressure and fluid retention in her ankles. P2 worked in a public bar/restaurant for 4 hours per week and attended day service activities for the remainder of the time. P2 had a mobile phone and a bank account but had difficulty with money, numbers and remembering time frames. P2 wanted her own independence but accepted that she depended on others for support.
P3 was a 43yr old female. P3 had both parents alive and very close family contact. She stayed in a supervised community residential house during the week and went home every weekend. P3 travelled independently on public transport, did voluntary work in a nursing home for 1.5 hours on a weekly basis and attended day-service at other times. P3's physical health was generally good but she reported that at times she heard voices and when she did she reported this to staff. P3 had a mobile, a bank account and access to some money in her possession on a daily basis. P3 wanted independence but did not want to live independently.
P4 was a 45yr old female. She had limited family contact as she reported she went home once a year. P4 had a diagnosis of epilepsy, but did not report having any seizures. At the outset of this research study P4 was overweight and had high blood pressure. During the course of the study she lost a lot of weight as her exercise regime was increased and her diet altered. P4 did not have paid employment or do voluntary work; lived in supervised community residential house and had a mobile phone. Initially P4 was not allowed to use public transport independently but during the course of this study was allowed to use the public transport with a peer. P4 did not want staff telling her what to do.
P5 was a 41yr old female. Her mum had died but she met her father once a month. P5 had a steady boyfriend whom she met regularly. P5 had paid secretarial work in a solicitor's office for 9 hours per week. P5 had good health, her own bank account, used the public transport independently and had a mobile phone. She lived in a community residential house with two others peers with minimal supervision (houseparent one night a week).
P6 was a 42yr old female who had been happily married for two years and lived with her husband in an apartment in a secure retirement complex in the community. They had a council contract and paid rent and bills. P6's parents had both passed away but she did have contact with her uncle. P6 was employed as a hotel chambermaid, worked 24-36 hours per week, used public transport independently, used a mobile phone and had very good health. P6 was very satisfied with her life. She wished to become a counsellor.
P7 was a 28yr old male who lived at home with his parents. His father was extremely ill at the time of the research study. P7 did not engage in voluntary work or employment. P7 attended the day service but at the time the study started his bus service had been stopped and his respite cost had risen. His mother did not drive. He did not use public transport. P7's general health was good but he had gait and mobility problems. Did not have a mobile phone. P7 worried a lot about the uncertainty of all that was happening with his Dad and the recession.
P8 was a 37yr old female. At the outset of the research study relationships with family (mum) had been strained and she seldom went home. Was very close to her grandmother who was in a nursing home and died during the course of this study. Did not have paid employment or do voluntary work. P8 suffered from depression, lethargy and had had a diagnosis of cancer. She did not use public transport independently. She had a mobile phone. P8 hated being disabled. During the study family relationships improved and P8 visited home. She wanted a home and somewhere to belong.
P9 was a 39yr old female. Both parents had passed away and she had been fostered by her aunt. She had lived at home and attended service but at the outset of this study found that she was now committed to full time community residential care only getting to go home every second weekend. She was extremely stressed with this situation. P9 did not have paid employment or do voluntary work. Had a mobile phone. She did not have access to her own money. P9 wanted to get out of the service.

P10 was a 39 yr old female. Both parents were alive and P10 lived at home. Her mother who was an alcoholic and P10 had frequent fights with her. P10 engaged in self-harming behaviour especially at times when she fought with her mother. At the outset of the study P10 had paid employment as a church cleaner for 2 hours per week and attended day service. During the course of the study, this employment was terminated. She had a mobile phone. She wanted her own apartment and her own independence.
P11 was a 32 yr old female. She had very good family relationships with her mother, sister (who had intellectual disability) and brother. Her dad had passed away. P11 went home every second weekend and for holidays. She was employed as a swimming pool cleaner for 2 hours per week and attended day service. Had a mobile phone. Had difficulty with reading and numbers and was accepting of the support received. P11 was generally satisfied with what she was doing.
P12 was a 47yr old female. Both her parents had passed away. She had a close network of extended family of aunts and nieces. P12 went home every weekend. She had two brothers at home one of whom was very protective of her and the other whom drank a lot and argued with her when she was at home. P12 had hemiplegia, and recent declining mobility. At the outset of this study it had been recommended that she used a stick. She did not have paid employment but enjoyed making cd's. At the outset of this study P12 had used the public transport but due to declining mobility and some episodes of being ridiculed and harassed at the bus stop, she changed to using a taxi service as a method of transport when going home. P12 wanted to be respected by others.

4.3 Physical and psychological health

This section explains the adult’s functional diversity as it pertains to their physical health and psychological health.

Three adults reported very good physical health, while nine reported that they suffered from a variety of physical health conditions. One adult suffered from skin conditions, sinus and ear infections, headaches and weight gain. Another had epilepsy, had had varicose veins removed, and experienced weight gain. One adult reported difficulty in articulation of speech, and two suffered from high blood pressure and weight gain. A total of three adults reported limitations in mobility, with five reporting sight problems.

In conceptualising psychological health three adults relayed experiences depicting positive mental health, nine reported diverse experiences of feeling psychologically distressed, one reported self-harming behaviour, another episodes of hearing voices and two of being depressed:

P8.1.46:45:00 being depressed
P8: sometimes my head is spinning, my neck and my head gets stressed. I have sickness; my head don't be well sometimes some-times I get depressed sometimes. I'm on medication for that

Various combinations of these functioning domains were reported, for example, one adult who reported episodes of depression also reported a diagnosis of cancer resulting in mastectomy, while another who initially presented with a sense of desperation, later revealed that she is medicated for a thyroid condition. Four others reported frequent experiences of lethargy. The following discusses their access to general practitioner (GP) and registered intellectual disability nurse (RNID) resources.

4.3.1 Healthcare and general practitioner resource

From adult reports of accessing healthcare resources such as psychiatrists, psychologists and general practitioner (GP), the GP was the most commonly service accessed. Adults who lived in the community accessed mainstream healthcare services, and those who lived in the community residential services accessed the services of healthcare professionals working within the residential service. Adults reported varying experiences of who had most influence on how this choice rolled out in practice.

For example for those accessing mainstream healthcare services, one adult had set structures in place so that she made and attended her own GP appointments and was self-directed in doing this. However, another adult found restrictions in her freedom to choose, as either her social worker or sister both organised and attended her GP appointments with her:

FNID 25.09.13.P10.2.8 opposing views

P10: The social worker says XXX (names P10) you need to get your....your.....check-up like, you need to go to the doctor, I will talk to your sister. There's no need to talk to my sister, like, I tell her there's no need to talk to my sister and she says no I will talk to your sister

When the researcher asked P10 if she made her own dental appointments, P10 replied that she didn't mind about her sister making the dental appointment. She stated that sometimes her sister makes the dental appointment and sometimes she makes the dental appointment.

Another adult who in opposition to her own aspirations transitioned from community to community residential services and found that she was doubly disadvantaged as she was required to change from her own GP to the GP assigned to the service. She was restricted in her freedom to choose as she did not have the choice to retain access to her community-based GP and was not consulted with regard to these arrangements therefore had no control over this choice.

Adults living in community residential services were generally accompanied by an intellectual disability nurse when attending GP appointments and reported experiences of meaningful consultation. Meaningful consultation was also evident outside the remit of the residential services and in greater healthcare choices as one adult reported that she was fully involved when attending a surgical consultant, and expressed her total freedom to make the choice as to whether or not to have surgery, saying; 'it was my decision'.

4.3.2 Healthcare and registered intellectual disability nurse resource

From the accounts of those in community residential services the general role of registered intellectual disability nurse (RNID) was overseeing adult healthcare concerns, organising relevant healthcare appointments such as GP, consultant and in general hospitals, and attending same. For those living in the community without access to community residential services, it was often family members, social workers or they themselves, who organised appointments. In the community residential setting, arranged healthcare appointments were routinely slotted into their schedules. If and when new physical or mental health concerns arose they initially spoke to houseparent's or to intellectual disability nurses. In general, the support received from intellectual disability nurses was perceived as being receptive and accommodating to their healthcare needs:

FNID25.01.12.P5.1.20.8:15 getting support

P5: I suppose in a few years I would get married now...[if] XXX (boyfriend) decide to get married I would I'd get married. He was on about getting engaged all right there at Christmas but that won'tthat won't happen for another five years but I just want to give time to get used [to] XXX (boyfriend) a bit better do you know that can be brained you know caused I'm getting used [to him], getting to know him a bit better now and get more confident in myself. You know the course kinda helped me to be honest with you! Now before I went to the course I had low confidence but now the course... the course has helped me, yea but yea but I'd stay down the road and move in with him.... I can see that happening all right cause I can make....if I want.... if I was getting married now and moving in and decide to stay with him you see I'd like change and I'd like to stay with him do you know?

R: And would staff support you?

P5: Oh they would yea XXX (support staff) would support me and XXX (support staff) would, because at the very beginning they said if I ever wanted to go away for the weekend just to say it to them. I only have to get the you know injection, kind-of

R: What's the injection for?

Ahh no its just if you-no it's just that, it's if I want to go away for the weekend I can just go away with him but I'll leave that for another while, for another while anyway

R: Yes okay

And for one adult as well as professional support the nature of the relationship was friendship. P6 lived the community, remained in control of her own healthcare appointments while having access to advice and support from an intellectually disability nurse. She met the nurse on an informal basis for coffee or lunch with the meeting seen as a friendly catch up. She viewed the relationship as one of friendship. She trusted and respected the nurse and in turn felt trusted and respected by her. She could enlist the assistance of the nurse, to attend a day appointment with her in the out-patients clinic when necessary:

FNID06.01.12.P6.1.12.15:00 getting support

R: And if you got into difficulty?

P6: I would yea, XXX (RNID) calls she's the nurse but she's really a friend of mine now I have great time for XXX (RNID) I'm very fond of XXX (RNID) I think a lot of her like...she works hard you know.....and I feel she doesn't get the reward what she gets you know. She's a very hard

worker...she's very lovable you know....she's real ladylike and I sincerely mean it ...when I like a person like that I' thinks very highly of them...I think she's straight...I'm very fond of XXX (RNID). I thinks very highly of her

Conversely, while adults reported positive experiences in their interactions with intellectual disability nurses, the lack of continual presence of these nurses raised some concerns. For example, the detection of the presence of physical health or psychological health conditions varied, either by these individuals reporting their concerns, the observational and reporting skills of houseparents, or during routine meetings with nurses and GP's. Additionally, while the nurses organised and attended appointments, the implementation of healthcare interventions for one person appeared ill -defined. P1 was on antibiotics as her skin had become dry, her eczema had erupted and she required cream. The nurse told her to get a small empty tub, take cream from the big tub, put it into the small tub and take the small tub to the day service. P1 knew what the nurse had told her to do. She said that she must ask the houseparent for a small tub. But at the time of the interview she had not taken a small tub of cream to the day-service (FNID07.02.12.P1.2.30:35). And P1 appeared somewhat vague when reporting what she would do in the context of getting pain relief for symptoms while in day-service:

FNID07.02.12.P1.2.14.7:40 getting pain relief

R: Have you pain killers here at work today?

P1: I'm not allowed. It's the policy. Because if anyone took them or anything like that so I have to take them at home if I need them

R: If you got a pain today in your ear what would you do?

P1: I would have to wait....ask for tablets or something...XXX (Administration staff day service) would give me something. I got two pain killers this morning before I came to work to be honest with you

R: Had you pain at that time?

P1: I had a touch of it

R: Did you ask for the painkillers this morning or did the houseparent give them to you?

P1: She gave them to me this morning, now I was complaining of the pain yesterday and they said that I would have to ask for them when I need them, when it gets bad like the ear like.... of the antibiotics, those are not strong enough for me

R: So you don't manage your medication in the house yourself or do you?

P: No the houseparent does that for me

4.4 Social health

Social health explained their relationships with family, friends, peers, boyfriends and social care professionals. The nature and extent of interpersonal relationships were multivariate.

4.4.1 Interpersonal relationships with family

In their self-reports of family relationships three adults had both parents living, three had a mum living, one had a dad living, one was a ward of court, one had lived with an aunt whom she called 'mother', one was married, and four did not have parents alive. Six reported experiences of satisfactory family relationships, two were unforthcoming about family relationships and four reported negative experiences of family relationships.

Those who felt more of a sense of belonging and connectedness with family and friends demonstrated greater certainty in their identity and satisfaction with choices made. For example, P11 felt that she was missed when she was not at home. She said that her mum missed her help around the house (making coffee and cleaning) and walking the dog:

FNID27.01.12.P11.1.20.35:25 a sense of belonging

P11: Yeamammy, my mammy keeps missing me when I'm not at home. Yea for making tea and coffee she misses me, yea for taking the dog for a walk my mammy misses me...she misses me help....my mammy misses me ...for taking the dog for a walk. XXX (dog's name) is my mam's dog and XXX (sister's name) dog and XXX (brother's name) dog.

P11 enjoyed talking about her happy experiences from home and of feeling valued and of belonging. She enjoyed connection with a home environment a loving family, a sense of acceptance and a sense of value. She looked forward to her visits home. Her contributions were valued and she had a sense of well-being and belonging.

4.4.2 Interpersonal relationships with peers, friends and boyfriends

Reports of social health pertaining to relationships with peers, friends and boyfriends were variable in nature and extent.

With regard to peer relationships, those who shared their lives in group settings were resigned to the reality that they got on with some peers better than others. Interactions with peers in group managed services were often challenging, for example, one adult did not want to move house because those in the other house would be 'bossing', another felt exploited by peers as her belongings had been stolen, another was being 'followed around the house' by a peer, while another had peers entering the bathroom while she was bathing.

Rules impacted on choices made. For example, the rules stating that bathroom doors were not to be locked had consequences for a lack of privacy. Rules also affected adult privacy during coffee/lunch breaks with their friends. As they were accompanied by houseparents' they felt that they did not have

the opportunity to have a private conversation with their friends. Additionally, living in community residential houses also restricted individual privacy to receive visitors. One adult who lived with two others tended to visit her boyfriend in his apartment rather than her boyfriend calling to her house. In doing so, she left her own home to ensure privacy. However, this freedom to choose was not available to many.

With regard to friendships, while seeking to talk to most people she met in differing contexts, one adult did not express the desire for close friendships or present with having any close friends. Two adults reported close friendships with other peers. Four identified having three to four close friends. Ten spoke of friends in the context of acquaintances who occasionally went for coffee together. Another who lived at home did not identify a specific friend or did not speak of going for coffee with friends. One regarded a paid employee as a friend. One had a friend (who was a nun) outside of the service. And during the course of the research the service organised a 'volunteer friend' for another. Two reported that they had boyfriends in the past but at the time of the research study were not in a relationship and two were in long-term relationship with boyfriends. The following demonstrates how one adult allowed a relationship to continue even when being treated disrespectfully until on the advice of a houseparent, she eventually called it off:

FNID01.02.12.P8.1.51.56:00 feeling disrespected

R: So if you would like to change something what's the biggest thing that you would like to change at the moment?

P8: *I broke up with my boyfriend about a year ago. He wasn't right for me, he was calling me names and everything, he was calling me 'fatty' and 'four eyes' and all this, I give him the boot. I give him the boot a year ago.*

R: Had you been going out with him long?

P8: *5 years and I give him the boot*

R: That was a long time

P8: *It was, it still hurts me. I cry about it. I see the others in the house and they all have boyfriends and they all go on about it and I have to listen to itI'm meeting my boyfriend, I'm meeting my boyfriend and I'm doing that. That makes me annoyed. I do get annoyed listening to it all the time. I don't like Christmas. I don't like Christmas this year or last year. I don't like valentines nothing like that. I was very upset one weekend. I rang my sister one weekend I was so upset about it. I would love to have somebody in my life. I would love to have somebody in my life, somebody to treat me decent. He treated me like crap! He did calling me names and everything that's why I had a couple of months before Christmas, a bad couple of months before Christmas. I was feeling very low down. That's why I'm not looking forward to valentines. I do cry I'd love to meet somebody...someone decent now...I miss all that now...I miss the romance everyone is talking about that now it's sickening to be listening to each. You know XXX (peer) on the wheelchair she has a boyfriend...and XXX (peer) has XXX (peer) and XXX (peer) has what's his name I forget his name and XXX (peer) has a boyfriend they all have boyfriends except me and I'm listening to it every day: "Ohh I'm after getting my valentines card and all this"*

P8 found it hard to meet somebody. She believed that there was nowhere to go to meet people. She went to the disco in the day service when it was on but believed there was nobody there that would interest her. She didn't go to discos in town, but just went locally to discos organised by the service.

She found it boring to go to the same disco and said that she would love to meet someone who would treat her decent (FNID01.02.12.P8.1 46.45:00 seeking relationships).

For some, a change in service provision meant a change in the nature of friendships. P2 had the routine of going up town each Wednesday with a friend to have a cup of coffee. She used to go with a friend on Wednesdays for coffee and now the friend has gone to another day service. She missed her friend and having cups of coffee with her. She accepted that she now had no one to go to coffee with. She didn't consider any options of how she might continue the relationship with her friend or of opportunities that she might have questioned the situation. She accepted the external control:

FNID19.01.12.P2.1.39.26:00 missing friendship

P2: XXX (peer friend), XXX (peer friend) is going out to XXX (new day service). I miss her now yea; I miss her now from XXX (current day service). because she used to come out with me every Wednesday to.... we used to go out for coffee every... when she was in the workshop we used to go out for coffee every Wednesday now since she has gone to XXX (new day service) we don't meet of a Wednesday and I've no one to go for coffee with me now none of the girls like, inside. We would just go to XXX (near coffee shop) because my legs the way they are we wouldn't go that far like; because the way my legs are I wouldn't put them under that pressure.

Another adult (P8) had access to a volunteer organised by the service. She was delighted with this arrangement, as she had freedom to choose what to do and it gave her a sense of independence, increased her opportunities for control and she described the relationship as 'fantastic' (FNID25.09.13.P8.6.6.1:00 one-to-one). P8 who suffered from depression had previously felt disrespected by her boyfriend, and in a later interview reported better relationships with her family and with her boyfriend:

FNID25.09.13.P8.6.6.1:00 feeling connected

P8: I'm back at work. I'm back with my boyfriend.

R: Is that they boyfriend that you had before?

P8: Yes I'm back with him now He's very good to me. I goes home now at the weekend. I'm going home this Sunday. I have a volunteer now. I have and she's good to me. I meet her next week, next Thursday.

R: how is that working out?

P8: She calls and I go for out for walks and everything. I can call the volunteer and she can call me. I can choose what to do. She comes and takes me out for walks. It's fantastic. I look forward to meeting her.

Gossiping emerged as a significant feature in how adults made sense of their domains and levels of functioning. By gossiping they compared how they were doing with their peers, family and with the general population. And while gossiping by nature contributed to their sense of connectedness, for some, constantly guarding what they said was as important. Conversely, some proffered their personal information, and once others heard it, they considered what was happening with others and how this related to their circumstances. For example, when they heard that another peer had a volunteer, they rationalised what was happening in the context of their own circumstances, and told

others about it. They sometimes told each other about things that they were doing, only to later find that their peers had divulged this information to those in power positions which subsequently had consequences for them being denied control over choice arrangements and their freedom to choose being restricted.

Having friendships and relationships emerged as significantly important aspirations. They compared their friendships and relationships with those of family and others they know. But creating and maintaining of friendships and relationships was highly contingent on the adult themselves and support. Regardless of the types of friendships and relationships identified, opportunities to access friendships and relationships, whether facilitated or restricted, and the nature and extent of the friendships and relationships accessed, impacted on how they responded emotionally.

4.4.3 Interpersonal relationships with social care staff

Adults referred to agency as 'staff' or as 'houseparent' in the context of social care staff working in the community residential houses. While the frontline houseparent-adult interactions happened in an arena of close proximity, there was a wider proximity in interactions between adults and agency in higher order management who they regarded as being 'over the houses'. Adults did not have the freedom to choose their houseparent's and they accepted that they may get on better with one houseparent than another. While some adults experienced some consistency, houseparent's were frequently reallocated to different houses and often took leave of absence. One adult was only informed of the imminent change of houseparent. Interestingly, adults felt indebted to houseparent's with whom they had good relationships, and contributed to taking them out for a meal when they were leaving. But two adults reported moving house and two reported moving day-service with no celebration.

The attitudes and practices of houseparent's influence what adults actually do. P8 said that she had been feeling low and wanted to stay in her bedroom. One houseparent told her to get out of her room and mix with others. She reluctantly complied with the orders of the houseparent and left her room. There was an implicit understanding that the orders of the houseparent had to be adhered to. Whereas another houseparent talked to her and told her to stay in her room when she wanted to and that nobody should stop her doing this:

FNID 01.02.12.P8.1.63.1:20:00 mixed messages

P8: Last year I said loads of stuff and I got ate. I am wasting my time saying things, nothing is done, I am annoyed things. I'm very annoyed about things. We're all annoyed but we're wasting our time. I don't get on with XXX (houseparent)! She's too cross she's too strict! She hunted me out of my room a couple of times last year. She told me to get out of my room and mix. I didn't

want to do that. It's fine when XXX (houseparent) is on. XXX (houseparent) told me to go up to my room when things get hard or when the others are fighting, you go up to your room and don't mind anyone else XXX (houseparent) told me to go up to my room. I ask XXX (houseparent) if it's all right and she says no problem

P2 depended on the houseparent to support her to make choices when buying clothes. This was principally due to the fact that she had difficulties in making sense of sizes (numbers). P2 was satisfied that she made her own clothes choice and accepted the support of the houseparent (FNID 19.01.12.P2.1.24.13:50 dependence).

FNID19.01.12.P2.1.24.13:50 dependence

R: Do you manage your own money?

P2: *Well the houseparent gives me money when I'm going home and that*

R: Does she give you a certain amount a set amount a week or do you say what you want?

P2: *Well she just tells....gives me the money*

R: Do you buy your own clothes or does someone help you out?

P2: *Someone helps me out, the keyworker*

R: The two of ye would go shopping together?

P2: *Yea I'm happy to go with someone because I'm not good at the sums or sizes and I'd need someone to help me.*

R: Do you feel you make choices about the clothes you get?

P2: *I do yea.*

Attitudes and practices of those in power positions which threatened their social health were evident in reports of 'favouritism', 'not treated fairly' or 'not being listened to'. However, one adult who felt intimidated by what the houseparent told her to do availed of the opportunity to report such attitudes and practices:

FNID25.09.13.P4.6.24:06 being told what to do

XXX (houseparent) told us all to do certain things in the house. She told me to do the presses and I said I told xxx there are a lot of presses in the house. And she said do them I know what to do and she stands over us. I told XXX (Clinical Nurse Manager) and I said there's a lot of presses in the house I'm cleaning all that. I said I did the press, three presses I'm doing all that – I did three presses. I said I've finished and she came down and I said and she shouted 'GINYMAC' she shouted, shouted 'GINYMAC' she shouted; I told you to wait for me. I knew myself I could do them but and then the next time then I was doing em...like quietly doing em away and she and she said do this, get a basin and all that and I was doing it like and she standing around like I let her I let her off and I know myself how to do them like. She did the same with XXX (peer) but XXX (peer) can't you see, she gets a little bit upset and can't help that and she needs help. She wrote out a list and she said to P4's XXX (peer) what would you like to do. XXX (peer) can't read properly. I said I'd help her no you won't she'll do it herself XXX (peer) said she can't read. And then am I just gave her a hint.

P4 felt intimidated by the houseparent who told her to do work and stood over her as she did it. P4 met with the XXX (Clinical nurse Manager) who asked her how things were going and P4 told her what is happening. XXX (Clinical nurse Manager) said to P4 'you do not have to do all the presses, do only one – I will write that down' and XXX (Clinical nurse Manager) wrote it on a notice board. The houseparent came back on duty and read the notice board. The following Friday P4 did only one

press. She felt that the houseparent was then being nice to her because the XXX (Clinical nurse Manager) must have had a word with the houseparent (FNID25.09.13.P4.6.24:06).

In saying that, positive experiences were reported by adults who enjoyed positive relationships with social care staff, and felt indebted to some social care staff because they felt cared for and nurtured. One said 'she was like a mother to me' and another was grateful that she could 'talk to the social care staff about her needs for a stepper onto the buses'. One adult felt 'respected' especially in terms of greater freedom to make her own choices. For example, P5 was going to a party on Christmas Eve which was organised between community residential houses for adults with intellectual disabilities who lived in these houses. P5 routinely reported to the houseparent that she was going to meet her boyfriend and would be back to the house in time to go to the party. Going to the party was important to her and she made sure she was home in time to go to the party. She organised her evening around being home in time to get ready to go to the party. She met her boyfriend in town, but left early and got a bus out to her community residential house:

FNID 25.01.12.P5.1.14.4:50 self-organising

P5: But I met XXX (boyfriend) now Christmas Eve and then I left him around 3.40pm got the bus out to XXX (community residential house) because they were having a party Christmas Eve night so I wanted to be home kind of early. They had.... XXX (names community residential house) house came over, XXX (names community residential house) house and maybe XXX (names community residential house) came over and maybe they had just a small party in the house, but I stayed with XXX (peer) and XXX (peer) and XXX (peer).

For most participants the unpredictability of what was happening with regard to their 'disability allowances' due to the current fiscal climate of changing policy and legislation also affected choices. They depended on their disability allowance as support to engage socially with their peers and threats to their social health were presenting when there was a divergence between what they were doing and what others in the general population did.

4.4.4 Interpersonal relationships with social workers

The reports of adults indicated that social workers had differing work caseloads, as some were assigned to those living in the residential setting, others assigned to those living in community residential services and others assigned to those transitioning to the community. Notably, when one adult was transitioning services, for example from community to community residential, she had to 'fit' with the system and accept a change in social worker. Being excluded from the arrangements made she found herself in full-time community residential services and was confused, very distressed and overwhelmed by what was happening. This was compounded by the fact that she was only told

by the social worker when choice arrangements had been made. As these choice arrangements opposed to her aspirations she perceived social workers attitudes and practices to be wrong, unfair and detrimental to her needs:

FNID30.01.12.P9.1.3.1:00 feeling unjustly treated

P9: But like, you can't have someone following you around the house the whole time like, you can't She's following me around the house the whole time like and (cries) she's following me around the house the whole time like and it's getting on my nerves

R: and have you said it to the houseparent's?

P9: yea the houseparent's knows she's following me around the house and they're doing nothing like, they're just sitting there and they're doing nothing for me like they know she's following me around the house and they're doing nothing, they're doing nothing like. I keep telling them she's following me around the house and they're doing nothing like. Eileen she's following me around the house and wearing my clothes. She is taking my clothes out of the wardrobe and not even asking me for them. Now I bought new slippers and didn't even put them on my feet and she's wearing them the whole time (x2). Do you know what I mean, it's not a good thing, it's not a good thing on me, it's not a good thing on my part.

R: your aunt wrote a letter to xxx?

P9: YEAH!

R: what happened with that?

P9: Nothing! I don't think it's there I don't know. She told me she did but I don't know if she wrote a letter. She told me she did all right but I don't know if it's there. All I know is that she was taking to xxx (CRS manager).

P9 felt that she was deprived of the opportunity to participate in the discussions about the choice of where she lived and whom she lived with. She felt that she was deprived of her freedom to live in the community with her family. She felt that she was deprived of personal control to make a choice about where she lived. She felt that she was deprived of the opportunity to have personal control over her belongings as another adult who shared a room with her took her clothes and slippers without her permission and wore them. She had lived in a foster home with her aunt. She believed that it have been decided by others that community residential services would be a better placement for her. She initially understood that she was in community residential services to give her aunt a break not to be there full time. She experienced a sense of injustice as she explained that this was not right and not fair. She was stressed over the situation and continually revisited the stress by verbal repetition (FNID30.01.12.P9.1.3.1:00 feeling unjustly treated)

And furthermore not being in control of this choice situation she opted for non-engagement with the social worker and considered offers of consultation threats rather than assistance:

FNID30.01.12.P9.1.16.23:15 feeling threatened

P9: It's not good for me it ain't good for me it doesn't matter what you say or what you do But I don't know Eileen it's not fair on me, it's not fair on me things are not good like, things are not good like things are not good

R: Do you have access to a social worker?

P9: Don't mind her! She'd do nothing for you" Don't bring her down on top of me. I say to (xxx)(manager of day-service) don't bring her down on top of me. She did nothing for me. She's the one that turned it around I was only supposed to be part-time and she's the one who got me put in full time. I didn't even want that I only wanted part-time. I told her that and she told (xxx) (manager of day-service) to put me full time. That's not good for me, this situation of mine is not good for me! What are my supposed to do like? What can I do like? Get my brother to do something? I want to tell xxx to get me out of the fucking dump (cries).

When the manager offered support from the social worker P9 saw this as a threat. She blamed the social worker for placing her in community residential services without consultation and she did not want to engage with the social worker as she says: “don’t bring her down on top of me”

Conversely P10, when seeking to maintain and possibly raise current levels of control over her choice arrangements, she learnt that she needed to engage with social workers so as to maintain the current levels of control while receiving support. Having greater freedom to choose and wanting to sustain and possibly increase opportunities for control of choices, she was challenged with negotiating a balance between needing support and complying with the expectations of those in power positions:

FNID25.09.13.P10.2 seeking more control

Like planning to go away with one of my friends from the workshop, only my sister doesn't agree with that because I have a disability and I can't manage and I can manage like I'm not on a wheelchair, like, it's really annoying, like, and I can't go away with one of my friends

P10 told XXX (day-service manager) that she was trying to get on with her social worker. She also said it to XXX (day-service manager) that she would like to get away with her friends. Her manager told her to ask her family and to talk with her sister. P6 was willing to go away for the weekend with her but P10's family did not allow this. P10 said that her sister met with the social worker once or twice. P10 could not understand why she was not allowed to go away with her friend. She stated that there was no need to worry about her that she was fine. She did not know why she was not allowed to go and she said that she was not stupid (FNID25.09.13.P10.2).

Conversely, having learnt rules for coping emotionally through counselling sessions two adults reported positive experiences with social workers. Such rules reported by P6 were, ‘when you’re feeling down, don’t keep it to yourself, talk to someone about it, light a candle, have a bath, go for a walk and swing your arms’. P1 felt that meeting and talking with the social worker created a safe space and that she could trust that her social worker to maintain her information as confidential. While this adult had control of the choice to make an appointment with her social worker, she had forgotten to turn up for the appointment and was reprimanded by the agency. On direction from the agency she had subsequently phoned the social worker and apologised.

4.5 Occupational activity

Occupational activity was multivariate, ranging from putting milk in tea to leisure pursuits to having paid employment. The occupations they had in the societies they lived in inspired their feelings of being valued. All accessed the day service, but the hours accessed were variable and dependent on other paid or voluntary work undertaken by the individual adults. Nine accessed one day service and three accessed another. Some also engaged in differing employment opportunities, such as cleaning and secretarial work, and one enjoyed voluntary work. One worked 24-35 hours paid work per week as a chambermaid, three were in paid employment ranging from 2 to 8 hours per week (cleaning jobs and secretarial work), another did voluntary work in a nursing home for 1.5 hours per week (taking older adults to and from activities). Overall, most were satisfied with the mix of hours which they have. Having a working status and getting a wage brought their actual experiences closer to identifying with the ideal adult status.

Routine leisure pursuits were incorporated into the day service schedule. These included basketball, creative dance, arts and crafts, drama, baking, sewing and acting. Adults were also afforded opportunities to engage in drama productions or to display their work in the day service and at art exhibitions. These activities were either within the day service, residential based or community based. The Special Olympics, which provided enhanced opportunities for them to experience self-worth, a space to make meaningful contributions, and for others to acknowledge their achievements, boosted the development of positive identities as they engaged in opportunities which similar to those of the general population.

4.5.1 Eating and drinking

In the daily realities of how choices were made, the simple matter of eating and drinking emerged as a key issue. In the day-service eating and drinking times were structured within schedules. In the community residential houses, choices made with regard to buying, preparing, cooking, and accessing food when eating and drinking, were variable. For example, some were 'not allowed' to put milk in their tea, as houseparent's put milk in their tea and made their lunch. The attitudes and practices of the houseparent's on duty were highly influential in telling them what to eat, when to eat, and who to eat with. But even if what they were told to do was opposed to their aspirations, they generally complied with instructions. For example, P4 wanted to be involved in cooking the turkey on Christmas day but her suggestions to help with the cooking of the turkey were rejected by the

houseparent. P4 complied with the order of the houseparent and did not help cooking the turkey on Christmas day, the houseparent decided to cook the turkey:

FNID15.01.12.P4.1.10.14:00 being told what to do

P4: I wanted to stay in my own house for Christmas but I was told OHH NO YOUR NOT. I wanted to help cook the turkey for Christmas but they said no. I can cook. ohh you can do the wash up now xxx you'll help around the house. XXX (peer) did the wash up with me and the rest of them just sat around.

R: What did the houseparent do?

P4: She just sat down watching TV (television) while I did the wash up that wasn't my house and I was told to do it I couldn't wait to go back to my house – I feel happier in my own house.

On one particular visit to a community residential house just as the houseparent left to go shopping. P1 jumped up excitedly, went to the press, got out a cake and ate a huge slice, while laughing and telling the researcher that she was her chance to eat cake. Conversely, when visited on another occasion P1 had come out in a chronic persistent rash, and was complaining of tiredness, tension, rash and pain. She told the researcher that she needed to watch her diet, eating only eat rice cakes and no junk food.

The above depicts a situation where the adult lived in an environment where she was not in control over her choice of eating and drinking and in the presence of the authority figure she complied with the requirements for her behaviour. However, in the absence of the authority figure, she went against the requirements for her behaviour, doing what she knew she was not supposed to do. But her efforts of taking control in the choice situation rebounded back on her as she ate food which did not agree with her and subsequently feeling unwell, fell back within the remit of being controlled.

Routines with regard to eating and drinking exist in each house and were conditional on the houseparent's on duty. Over time adults adjust by adapting to unwritten rules. For example, P2 had helped the houseparent to prepare dinner on the evening that the researcher visited her. This was not a routine; she said that it happened sometimes. The choice to help prepare dinner was subject to the invitation of the houseparent, and for P2 the unwritten rule was that she waited until she was asked. If she was not asked then she didn't participate in the activity. The level of involvement in the choice to cook dinner was determined by the houseparent and P2 responded to requests:

FNID19.01.12.P2.1.44.27:05 responding to requests

R: What happens for dinner?

P2: Well, we am... sometimes, we help prepare it like you know, sometimes we help prepare it. They cook it as such and we'd help prepare it. We'd clean up the house ourselves and clean it up and keep it tidy you know.

R: How do ye sort the jobs in the house?

P2: Well we all have our thing like. I does the bathrooms; well they just tell us what to do about our jobs. They tell one person to do one job and another person to do another job. I just do the bathrooms during the week like and I get a break at the weekend. I tend to not do them at the weekend cause I likes to take a break at the weekend. Cause I does cleaning in my job like and I want a bit of a break like you know.

While occupational activity was significant for all, those with lower levels of psychological health were challenged to sustain occupational activity. For example, P8 who suffered from depression and had low cognitive functioning had a routine job of peeling potatoes. She reported that she got 'fed up' and refused to peel potatoes and the houseparent's responded by saying, 'it's your house, you do it'. On occasion she had not completed what she was told to do and was challenged to understand what was happening, later apologising to the houseparent for not doing what she was told to do.

Some houseparent's took on the role of cooking the dinner and adults were advised to stay away from the cooker. Conversely, P11 who had a tremor in her hand had burned it while at home doing some cooking. Subsequently she said that she helps her mum to prepare the vegetables, but her mum puts the dinner in the oven. Adults reported variable experiences in their freedom to choose the groceries they bought prepared and ate. Some baked scones in the day service and in the community residential services house with minimal supervision. In some houses they walked as a group to the local supermarket and did the shopping as a group using money and list provided by the houseparent. Once the shopping was done they phoned the houseparent who collected them in the minibus. In another house one adult living with two peers and minimal supervision, walked with her peers to the shopping centre on a weekly basis and did one big shop. They walked back to the house with the trolley of shopping taking the trolley back afterwards. P6 did her own shopping with no supervision. P6 regarded eating well as a significant choice in life. Having a level of awareness and knowledge impacted on the choices she made. P6 talked about the rules of healthy eating when shopping for food. She engaged in listing the fruit and vegetables that she ate that are recommended as being good for you:

FNID06.02.12.P6.1.15.18:06 rules for healthy eating

P6: You have to be healthy now. The reason why people are healthy is that they are happy. You eat well, eat healthy, that's very important -broccoli cabbage carrots parsnips turnips potatoes are all good for you. Fresh vegetables are better than frozen vegetables and it is important to cook fresh vegetables each day.

4.5.2 Day service activity

The adults engaged in a variety of leisure pursuits mostly facilitated within the residential services of the organisation. However, service providers also sought to progress the agenda of integrated leisure activities to promote greater choice range in occupational activity. For example, P10 had previously been involved in drama productions in the community which she had thoroughly enjoyed. However, she told the researcher that the XXX (drama company) closed and the XXX (another company) has taken over, so the drama productions which she had previously engaged were not currently available. P10 stated that 'it's all over now' (FNID25.09.13.P10.2.11 "it's all over now").

Those who perceived that service employees had greater control over what they did as an occupational activity, externalised responsibility for these choices to others in power positions. For example, P10 informed the researcher that she was let go from the job. Her job coach was out on maternity leave and she was waiting until her Job coach returned to work to look for a job. When asked if somebody is filling in instead of her job coach P10 replied that XXX (day service manager) was. She had an idea of what she would like to work at. She did not want an office job but had thought about working with children. She stated that she would have to talk to XXX (day service manager) first to see what he says (FNID25.09.13.P10.2.10 procrastinating).

While many expressed satisfaction with the activities undertaken in the day service, some believed that the purpose of these activities was just to give them 'something to do' or keep them occupied. Many expressed disappointment that the day-service shop, where they sold their products had been closed and were annoyed that this had been done without any consultation. Having the shop to sell their products had provided opportunities for them to experience meaningful contributions and develop identities similar to other adults.

4.5.3 Employment

Of the four adults who had opportunities for employment, each appeared to have employment opportunities tailored to their strengths and needs. Earning their own money afforded them greater freedom to choose, but one adult expressed concern that in increasing her working hours, her disability allowance might be discontinued. Irrelevant of hours worked or payment, having employment afforded them opportunities to identify with adults in the general population, and to make a meaningful contribution to the society they lived in. For example, P6 and her husband were in employment so they had access to finances with which had consequences for personal control and feelings of independence. She and her husband paid rent to city council for their apartment. Having work and paying her way gave her a sense of making a meaningful contribution and of independence. Therefore, P6 had greater beliefs in her own self-worth:

FNID06.02.12.P6.1 49:49:45 meaningful contribution

P6: You have to have a proper approach if you're going to be a counsellor and a proper manner I might ask XXX (day service manager) about being a counsellor.

R: Where would the course be on?

P6: Properly in limerick somewhere

R: Would you say it to XXX (day service manager)?

P6: it's nice to be considerate. If someone is going through a hard time it's nice to listen to them. I'm delighted the recession came in because it makes you realise what life is all about. Before the recession came in people were all about themselves. I like to like I'd like to be a counsellor

R: Do ye have a keyworker system or a system where you set out your plans?

P6: We would yea

R: Would you say it at your PCP meeting annual meeting that you want to be a counsellor?

P6: *That wouldn't ever come up at that meeting*

R: Why not?

P6: *I'd say they wouldn't want me to be a counsellor that's the expression I get like. I feel that being my own choice because I like listening to other people. I know that it can be a stressful job but it's up to yourself to control your stress. I'd like to be a counsellor.*

R: When your next person is centred planning meeting?

P6: *That's in December and our appraisal meeting in July. I would like if you would say it to XXX (day service manager)*

R: I don't think that that is within my role in this research project, you know that I have told you that I will keep in confidence what you say to me?

P6: *Yes, that's very important*

Conversely, P6 spoke of aspirations of 'becoming a counsellor' and spoke about the skills she possessed of 'listening to others' 'letting others talk' and 'offering advice when they wanted it'. Yet this adult did not raise these aspirations to agency, feeling that agency would be hostile to seeing her 'get on'

Aspirations of sharing an adult status similar to those in the general population was entrenched in the significance of these adults did and how this compared with adults in the general population. While many were aware that the ideal adult status might never be achieved, it was important for them to be able to identify similarities with the general population. This process of continually comparing what they do with what other adults do highlight that access to opportunities for meaningful occupational activity and of having their contributions recognised are profoundly important to these adults. Ultimately their occupational activity accounted for their perceptions of the value of their contribution to society and influenced their beliefs and perceptions of control. When they sensed that their occupational activity was limiting or meaningless, or when they were confused about the value of their contribution, they were more negative about the control they had over choice situations. On the other hand, those who sensed their contribution were meaningful had a greater sense of self-worth, and of being valued and of influencing choice situations.

4.6 Cognitive intellectualising

While all of the adults engaged in various activities in day services, many of them had simultaneous opportunities of attending a number of programmes in third level institutions. One had attended a Human Rights programme, one had attended a Programme in Contemporary Living, four had attended an Advocacy and Leadership programme, and one adult had attended both the Programme in Contemporary Living and the Advocacy and Leadership programme. Attending educational programmes in third level institutions increased their likelihood of achieving a sense of meaningful

contribution and they welcomed the opportunity to do so. One expressed a preference of repeating a course in third level education. Undoubtedly, these programmes afforded opportunities for them to develop further acquaintances.

For many, the cost of the programmes was a factor, and while most were enthusiastic and willing to engage in numerous programmes they were aware that access to programmes would be limited due to the availability of monies. For example, P10 was excited about the new course she was starting in a third level institution. She stated that she did an interview for the course and that she was nervous about starting the course. She had not informed her family that she was applying for this course. She opted not to tell them until she was accepted on the programme. The cost of the course is 700 euros half of which she reported was being paid by the day-service manager (repeats this) (FNID11.01.12.P10.1.12 opportunities for education).

While experiencing difficulties with reading, writing and using the computer highlighted the realities of how the functional diversity of some adults diverged from social norms, (that adults generally read and write), and being continually confronted with the divergence challenged her adult identity. For example, P8 did go to school but found it hard to read and write and use the computer. She depended on others to help her with computers, reading and writing, to take notes or sit beside her and type on the computer. She experienced lessened self-esteem and self-confidence – a lesser sense of self-worth especially when difficulties arose and she found it difficult to fit into the expectations of society. She appreciated the current support received from friends and carers. Her level of functional ability impacted on her choice to go to college, but she had been to college for one course and loved it. This course was held in a third level institution but reading, writing and computer skills were not required. She would love to repeat this course again:

FNID01.02.12.P8. 1.4.3:45 opportunities for education

P8: I have difficulty with reading and writing and computer. I get someone to do the computer with me, whoever comes in you know when the helpers come to the day service or in the house. The spellings are hard and writing in stuff I can't do that. I get helpers to do the email for me and in the house too I get someone to do the computer for me. And with the spellings and writing. I need somebody beside me writing everything down that's why I have someone with me XXX (peer) was there last year and wrote down everything for me in a little note book. I have it at home I'll bring it in and show it to you.

R: you did the advocacy and leadership course?

P8. I did that it was a dream come true for me. I did it last year it was 6 days in a university or something. I find it interesting your rights and everything.

4.7 Materialistic malleability

Materialistic malleability determined their access to and management of materialistic possessions and was variable in nature and extent. The following addresses the most prominent issues from their perspectives, namely, in terms of where to live, who to live with, money, transport and mobility.

Where and with whom to live

Where to live and who to live with emerged as a primary concern to the adults in this research study. In terms of housing, one adult lived in a rented apartment in a secure complex in the community. She and her husband had a council contract and paid rent allowance. Two lived at home with family, one of whom availed of a respite care facility. One lived in a two-story community residential house with two others and with minimal supervision (one night a week). Six lived in community residential services with full-time supervision and one lived in community residential services with limited supervision. None owned a house or held a mortgage for their own home. Most of the community based residential houses were two story houses and as a result some ground floor rooms were converted to meet the individual needs of some adults. Additionally, some adults had to move out of their room and move upstairs or move house to accommodate the housing needs of others. All either had their own private or shared bedroom. They were allocated to houses according to who went home for the weekend/holidays and remained, as houses closed at weekends and those that stayed back were moved to other community residential houses. Some voiced aspirations of 'living independently' in the community but when questioned about how this choice could be actualized, it was found that most wanted independence but still wanted support to be present. There was consensus that independence was strongly related to having control in their environments. And while having aspirations of 'independence', many were faced with realities that their aspirations may never be realized. For example, when asking P1 what support she would need to be independent, she replied: 'there is nowhere else I can go- I have to be realistic'.

While some are satisfied with their living arrangements in community residential services, others in stipulating aspirations spoke of 'wanting to get out of here'. For example, P9 asked to get out of the community residential services house and staff said no so she remained in community residential services care:

FNID30.01.12.P9.1.10.15:50 asking to get out

P9: I used to go in on a Friday (cries) no I used to go in for the week and go home on a Friday and then (XXX) social worker do you know her do you? She made it worse for me! I was only supposed to be there part time and I wasn't supposed to get full time at all! (crying) I was only supposed to get part time to give my aunt a break and she told me and she said to me and I asked her could I come out and she said no you can't but like I'm able to look after myself (sobbing) I can look after myself like.

P10 who was living at home and did not want to be told what to do by family members, also wanted to move out of her home and into her own apartment believing that having her own apartment would increase the control she had over her choices:

FNID25.09.13.P10.2.3 wanting out

P10 is motivated to see change with regard to the choice of who she lives with. She reports that she is getting her own apartment and this means that she can come and go as she pleases. She believes that she cannot come and go as she pleases at the moment and believes that getting her apartment will get her control and independence. She wants out of where she is now.

In waiting to have her own apartment despite not being fully satisfied with the circumstances at home, she weighed up living at home against living in the community residential services, and complied with what she was being told to do so as to sustain the control she currently had:

FNID25.09.13.P10 distancing

P10 says that she prefers to stay at home anyway. She considers staying at home in her own house is independence of her rather than staying in community houses. She reports that she cannot stay in the community residential house when sick. When asked if she feels that she has control over choices she replies "Yea". And when asked if she feels that she is able to manage herself at home she replies "Yea". When asked who she goes for help if she needed it she replies that she manages herself, she's fine on her own "I don't want to be near the service XXX, I will be next door to my sister. I'm out and they can't do anything about it...bye, bye, I'm never going back in there anymore. I never liked it there in the first place. Girls following me around and calling me names"

For some, wanting a bedroom of their own is a more significant aspiration than which they live with or where they live, while for others being safe and secure are important factor in choosing where to live. For example, P5 expressed concerns about safety and depended on staff for reassurance of safety. She was satisfied with the arrangements of living with two peers in a community residential house as she felt safe. She expressed if she was to live on her own it would be in the XXX (Secure community complex) as there is security there and she would be safe there, but she did not want to live in town on her own. She saw herself as being safe and secure whilst still in the remit of the service and while she could visualise the possibility of living in a secure environment in the community she was happy with her routine, her boyfriend and her days out. She felt that she was protecting herself when reporting to staff of her whereabouts:

FNID25.01.12.P5.1.28.17:50 reporting to staff

P5: But if I was going away with XXX (boyfriend) for the day I just give (staff) a ring to say that I'm going

R: Would you have any concerns or worries about being on your own?

P5: I suppose at the moment the girls are in the house. I wouldn't like to live on my own totally. Well I suppose XXX (secure community complex) would be safe but I wouldn't like to live in town on my own. At the moment I feel safe when I go down to see my boyfriend in (xxx secure community complex) there is security there, there is 24 hours security. The nursing home is there as well they have old people there. I only go there to see XXX (boyfriend) I don't know the residents I don't go to see them I just go to see xxx (boyfriend)

Service structures supported another adult to live independently in a secure community setting. At the time of this research study P6 was married one year and 5 months. She had gone out with her boyfriend for 14 years and then got married and lived in a secure complex in the community. She regarded this as a significant choice in her life and articulated the associated rules or guidelines for the expectations of a married life “for better or worse, for richer or for poorer” She was married for the past year and expressed the importance of the marriage vows taken. She lived her marriage by continually referring to her marriage vows. As she saw her marriage vows as rules to follow and referred to her marriage in the context of the rules of married life. P6 repeated the rules of married life and applied them to her life each day. Having a husband gave P6 a sense of belonging- it also brought her nearer to the sameness that she desired. Time was an important factor when making choice to get married (FNID06.02.12.P6.1.6.9:47 living independently).

4.7.1 Money management

Policy and legislation impacted on adult choices with regard to money. P7 was 28 years old and lived at home with his mum and dad. When services were cut by government regulations P7 became more dependent on his parents. The free bus service for P7 was being cut and his parents had to pay 70-100 euros per week for transport. A charge was also being installed for respite care of 22 euros and his weekly wage of 13.50 was being stopped. P7 depended on his parents to stand up for his rights. He depended on his parents for money. P7's mum didn't drive, his dad was sick so he was unable to attend his day service facility when his bus service was stopped. If P7 was unable to attend day service the day service place may be revoked. He was aware of the distress the cuts have on family members and subsequently he was worried about what was going to happen and was carrying the burden of the burdened:

FNID30.01.12.P7.1.1.0:0 carrying the burden of the burdened

R: What is this about?

P7: See what's happening, sure I mean I get my money of my mother now and ahh.

R: Used you get money from the day service here?

P7: I don't get my thirteen euros anymore I don't. It's just an awful shock it was.

But, my mother now the shock is my father is just really recovering really from being in hospital with ahh amm I mean like he is still in hospital in Dublin well say. At the moment we'll say. I mean it was like an operation he had they took away the rest of his stomach. So he has a lot of tubes around him he has so but this is he is starting to talk about golf now so there mustn't be much wrong with him now.

R: And your transport isn't stopped at the moment?

P7: No it's like, it's just this this month it's still going ahead but this month. They're still going ahead with it for this month then them...I don't know what for next month. It might stop next month. I don't know but they they but they sure I mean sure it the same my father he's a big celebrity. I'm not sure I mean like sure I was on the paper before and as I say my name was on the paper before when I was very young well say and am am I was uumh I don't know was it I think I was on the leader again it was well not this time. We have to pay by you know by you know by you know by you know by what would you say what would you say what would ahh the think you know that you that you sign you know, you know one of these books that say a check is it I think of it you've to send in one of those a month.

Having an intellectual disability meant that adults were entitled to a disability allowance and while they had individual bank accounts service staff controlled the distribution of monies allocated to adults living in community residential houses and general running costs of the houses. Significantly, at the time that the data gathering part of this research was being undertaken cuts by the government budget to their disability allowance meant that their weekly allowance of €22 was discontinued; a bitter blow creating much distress as it had afforded them opportunities to go up town to have a coffee with friends. Additionally, it was regarded as a 'wage', which constituted part of their adult identities.

Eight adults who accessed community residential services reported varying levels of control over their money necessitating continual negotiation between their perceived need for money and what money staff gave them. Four reported that they individually accessed their own bank accounts. But a sense of frustration was experienced by not being allowed to keep pocket money. P4 reported that the house parents give her pocket money and at the end of the week if she had money left over she had to give it back. The previous weekend she had had €5 left over and she would have loved to have kept it for herself but she was not allowed, she had to hand it back:

FNID25.09.13.P4.6.36:30 not allowed

P4: I would like more freedom

R: Do you have access to your own money?

P4: no they my houseparent manages my money. They manage it

R: How do you feel about that?

P4: I'd like to manage my money

R: Do you think that you would be able to do this?

P4: I would yea I'd say I would, they give us half the money. They give XXX (another peer) and I money every Sunday night and say if we had three euros left over we have to hand it back we can't keep it. I don't know why xxx and I have to hand it back. XXX says there my money. Can I keep it and the houseparent says no you can't it's going back into the purse and I had a fiver left over after last weekend and I had to hand it in – I'd love to keep it

R: How much to you get a week?

P4: It depends on the houseparent; they give us whatever we don't ask they give it to us. They give it to us

R: And how much would they give you?

P4: Sometimes 20 sometimes 30 it depends really

And P9 was denied access to her own money. P9 asked to get out of the community and staff said no. She asked staff for money. Her brother asked staff for money and they say no. P9 remained in community residential services care, lacked personal control over her money and her brother did not get access to her money:

FNID30.01.12.P9.1.10.15:50 lacking control of money

P9: they won't give you money when you ask them you know what I mean they give you fuck all like you don't even get that. Even my brother asked and he didn't get it and he was saying the same thing you don't get it. Do you know what I mean like they don't give it to you like? You have to ask for everything. It's not good for me at all Eileen it's not good for me

P5 lived in community residential services with minimal supervision where set structures ensured that bills were paid had access to her bank account and could withdraw money. Similar structures were set up for P6 who lived in a secure complex in the community and managed her own money while complying with set structures. P7 and P10 lived in the community and their money was managed outside the remit of the staff working in services. However, while P10 had responsibility for she was not able to control how her money was managed. P10 said that the last time she had been paid for her cleaning job her other sister who lived down the road from her took her money. Her sister took her to the bank and got her to take out her money and give it to her sister. P10 was very annoyed over this. While P10 said to her sister "how dare you! I know my rights". When asked if she told anyone what happened she firstly said that she kept it to herself, then went on to say that she told her younger sister. Her younger sister said that she needed to go down to her sister and get the money back from her, but she never got her money back. She engaged in ways of thinking about what she would do in the future and how she could avoid being robbed by her sister. She said that she was going to get a new job and a new bank and her sister wouldn't know about it (FNID25.09.13.P10.2.9 identifying powerlessness).

In the community residential houses, those who had limited understanding of how much money they needed were more likely to accept the amount of money given to them by the houseparent on duty. For example, those going out for the night were given money from the houseparent, the amount of which was often determined by the houseparent on duty as P4 reported:

FNID25.09.13.P4.6.36:30 external controls

some house parents give €20, others give €30, they give it to us, they tell us

Some adults in community residential services who attended the day-service did not routinely carry money or a handbag. Negotiations of asking for money or houseparents giving them money were continual and of those who brought money to the day service, some had their money taken by others, some were told by staff to hide their money, and some kept their money safe. Those who experienced greater difficulties with counting and numbers had greater difficulty with managing money, so were

more dependent on others for support. In terms of banking, some report difficulties and needed help to manage money e.g. to withdraw cash. The more obligated they felt to those in power positions the more their perceived need to spend their money on the houseparent. P3 had her own purse and money and went to town on her own and bought small items. Others were given a certain amount of money to buy toiletries, after which they returned receipts to those in authoritative positions. For example, P11 stated that she took her payslip to the staff room and gave her payslip to the houseparent. P11 was unable to read so she depended on the houseparent for current support to manage her money. The houseparent gave out money as P11 needed money and she also asked the houseparent for money when she wanted. Money was given out based on conditional choices e.g. conditional choices were that she bought personal hygiene items (shampoo, toothpaste, and deodorant) and gave the receipts and change back to the houseparent. This all happened in a routine fashion. When routines happened expectations of roles were transparent and P11 complied with expectation. She appeared conscientious of the need to keep and give back receipts. She took it for granted that the houseparent's had control of her money and that she asked for money, spend it on what was expected and complied with the expectations of keeping, minding and returning receipts to the houseparent's. She was agreeable and willing and responsible in doing this and so had greater beliefs of engaging in self-control:

FNID27.01.12.P11.1.15.21:42 engaging in self-control

R: Do you keep the money that you get paid on the job, do you manage that yourself?

P11: I get payslip last Friday. I get Mon (money)...I get payslip and I give XXX (houseparent) my payslip. I put my I put my payslip in staffroom for XXX (houseparent). The houseparent gives me money for toiletries and dinner I get receipts and I give receipts back I give mine back

R: So when you want money you go to the houseparent?

P11: yeah for toothpaste and deodorant and washbag and I get the money and I get the receipts and take them back

R: Do you do the shopping on your own?

P11: I get stuff shampoo and toothpaste and deodorant and am get mine for dinner

R: And would you go on your own to do all that?

P11: No staff come with me I can't read so staff come with me and come to the bank with me to take out my money and keep it safe.

R: Do you mind that?

P11: No I don't mind

P6 had set practices for specific choices regarding the use of money and used rules to make choices. For example, when planning for the Madonna concert in June P6 stated that "you get out your money, you see what you have and what you can afford" She then went up to the ticket master in XXX street and booked and paid €99 euros for tickets. She also booked the XXX hotel as they had been there before and had been pleased with how they were treated so she choose to go back there again :

FNID27.06.12.P6.4.0:00 re-visiting positivity

P6: We decided before Christmas that we would go to see Madonna

R: How did you decide on Madonna?

P6: We decided that there before Christmas there that we would go to see her

R: So both of you enjoy her! How much were the tickets?

P6: They were €99 euros, we got them after Christmas. You get out your money; you see what you have and what you can afford.

R: How did ye get the tickets?

P6: We got them in the Ticketmaster in XXX Street up in town

R: How did ye decide to go?

P6: And we have the hotel booked (names hotel and address)

R: Who decided on XXX (hotel?)

P6: Myself and my husband we decided together and not behind each other's back and that what's it all about you have to be realistic about it.

R: Why did ye decide on that hotel specifically?

P6: We stayed there at the time of Neill Diamond last year and the staff were very good to us and they were very friendly to us. That's why I would stay there again. If they were not that friendly I would not stay there again. Staff friendliness and cleanliness and all that! The XXX stadium is near enough to it.

4.8 Transport and mobility

In getting around their communities adults used multiple modes of travelling, from walking, community residential service transport, public bus, taxi, trains and planes. Choices of transport available were usually community residential services bus/car, health service bus, public bus or taxi. None held a drivers licence or owned a car. Transport facilitated through the service primarily accommodated group needs and when travelling as a group member they used in the group bus. Choice of transport also impacted on other choices, such as going to the cinema, shopping, or outings and holidays, as individual choices were contingent on group decisions. Travelling in the group bus threatened their identity as one adult considered they were: 'buses for the disabled'. Where they felt that they were being treated well, the more they re-directed choice options to those places and people. When they perceived others as being kind and respectful, they continued to sustain engagement. For example P12 regularly phoned the owner of a taxi company when she wanted a taxi to take her home :

FNID 06.01.12.P12.2.15:00 familiarity

R: Do you book the taxi yourself or what happens?

P12: Well I just have my lunch. I sit down first and I might ring at quarter to two. XXX (Day-service staff) asks me do you want to ring at quarter to two yourself, it's up to you what you want to do. So don't anyone boss you! You are the oldest in paperchain, put your foot down.

R: So you decide what time you want to go so how do you get the taxi?

P12: I ring my company. XXX (taxi driver's name) is my best friend. He says XXX (p12) anytime you want to go home ring my company and they will come out and collect you straight away. They are very good to me and they give me a hand. And I book it for Monday morning then.

R: So the taxi costs you then?

P12: It is €7 euros for the taxi journey. I don't really mind and XXX (houseparent) was saying something about cabs. XXX (houseparent) says you don't have to get no receipt, cause she says you're not a child, she told me I'm not making you out a baby, you're an adult you can do things for yourself.

P6 and P5 accessed public transport independently. One had organised holidays abroad and travelled with her husband. Those who were safety conscious had greater freedom to choose when travelling

independently. For example, P6 felt safe in the community that she lived in. She felt safe in accessing transport. She stated that she had no fears, that she was not afraid of anything. P6 says that it was important to be safe and not to be afraid and she adhered to instructions/rules:

FNID06.02.12.P6.1.40.41:40 feeling safe

It's important to be safe and not to be afraid and don't give out any of your details, mind your handbag, as long as you can keep to yourself, be careful, if they say hello, you say hello back, if they say happy New Year, say happy New Year back, just smile back

P6 was aware that some people can be nosy and expressed how she was aware of how to use social rules to stay safe. She believed when you are out in the community you have to learn your own instincts.

When public transport was not available on a bank holiday P5 sought assistance from staff for her travelling arrangements and by doing so, while normally independent in accessing public transport, she became dependent on houseparent's to go where she wanted to go. While taxis were available they were expensive, and there were no subsistence's available. Some had to forgo the opportunities to attend their programmes in third level institution as when day-services are on holiday, resources were unavailable to take them to the third level venue. Furthermore, available resources sometimes fell short of the requirements necessary to facilitate their aspirations and they were less in control. For example, with regard to public transport, one woman had a specific physical disability and found it difficult to access appropriate public transport:

P12 had difficulty getting on and off the public transport bus as it was too high and she was at the time experiencing limitations in physical mobility. She told her houseparent, who told her not to worry. Her houseparent was going to tell the company. Her houseparent was going to write to the company. P12 and her houseparent were going to go up to the company the following week :

FNID06.01.12.P12.2.7:48 difficulty using transport

P12: I'm not getting the bus anymore because if I had my laptop and bags..... and they said if you want to get a cab on Friday, its' up to you- you can make up your own mind. I'm getting the cab all the time, all the time, because with the bus I was telling XXX (houseparent) bout some of the buses the buses being too high and I couldn't get up and she said don't worry I'll deal with it. I'll talk to CIE buses and tell them you're not able and every Saturday I would be meeting my nieces and I always try to get the CIE bus and too high so she's going to tell them. I should be able to get the bus XXX (houseparent) said don't mind getting on and getting upset and crying well go down and say it and I'm not able with the CIE buses being too high and everything.

R: Is the houseparent writing a letter with you to the bus company?

P12: Yes she is on Monday and on Thursday week we're going up together and going to say it together.

When the public bus available did not have a lowered step, she was unable to get on the bus comfortably, and so resorted to a more expensive option of a taxi. Others also used taxis for travelling. Two have the phone numbers of taxi drivers, who they are familiar with and phoned

routinely when requiring a taxi. When they were comfortable that they were being treated well assured of respect by their taxi driver, they consistently used the same taxi driver or company. For others when their aspirations to access public bus transport independently was denied and they were restricted in their freedom to choose this method of transport, they did not have control of this choice.

P11 travelled on the bus to go to work in the day service with two other girls from community residential services. P11 visualised and verbalised the steps to be taken when accessing public transport independently. In this way, she felt more competent in what she was about to do. She had a bus pass and knew that she showed her bus pass when she got on the bus. She said that she had no problem when she was on the bus. She knew that her bus pass allowed another person to travel with her on the bus and said that some people travelled with her for the use of the bus pass. She was conscious of the steps that she needed to take in order to work the bus pass and took responsibility for minding the bus pass:

FNID27.01.12.P11.1.18.31:31 visualising and verbalising

P11: I have a bus pass. My mammy and myself have bus pas

R: Do you have any problems getting the bus?

P11: No I show when I get a ticket. I show bus pass I show the bus pass we don't pay we have bus pass

R: Any problems on the bus?

P11: No people I can bring some people with me on my bus pass. The bus was packed yesterday.

R: And you were on your own?

P11: No there was XXX (peer) and XXX (peer) and XXX (peer). We go down to XXX (names bus stop) bus stop and the bus comes and sometimes in the morning time we walk to the bus stop and sometimes the bus packed so we get a bus that's not packed buses are really big but sometimes college students and school students on the bus.

Conversely, P4 who knew what to do when accessing public transport was generally confident and satisfied when doing so. However, when one bus driver told her to 'hurry up' she became stressed as she tried to rush but was unable to go as quickly as others. Her self-esteem was threatened as she felt that she did not control the choice situation. P12 felt that her needs were accommodated when the bus driver ensured her safety, from 'being called names' by other passengers, telling her to sit near him. She was glad of his advice and did what she was told so she felt safer while travelling on the bus, knowing that the bus driver was protective towards her. However, having had experiences of being intimidated by bystanders while waiting for the bus and with declining mobility and having difficulties getting onto some buses she resorted to paying for a taxi. Ultimately, if these adults are to access transport independently, the degree of respect given by those who live in society is outside the remit of control of their service support.

4.9 Pacing

Pacing explains how the speed of what adults do compares with what they are required to do. Pacing was variable in nature and extent and different for each adult in each choice situation. When they were physically or mentally able to keep up with what was happening, their pacing met the requirements of what they were told to do and vice versa. For example, P7 took time to think, talk and converse. He repeated single words or says phrases while trying to think of words, for example 'he was what will we say' he needs to have a conversation at his own pace and needs time to repeat words and to think about phrases (FNID30.01.12.P7.1.14.18.30 timing). P12 experiencing declining mobility found it more difficult to keep up with the others 'to get to the bus in the evening' reported that staff told her to finish up earlier so that she would make the bus on time. P11 reported that she got up at six am each morning so as to be ready to get the bus to the day service at eight am.

For life changing choices, such as moving in with a boyfriend, or getting married, P5 felt she might do this 'down the line, maybe in five years', and P6 went out with her boyfriend for thirteen years before getting married demonstrating that these adults need greater time to pace themselves to make such choices. From the adult reports when the pacing of what they actually did was aligned with what they were told to do they had a greater sense of control in choice situations. And from the above in some instances services 'fit' their pacing needs, whereas in other instances adults adjusted to 'fit' with the service requirements.

4.10 Aesthetic acceptance

Aesthetic acceptance explained their views of their personal appearance and how they perceived they are viewed in society. P1 spoke of not wanting to be associated with disability such as 'handicapped buses' or centres for 'disabilities'. P8 believed that she looked disabled and said that she became upset when she looked in the mirror each day and saw 'disability':

FNID01.02.12.P8.1.58.1:04:45 despising disability

P8: I have a learning disability. I get very upset over it. I have a learning disability it upsets me a lot

R: What is it that upsets you most?

P8: I do cry about it I do cry a lot about it

R: What would be the main reason?

P8: The way I am....the way I amthe way I lookYou know being slow in picking up stuff. I do find it the way people look and staring at you

R: And you know you're so good you know you look very pretty?

P8: I don't think that I always put myself down – I don't think that at all

R: You shouldn't put yourself down?

P8: I got used to people putting me down I got used to it. I find it hard to say nice things about myself. I do I find it hard to say nice things about myself. I do find it hard to say nice things about myself, I do. I wish I was normal. It hurts me. I can't understand I have a learning disability and my brothers and sisters haven't I can't understand that and my nieces and nephews don't have it how come I.... When I see them I say why can't I be normal? It does hurt me when I see them normal. It does hurt me I hate it having a learning disability. I do hate it I hate it I do hate it I do cry about it. I have to live the rest of my life with it. I find it hard to, I do find it hard to, I do find it hard to, I do find it hard I do (cries) And it does upset me And I do look at myself in the mirror I wish I was normal. I look at my brother and sisters and their normal and my nieces and nephews and their normal (cries) I just find it hard to accept it why it happened to me and not to the rest of them. I blame my parents over it. I do blame my parents over it. I do blame them. I said to my mother I do blame you what you did to me I do blame her. I told her that once. She said it's not my fault; it's something that happened it's not my fault. Then I look at other people teenagers and it just gets to me it does gets to me.

For many their personal appearance was significant and opportunities to visit community-based hairdressers were welcomed, but they often had to be pragmatic about money when making choices about personal appearance. P1 explained, when having her hair cut, she 'gets it cut very short so that it will do her for a while'.

Their interest in clothing and general appearance repudiates the idea that adults with intellectual disabilities are passive and dependent. In fact, those who emphasized their own interests in personal appearance, clothes, bags, and so on, demonstrated higher levels of emotional stability while those who experienced criticism from agency regarding their appearance had lower levels of emotional stability.

4.11 Aspirations

Aspirations explained what adults wanted to do and many have been highlighted throughout the above sections. Basically these adult aspirations are to live lives similar to other adults in society, to be respected, to have a place to belong and a sense of value. Adults spoke often of being independent and having independence which in the emergent theory influenced their perceptions of their freedom to choose. When the aspirations of how they wanted to live were fulfilled in the realities of what they actually did these adults were more satisfied with choice outcomes.

4.12 Conclusion

The above domains and levels of functioning were the initial introductions to a concept which was to emerge of in the theory of functional diversity. While the functional diversity of the adults in this research study was multivariate so were their experiences of accessing health and social care services. They generally perceived the support received from intellectual disability nurses and relevant healthcare practitioners as being receptive and accommodating to their healthcare needs but expressed greater challenges in their relationships with social care staff and social care workers. Based on this research study, the challenge for service providers is to identify and address current disrespectful practices within the remit of service provision and from family members or the wider community. As these adults progressively integrate into their communities the primary care teams and mainstream services accessible to these adults will be hugely influential in offering choice and control to this group of people. While functional diversity had an immense impact on how these adults make choices it was not their main issue of concern when choices were made. The following chapter focuses on their main issue of concern and the emergent theory.

5 Emergent theory – aligning with the flow of control

5.1 Introduction

The previous chapter introduced the adult participants in this research study and key issues pertaining to their functional diversity. The main issue of concern for these adults is control in environments that are controlling of them. They respond to this main issue of concern by aligning with the flow of control. The conceptual theory which emerges from the empirically grounded data, has been developed through rigorous adherence to the systematic methodological classic grounded theory approach of conceptual field note, associated memos, theoretical sampling, constant comparison and interchangeability of indicators (Glaser and Strauss 1967; Glaser 1978; Glaser 1998; Glaser 2006). Appendix 9 presents an overview of reflections on the researcher's journey using classic grounded theory explaining how the theory emerged. The main focus of this chapter is to present an explanation of the emergent theory. Explanation of concepts are provided when presenting the conceptual theory and are available to the reader on page iv and Table 5-1 on page 133. It is important to emphasise that these explanations are not exhaustive and are not intended to quantify concepts. They simply offer further examples of indicators relating to the same category as a means of attenuating the density of the theory while explaining the process through which the theory emerges. The following addresses the main issue of concern, an overview of the emergent theory, aligning cycles evident in the theory and explication of the emergent categories of framing control, emotional connecting, adjusting compliance being told and actual doing.

5.2 The main concern

Control in environments that are controlling of them emerged as a main concern for adults participating in this research study. Having personal needs and aspirations, while engaging in activities of living, these adults contend with having intellectual disabilities, accessing group-managed services, availing of supports, and living with choice outcomes; all of which impact on choice. The service providers contend with facilitating a group-managed service while seeking to meet the individual needs and aspirations of these adults, who operate neither at one extreme (totally in control) nor the other (totally controlled), but move continually between these opposing spheres. Furthermore, as adults oscillate in the multivariate and complex nature of choices, all adults in this research study frame control, emotionally connect and adjust compliance to what they are being told to do within the boundaries of what they actually do. The following Table 5-1 is a theoretical overview of the concepts and their interrelationships in this thesis as it emerges from the classic grounded theory methodology used.

Table 5-1 Summary of substantive and theoretical codes in the theory 'aligning with the flow of control'

government cuts, policy over us, disability assessments, respite/transport allowance			policy and legislation	external influences	being told
having a/living at home, having a job, getting married, independence, having a family	respectful attitudes		social norms		
being listened to, being mothered, talking, when others are nice	dis-respectful attitudes		attitudes	enacting practices	
Not listening, criticism intimidation, harassment, bullying, favouritism	verbal directives		practices		
orders, telling, instructing, advising	non-verbal directives				
body language, tone of voice, spatial distance, time use, silence	rules				
written rules					
Unwritten rules					
physical health, psychological health, social health, occupational activity, cognitive intellectualising, materialistic malleability, aesthetic acceptance, pacing and aspirations				functional diversity	actual doing
agency, information, supervision, time, equipment, funding			resources	support	
lacking consultation, limiting consultation, reasonable consultation, full consultation			consultation		
pre-arranged arranged self-arranged			choice arrangements		
non-engagement, selective engagement, partial engagement, full engagement				engagement	
being self-directed, effecting actions, self-controlling			in control	positioning control	framing control
increasing self-direction influencing choices gaining control					
being externally directed, having less influence, accepting external control			engaging in self-control		
lacking self-direction, ineffectual actions, lacking control			greater external control		
competent knowing, experiential knowing, factual knowing	automatic knowing		not in control	interpreting	
inquisitive thinking, meticulous thinking, procedural thinking	determined thinking		targeting set practices		
root learning/knowing, practising, self-telling, knowledge repeating, verbalising	vigilant knowing		tracking transparency		
visualising, planning and organising, futuristic thinking, anticipating consequences, insightful thinking, reasoned thinking, reflective thinking	vigorous thinking				
illogical knowing, dependency knowing, routine knowing, knowing rules exist, knowing problems exist	discriminatory knowing		bounded understanding		
limited thinking, limited questioning, naive thinking, not thinking, problematical thinking	selective thinking				
Knowing s/he is powerless to control a situation and not knowing what to do about it	powerless knowing		identifying powerlessness		
Powerless thinking (thinking that s/he has no power), negative thinking (revisiting negative experiences), Obstructive thinking (overly critical of self and others, nothing working)	non-productive thinking				

oppressed mind-set, dependent mind-set, pragmatic mind-set, independent mind-set			frames of reference	
finding it easy, finding it doable, finding it difficult, finding it hard	ability perceptions	power frames		
Restrictive selective, liberating, empowering	freedom to choose,			
over us, over the houses, being under, xxx manager, 'don't bring her down on top of me' 'she's a friend' 'I have no one telling me what to do'	situating power positions			
belonging, contribution recognition, being valued 'my mum misses me' not having a place to belong, lacking contribution recognition isolation, objectification, being moved, being a number,	human identity frames	identity frames		
accessing opportunities for adulthood, doing things similar to other adults satisfactory adult status,	adult identity frames			
being treated like a child, lacking satisfactory adult status				
enjoying success, trusting self and others, confidence, self-efficacy		feeling optimal performance	emotional stabilizing	emotional connecting
securing health and safety, seeking validation, managing connectedness focusing on controllable		alleviating stress		
seeking clearance, seeking reassurance, self-guarding		emotional shielding	emotional self-protecting	
contentment, appreciation, gratefulness, revisiting positive experiences		emotional gratifying		
weighing up, anticipating, reviewing possibilities, problem solving		emotional rationalising	emotional self-preserving	
accepting uncertainty, pleasing acquiescence, drifting passively, generalising (I'm here a while)		accommodating obscurity		
avoidance, don't rock the boat, things are good for me now, fear of complaining, indebtedness		keeping fear at bay	emotional de-stabilizing	
unhappiness, nervous tension, anxiety, strain, hassle, pressure, constant worry, mistrusting, feeling disconnected, doubting, overwhelmed		stressing		
mourning loss of normality, carrying the burden of the burdened continually revisiting stress, repeating		ruminating		
hopelessness, despondency, feeling rejected, not bothering, mis-fitting, giving up, wasting my breath, why bother, it's not good for me, nothing is done, nobody listens		despairing		
self-discipline, binding devotion, religiously complying, using rules to make choices by		committed complying	model complying	adjusting compliance
telling others what they should do, telling others what to do		compliance seeking		
cautiously doing as told, cautiously confident in doing, checking		tentative complying	functional complying	
does as told, meeting expectations, 'tells agency what she is going to do' making choices by rules		sufficient complying		
Does some of what s/he is being told to do, lacking completion, making choices with rules		partial complying	selective complying	
settling for less, 'xx sets up the schedule out and we do it'		submissive complying		
defiantly doing as told, mentally opposing 'I didn't want to go' making choices to rules		resistant complying		
failing to do as told, not doing as told, walking out, running away, ignoring the rules, breaking the rules		non-complying	dissentious complying	

5.2.1 Theoretical overview

The conflict for adults between being told what to do and what they actually do in their lives determines and is resolved by how they 'align with the flow of control'. This pattern of 'aligning' explains how they regimentally respond to the control they have of their own lives in environments that are largely controlling of them.

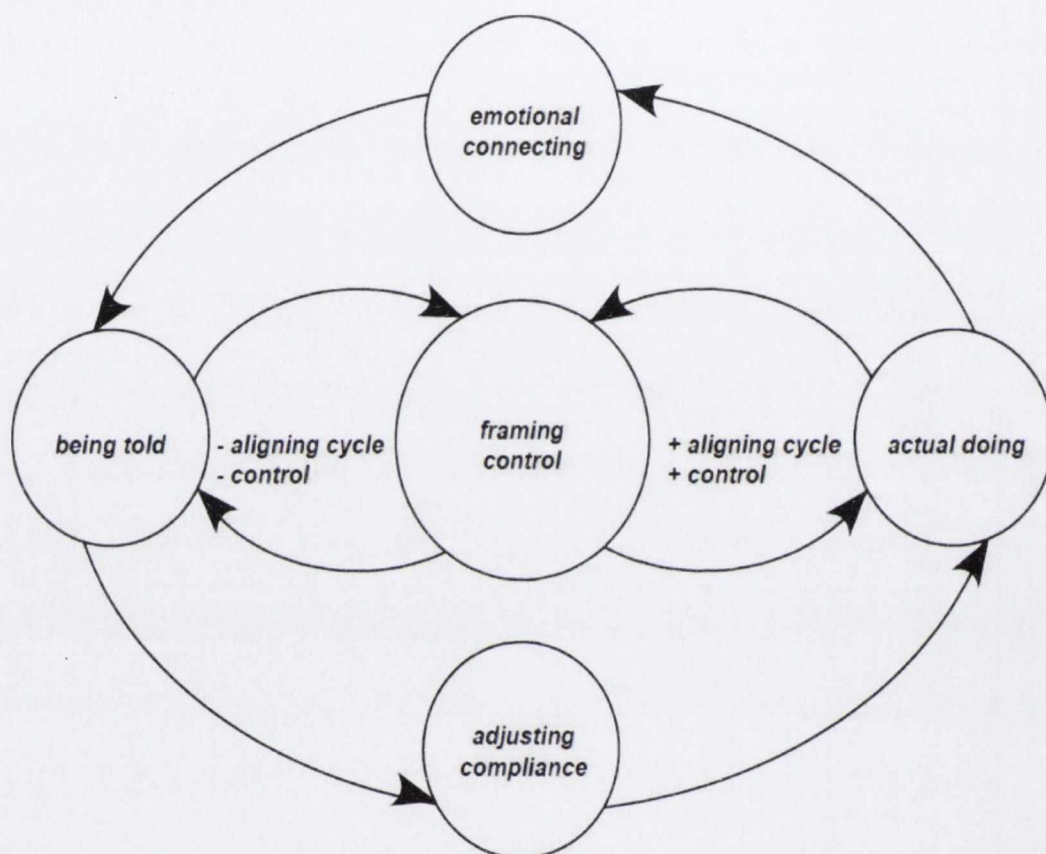


Figure 5:1 Diagrammatic representation of the theory *aligning with the flow of control*

This theory provides an explanation of interactions in the way adults frame control, connect emotionally and make adjustments in compliance behaviours within the boundaries of their actual doing while being told, all categories being connected through an interactive family theoretical code.

Framing control is a sub-core category of the theory which explains that adults draw on a bank of ideas, make interpretations and position the level of control they have in current choice situations. It explains the nature and extent of conditions which continually inform adults of their general control beliefs and specific perceptions of control in choice situations. In framing control they continually assess the compatibility between what they are told with the realities of what they do. Making comparisons about the nature and extent of compatibility between what they are told and the realities

of what they do has consequences for their emotional wellbeing and the adjustments and compromises they make, all of which feed back into how they frame control.

Framing the control they have, they simultaneously make emotional connections and adjust their compliance behaviours within the boundaries of what they actually do while being told. Taking cognisance of their feelings they emotionally connect with the control they have in choice situations. Emotional connecting underpinned by emotional de-stabilizing, emotional preserving, emotional protecting and emotional stabilizing explains the differing levels of adult emotional responses. What these adults are told to do is generally fixed, and even though negotiations are allowed, compliance is usually a requirement. Adults emotional responses are influenced by what they are actually doing and also indicative of how they make adjustments and compromises in their compliance behaviours. Adjusting compliance underpinned by dissentious complying, selective complying, functional complying, and model complying explaining differing levels of adult compliance behaviours. How adults frame control and respond emotionally is indicative of how well they adjust their compliance behaviours to being told to do within the boundaries what they do.

Being told underpinned by external influences of government policy and legislation, social norms and by agency attitudes and practices defines the boundaries of how adults are to behave. Actual doing underpinned by adult functional diversity, the support received and how they engage refers to their actual behaviour in the realities of making choices rather than how they are told to behave. The essential makeup of the factors which directs their behaviour when choices are made are rooted in what they are being told to do, but, their choice experiences differ in response to the multiple and diverse realities of what they actually do.

5.3 Aligning cycles

Aligning with the flow of control is the means through which adults come to terms with the control they believe they have in environments that are controlling of them. Aligning cycles denote the equilibrium that exists in the interactions that happen when adults frame the control they have over the choice situation, which is counterbalanced by how they emotionally connect and the adjustments they make in compliance behaviours, all within the boundaries of their actual doing when being told.

In normalizing routines, effecting or adapting to change, aligning maintains, creates or changes the state of equilibrium that exists in the interactions. Aligning with the flow of control is dual-directional. These dual directions are conceptualized as positive or negative aligning cycles, as adults respond by either assimilating what they are being told to do, creating personalization and ownership

and being self-directed in choice arrangements, or by being externally directed and retreating back within the remit of expected roles of subordination. The movement of the balance which exists between being externally directed and being more self-directed is therefore conditional upon the flexibility, rigidity and integrity of the boundaries of being told and their actual doing.

The direction and extent of aligning is determined by the sub-core category of how adults frame control, by which they weigh up influencing contextual factors relating to being told what to do within the realities of their actual doing in order to choose what to do next. Their choices are always situated in the customized, multivariate and ever-changing conditions that affect them and determine the nature and extent of aligning. In response to fixed situations their responses are relatively stable, whereas in response to changing situations, they refer to 'a new rule' when interpreting and considering its' consequences on the current choice arrangements. Ultimately, regardless of consistency or changes in choice situations, it is how they frame control that aligning cycles are set to move in either a positive or negative direction. The terms positive and negative are inspired by the notion of homeostasis, whereby framing control positively or negatively initiates changes or sustains stabilization in their experience of equilibrium.

Positive aligning cycles are indicative of those who have higher levels of control and emotional wellbeing and adjust well in what they do to meet the requirements of what they are being told to do. Positive aligning cycles underscore that they are more self-directed in what they do, rather than externally directed by being told. Those who frame control more positively set the direction of a positive aligning cycle which emphasizes their actual doing. A positive aligning cycle moves the equilibrium towards the realities of actual doing. A positive aligning cycle minimizes the significance that compliance is a requirement of being told. Positive aligning cycles are going with the flow of control and embracing the flow of control.

Negative aligning cycles illustrates that what adults actually do is more externally directed and maximizes the significance of compliance. Negative aligning cycles explain that those who frame control more negatively are more likely to have lower levels of emotional well-being and demonstrate lower levels of compliance. A negative aligning cycle positions the equilibrium by oscillating back towards being told what to do, contingent on their levels of compliance within the boundaries of what they do. It can be created when their actions are externally directed so as to bring their actual doing back into line with the boundaries of what they are being told to do. Subsequently, they can have lower levels of control and have varying degrees of satisfaction over the choice arrangements. Low levels of emotional connecting and adjusting compliance have consequences for the equilibrium moving towards being more externally directed. For example, when negatively framing control, they are more driven by the remit that they are being told what to do and as a consequence of intensified agency enacting practices, retreat within the remit of being told. Or alternatively, where they seek

help they re-direct the equilibrium back towards the remit of being told, until they feel well enough to engage in self-directed behaviour. Negative aligning cycles are resisting the flow of control and getting carried by the flow of control.

The direction of the aligning cycle is conditional on what they are actually doing. Functional diversity has consequences for their willingness and preparedness to meet the requirements of what they are being told to do. And how they respond emotionally is indicative of how they make adjustments in their behaviours to comply with being told so as to accept the way things are within the boundaries of their actual doing. However, when what they actually do deviates from what they are being told to do, enacting practices are amplified by agency and the equilibrium moves back within the remit of being told.

Varying degrees of deviations occur, from none at all to significant in the interaction of what they are being told to do and their actual doing. When levels of emotional connecting and adjusting compliance are high, aligning moves towards being more self-directed, and is increasingly guided by what they actually do rather than they're being told what to do. For example, with regard to being told what to do in the context of a choice to cook dinner, those who break down the elements of the required behaviour by targeting set practices and personalizing ownership and responsibility, committing and executing the choice as expected, and is satisfied with the choice outcome. Whereas reduced levels of emotional connecting and adjusting compliance have consequences for those who may experience anxiety and poor concentration and those adults may align their approach by seeking support and increasing external control rather than continuing to be in control. For example, an adult who recognizes that she 'hears voices' seeks help from staff, thereby repositioning her perceptions of control to greater external control and she relies on them to make the necessary choice arrangements so as to alleviate her concerns. While this deviates from the instructions of being told it does not constitute such significant deviation as if support was not sought. It facilitates emotional stability as the adult experiences a satisfactory sense of control. Whereas, when control is framed negatively the equilibrium is counterbalanced by lower levels of emotional connecting and adjusting compliance, and adults either retreat back within the remit of, or burst outside, the boundaries of what they are being told to do.

The opposing drivers of agency enacting practices and adult functional diversity further influence the nature and direction of aligning with the flow of control. When agency enacting practices emphasize how, where, what, and when, things are to be done, a negative aligning cycle is instigated. Furthermore, when enacting practices have consequences for choices being increasingly agency - driven, and when opportunities for engagement are minimized, this in turn decreases the likelihood of their achieving satisfaction within the boundaries of what they actually do and so reaching an unsatisfactory choice outcome. Additionally, while a negative aligning cycle emphasizes that they are

being told what to do, it can also double back on itself to decrease the attainment of compliance though non-engagement from those who are in disagreement with what they are being told to do.

Whereas when their own functional diversity is supplemented with support, and capitalized on by their engagement, the ultimate extent of positively aligning with the flow of control is optimally characterized by their experience of optimal control, while their actual doing influences and is influenced by being told what to do. For example when they successfully break down and assimilate what they are being told to do a positive cycle is created, as they are more self-directing in the realities of their actual doing. Through this continual reactive interplay, they cycle continually as they are aligning with the flow of control to the interaction of what they are being told to do with the realities of their actual doing, while operating within the remit of being told and the boundaries of their actual doing.

5.3.1 Resisting the flow of control

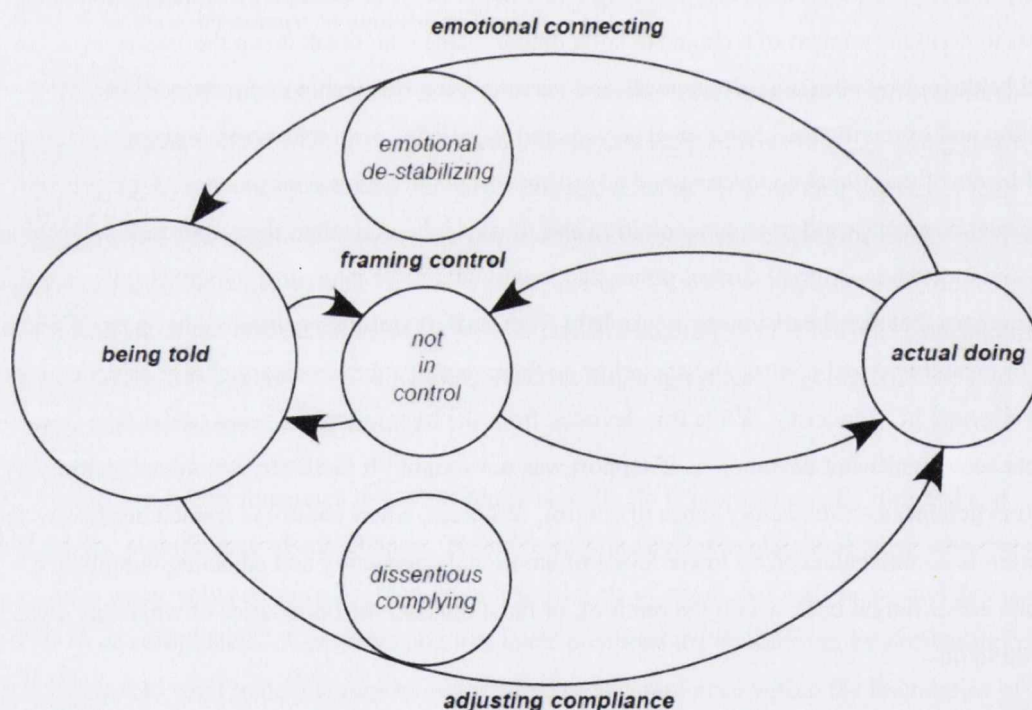


Figure 5:2 Diagrammatic representation of *resisting the flow of control*

Resisting the flow of control denotes adult responses when the reality of what they do is oppositional to what they are being told to do. The significant incongruence between what they do and what they are being told to do has consequences for these adults to frame control negatively. Lacking opportunities for self-direction they believe that they are not in control of choice situations, are more

emotionally distressed and the compromises and adjustments they make are dissentious. When incongruences exist between what they are being told to do and what they do, enacting practices intensify and they are compelled to align with what they are being told to do. The equilibrium moves towards being totally externally directed and lacking any opportunities for self-direction they are made to do as told. The following presents an example of resisting the flow of control:

FNID19.01.12.P4.2.4.4:15 resisting the flow of control

P4 stipulates that she wants to go to town for a coffee on her own with her friend. Her houseparent says no and goes to town with her and her friend. Rules impact on her choices as e.g. "having epilepsy means that you cannot go to town without staff". While, she wants to have a cup of coffee in town; the houseparent tell her and her friend to have dinner. In town after her dinner, she wants to have a cup of coffee but the houseparent tells her and her friend they can have it when they get home. The houseparent gives the orders and she complies. She is stressed by the situation and engages in resistant complying as she feels that there is no other option but to comply with what she is being told to do by the person in the power position. She believes that the houseparent controls what she eats and drinks, when she eats and drinks and whom she eats and drinks with. She has beliefs of not being in control of this choice of going for a coffee with a friend.

The adult in the above scenario draws from a bank of ideas where her adult identity, her oppressed mind-set, and the lack of power she has in the choice situations have negative connotations. Along with the negativity of these frames of reference as she interprets the choice situation she identifies powerlessness and she has no control in choice situations. Negatively framing the level of control she has, she is emotionally stressing while being dissentious in the adjustments and compromises she makes to comply with what she is being told. Furthermore this adult resents the control of those in power positions, which negatively feeds back into how she frames control, counterbalanced by emotionally stressing and dissentious complying wherein the equilibrium maintained at a negative aligning cycle. This in turn is limiting for her in achieving a sense of independence.

5.3.2 Getting carried by the flow of control

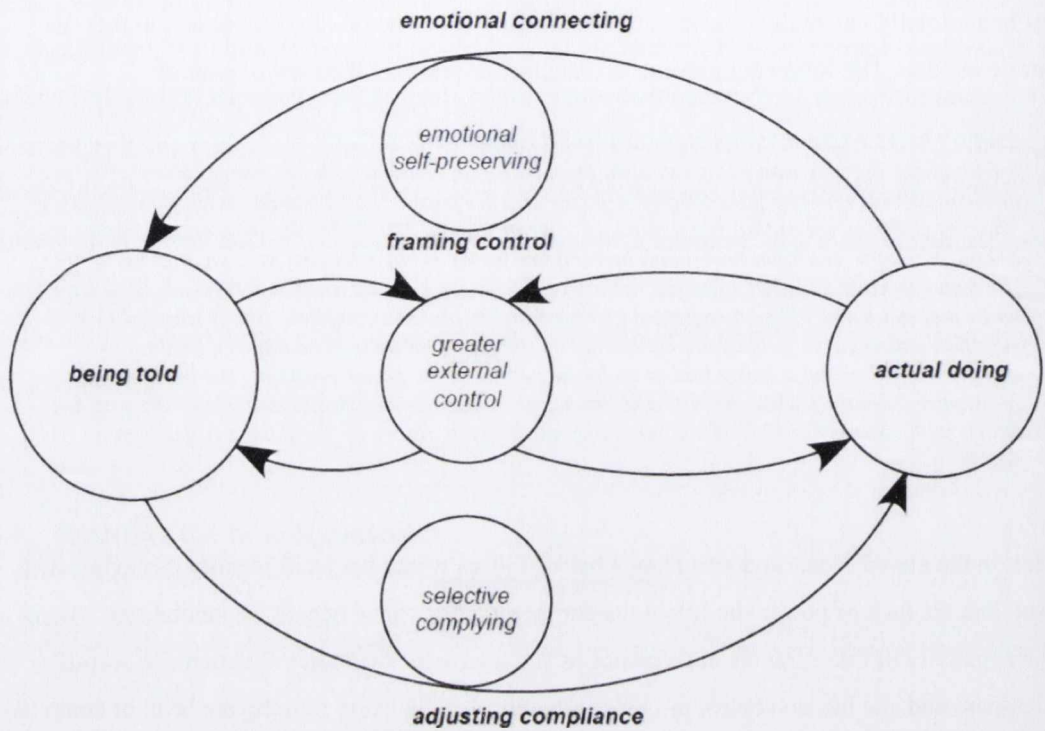


Figure 5:3 Diagrammatic representation of getting carried by the flow of control

Getting carried by the flow of control denotes adult responses when the reality of what adults do is continually challenged to meet the requirements of what they are being told to do and are routinely satisfied, fearful or unquestionably make choices within the remit of what they are told. Adults, who believe that others have greater control of choices situations, are more emotionally focused on their own self-preservation and the compromises and adjustments they make in their compliance with what they are told to do are selective. The following presents an example of getting carried by the flow of control:

FNID23.01.12.P1.1.5.6:25getting carried by the flow of control

P1 does not manage her own medication. She is given her medication by the houseparent. When asked if she would like to manage her own medication she procrastinates providing an immediate yes or no but rather discusses the implications if somebody happened to take the medication in error. She talks a lot about the possibility of somebody taking the medication and she appears scared that this would happen to her and her medication if she were to manage it herself. She is of the understanding that it is the health board has implemented such policies which subsequently are rules which have to be abided by. She has learned to abide by the rules even if she does not agree with them. She submissively goes to the office and takes her medication when instructed to.

In the above scenario what the adult does in the reality of making choices is challenged to meet or sustain what she is being told to do. The adult draws from a bank of ideas where her adult identity, her dependent mind-set, and the presence of external of external power in the choice situations have negative connotations. And along with the negativity of these frames of reference as she interprets the choice situation with bounded understanding, determines that there is greater external control of the choice she makes and counterbalances the equilibrium by her focus on emotional self-preservation while the compromises and adjustments she makes in compliance are selective.

When there deviations are likely between what she is being told and what she does, agency intensify enacting practices so as to bring her actual doing in line with required behaviour. The equilibrium moves towards being more externally directed as she operates within the remit that she is being told rather than being self-directed in what she does. The equilibrium continues to be maintained by a negative aligning cycle, wherein whether satisfied or fearful, she is more guided by the fact that she is being told what to do rather than being self-directed in what she is doing. She is accepting of the external control and externalizes control to those in power positions, as she focuses on self-preservation feeling fearful of failure in administrating her own medication and feeling safer with the control of the medication being with those in power positions. Whether satisfied or not with greater external control, such perceptions negatively feed back into how this adult frames control, which she counterbalances by emotional self-preserving and selective complying, all which in turn is limiting for her in achieving a sense of independence.

5.3.3 Going with the flow of control

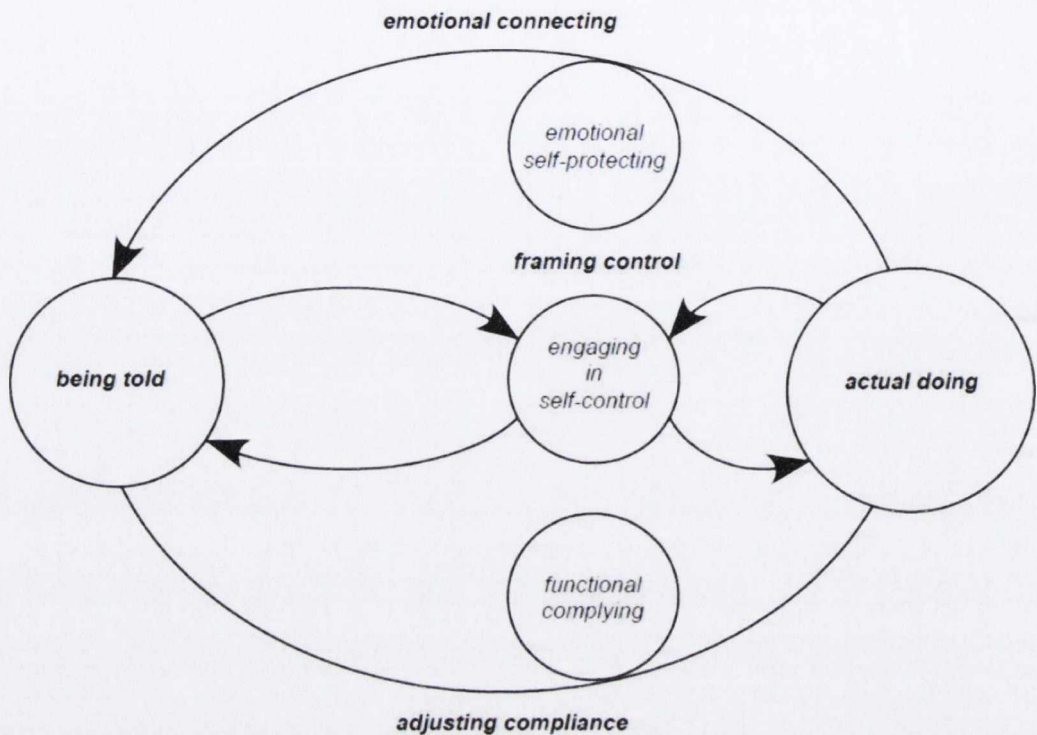


Figure 5:4 Diagrammatic representation of *going with the flow of control*

Going with the flow of control denotes adult responses when the reality of what they do continually meets the requirements of what they are being told to do when choices are made. Adults, who believe that they are engaging in self-control of choices made, are more emotionally focused on self-protection and they are functional in their compromises and adjustments they make in compliance with what they are told to do. The following presents an example of going with the flow of control:

FNID25.01.12.P5.1.2.0:25 going with the flow of control

P5 continually lets staff know what she is doing, who she is with and where she is going and when she is back. She says she can come and go as she pleases but the only thing is she lets staff know, "and they don't mind" P5 has a clear understanding of the unwritten rules and engages in reporting her whereabouts continually to staff. What P5 does is routinely done each week. Her behaviour is predictable. She feels more secure that she lets staff know where she is going and what time she is back at. She lives with 2 other adults in a community residential house, where staff stay just one night a week.

In the above scenario what the adult does in the reality of making choices begins to consistently succeed in meeting the requirements of what she is being told to do. The adult draws from a bank of

ideas where her adult identity, her pragmatic mind-set, notions of having power with regard to the choice situation has positive connotations. And along with the positivity of these frames of reference she interprets the choice situation by tracking transparency, engages in self-control, and counterbalances the equilibrium by her focus on emotional self-protecting while she is functional in the compromises and adjustments she makes to comply with what she is being told. Agency enacting practices are less intensified as there is less agency requirement of her to comply with she is being told to do. The equilibrium moves towards being more self-directed, as she begins to function more within the remit that she is doing rather than being told to do it.

Congruence between what she actually does and what she is being told to do has consequences for framing control by frames of reference with more positivity, and through tracking transparency and engaging in self-control, a positive aligning cycle is initiated. Here she breaks down and internalizes what she is being told to do while complying within its boundaries. Engaging in self-control is counterbalanced by emotional self-protecting and functional complying, which maintain the positive aligning cycle. The equilibrium moves towards being more self-directed, as she is increasingly guided by her actual doing she begins to operate more within the remit of being self-directive in what she does rather than being told what to do and the equilibrium is maintained by a positive aligning cycle. Engaging in self-control is indicative of emotional self-protecting and functional complying. She is cautious, gaining confidence and aware that she is gaining independence. This feeds back positively into framing control, emotional self-protecting and functional complying, which in turn, is facilitating opportunities for her to increase a sense of independence.

5.3.4 Embracing the flow of control

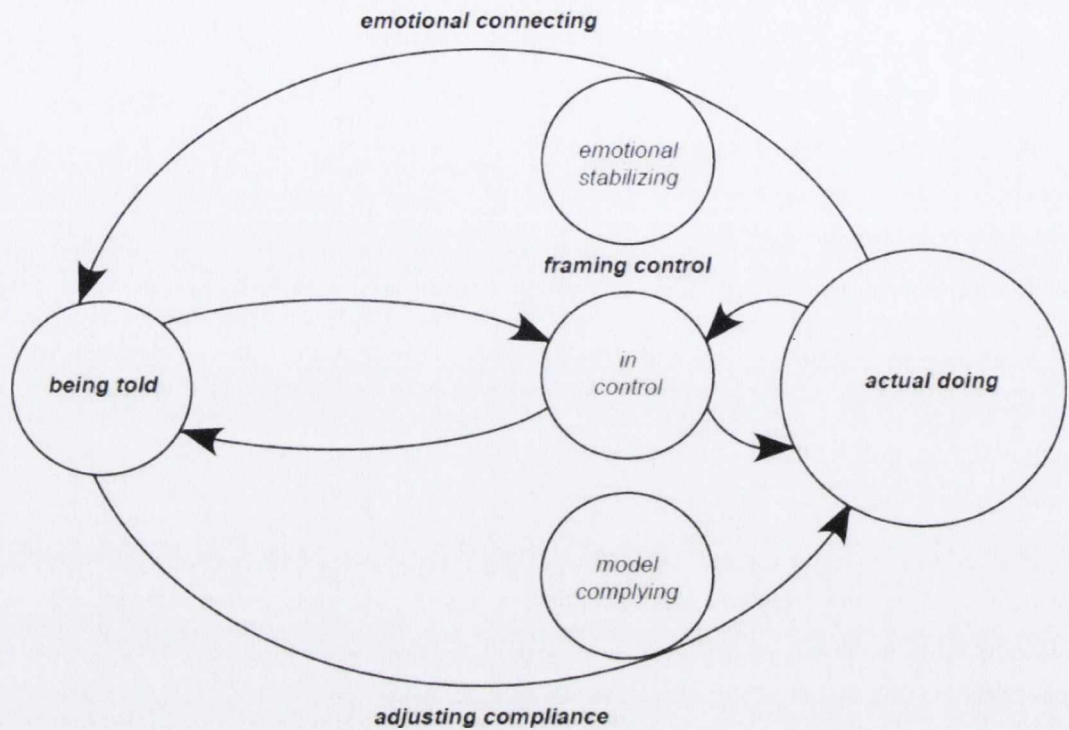


Figure 5:5 Diagrammatic representation of embracing the flow of control

Embracing the flow of control denotes adult responses when the reality of what they do consistently meets the requirements of what they are being told to do. Adults, who believe that they are in control of choices made, are more emotionally stable and the compromises and adjustments they make are ideal in compliance with what they are told to do. The following presents an example of embracing the flow of control:

FNID06.02.12.P6.1.32:33 embracing the flow of control

P6 goes shopping for her own clothes. She chooses what shops to go to and chooses when she does her shopping. P6 states that she likes shopping for bags and shoes. She loves clothes. She likes good quality clothes which she regards are in XXX and XXX. She prefers to go and do her own shopping and feels enjoyment and pleasure when shopping independently. She knows what suits herself and shops by using rules, for example "if you want help ask the shop assistant". She has no supervision while shopping and believes that she is in control of the choices she makes.

In the above scenario what the adult does in the reality of making choices consistently meets the requirements of what she is being told to do. The adult draws from a bank of ideas where her adult identity, her independent mind-set and notions of being powerful in the choice situations have positive connotations. Along with the positivity of these frames of reference she interprets the choice situation

by targeting set practices and is in control. Congruence between what she does and what she is being told to do has consequences for framing control with more positive frames of reference, targeting set practices and being in control, initiating a positive aligning cycle. The equilibrium is counterbalanced by her focus on emotional stabilizing while the compromises and adjustments she makes are ideally compliant with what she is being told to do maintaining a positive aligning cycle. She successfully breaks down and internalizes the requirements of what she is being told to do while complying within its boundaries. When what she does consistently succeeds in achieving and maintaining the requirements of what she is being told to do, agency enacting practices are minimal and there is no agency requirement of her to comply with what she is being told to do. The equilibrium moves towards being self-directed, as what she does has more significant than what she is being told to do. She is doing rather than being told to do it and emotional stabilizing and model complying counterbalances the equilibrium of the interaction. As she is self-directed in what she is doing the equilibrium is maintained by a positive aligning cycle. Being in control is indicative of emotional stabilizing and model complying. She is totally confident and aware of her independence. This feeds back positively into framing control, emotional stabilizing and model complying which, which in turn, is facilitating her sense of independence.

5.4 Framing control

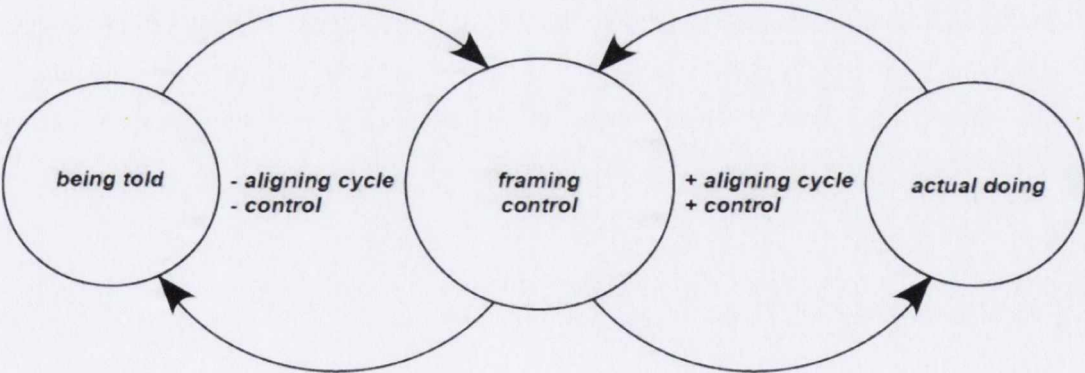


Figure 5:6 Diagrammatic representation of *framing control*

Framing control is the sub-core category of the theory of aligning with the flow of control underpinned by frames of reference, interpreting, and positioning control. The term framing control denotes the contextual, variable and powerful nature of what underlies approaches to aligning. It explains that adults draw on frames of reference from past and current choice experiences which they project onto current choice situations, while they make interpretations and position the control they have within the boundaries of what they are being told to do and what they are actually doing.

5.4.1 Frames of reference

Frames of reference explain the bank of ideas which adults draw upon and project on to current choice arrangements. Based on their past experiences and current realities, frames of reference are the grounding elements influential in guiding how they frame control.

Many factors influence frames of reference, contextualised as identity frames, power frames, and mind-set frames, which contribute to how adults frame control. Factors such as values, customs and individual and group views are the foundations for ideas formed and stored as a bank of ideas to draw from when faced with the daily realities of what they are being told to do. They use these frames of reference as counterbalancing coordinates, leading to, and indicative of how they frame control. Frames of reference may be positive or negative, ingrained or open to change, and influenced by themselves and agency. Frames of reference are articulated positively by those who identify themselves as having human value similar to those in the general population, living similar lives to other adults, and being generally satisfied with their lives. Negativity in frames of reference is indicative of those who perceive themselves as: having less human value, living lives that are different to other adults, and being generally dis-contented with their lives. Regardless of positivity or negativity in the frames of reference formulated, they are permanently open to being reformulated as a consequence of the continual interaction between what adults are being told to do and their actual doing.

5.4.1.1 Identity frames

Identity frames denote the nature and extent of how adult experience being a human and being an adult. Although they have each attained the legal majority of adulthood, the social norms which set the behavioural expectations of adult citizens mean that these adults grapple with their identities on a fundamental level. The greater the deviation between what they are actually doing and social norms

the more negatively they formulate frames of reference and vice versa. Positive identity frames represent affirmative experiences of being a human, such as 'being valued', and 'having contributions recognised', and of being an adult, in terms of 'doing similar things to what adults do', 'having a job', and 'having a boyfriend'. Negative identity frames explain reported experiences which lack humanity, such as, 'being moved', 'being a number' (e.g., when going shopping or on the bus), 'not having a place to belong' (e.g., "there's no room for me at home anymore") or being refused adult status, such as, 'being treated like babies', 'being treated like a child'. The contextualisation of identity frames explains their perceptions of being human and adult. An example of positive adult identity frames:

FNID27.01.12.P11.1.14.18:55 having independence

P11 gets her own breakfast. She uses the microwave to make porridge and likes this, as it makes her feel warm inside. She makes her own sandwiches for lunch herself before going to work.

And an example of positive human identity frames:

FNID27.01.12.P11.1.20.35:25 belonging

P11 feels that she is missed when she is not at home. She says that her mum misses her help around the house (making coffee and cleaning). She says that her mum also misses her for walking the dog. She enjoys talking about her happy experiences from home and of feeling valued and belonging.

Examples of negative human identity frames:

FNID23.01.12.P1.1.13. 14:00 despising disability

P1 has been to visit a day service where she says that there are 'handicapped people' there and that it is not for her. She says that she would be depressed being in that day service and looking at those people every day. When asked did she get a choice to go to the day service she says 'nobody asked me' But she had been there for a visit and did not like it.

And:

FNID15.01.12.P4.1.12.12:45 being moved

Managers organise amalgamation of groups during holiday time to facilitate staff holidays. When arrangements are made managers tell house parents who relay the message to P4 and others. P4 is being moved from her own house to another house for Christmas. There is a lack of consultation with her with regard to this choice and when protests that she does not want to move the houseparent replies "this is what I was told". She moves to another community residential house for Christmas

And an example of negative adult identity frames:

FNID01.02.12.P8.1.60.1:08:00 treating us like children

P8 feels she is being treated like a child because the houseparent does not allow her to make her tea, pour her milk or butter her sandwiches for lunch. She sees her independence as pouring milk in her own tea etc and resents when staff do this. She feels she is being treated like a child.

Whether positive or negative, identity frames lead to framing control.

5.4.1.2 Power frames

Power frames refer to the bank of ideas which they draw upon to make determinations of the likely and actual power they have to exercise choices. Power frames are underpinned by situating power positions, freedom to choose, and ability perceptions. Power frames set the agenda for their determinations of the likely and actual power they have to control choice arrangements.

5.4.1.2.1 Situating power positions

By situating power positions they make determinations on their position within hierarchical power structures. Situating power positions can determine positively: 'I have no-one telling me what to do', and negatively: 'over us', 'houseparent' and 'over the houses'. Situating power positions drives how they frame control.

5.4.1.2.2 Freedom to choose

Freedom to choose denotes the restrictive, selective, liberating and empowering degrees of freedom they have to make choices. They perceive their freedom to choose as restrictive, when, for example they are 'not allowed' relayed as 'not allowed to stay on their own when sick', 'not allowed to stay in their own house when sick', 'not allowed keys to the house', 'not allowed to travel on public transport', 'not allowed to use a mobile phone', 'not allowed to go into town without supervision', not allowed to meet friends, and 'not allowed to manage medication':

FNID23.01.12.P11.1.16.30:00 not allowed

P11 is not allowed to use public transport. She writes a letter of complaint. She has a bus pass and she wants to use this and use the public transport rather than using the community services bus.

The degree of selectivity in freedom to choose is influenced by the interaction of their functional diversity, the existing choice arrangements and what they are being told to do, but bounded understanding is the driver through which they perceive their freedom to choose selectively:

FNID27.01.12.P11.1.23.45:54 selectivity

P11 is part of an advocacy group in the day service. She likes knitting, and when asked what they have advocated for as part of the advocacy group she states more knitting and they get this 'more knitting'

And those who continuously engage in routines without question:

FNID01.02.12.P8.1.17.13:30 routine schedules

Routine schedules for chores are written in the day service and in the community residential house. P8 states that there are routines that grocery and clothes shopping occur on Fridays. Inherent in these routines is the fact that housemates take turns on who goes shopping.

They perceive their freedom to choose as liberating in reports that they have greater freedom to make choices:

FNID25.01.12.P5.1.21.9:00 getting permission

P5 has a houseparent staying in the community residential house one night a week. P5 accepts this as she is aware that for the other six nights no houseparent stays in the house. .

They perceive their freedom to choose as empowering in reports that they have full freedom to make choices:

FNID06.02.12.P6.1.5.7:40 freedom to come and go as she pleases

Structures are set up so that P6 lives with her husband independently in an apartment in the community. The council own the apartment and money for rent and upkeep are deducted from the bank account of herself and her husband. They live together in an apartment where security is present and the main door of the apartment complex is a code system so they has control over who she allows into the apartment. P6 works 3-4 days a week in a hotel adjacent to her apartment. The amount of work she has depends on how busy the hotel is on a weekly basis. On the days that she does not work in the hotel she either works at home or goes to into the day service. The days she attends the day service gives her a chance to catch up on what is happening with her friends in the day service.

Freedom to choose provides a solid source of information for adults to frame their inherent power frames with regard to what they are being told to do. While their functional diversity underpins the realities of what they are actually doing, it is through making determinations on their freedom to choose in the context of what they are being told to do that they derive an understanding of their autonomy.

5.4.1.2.3 Ability perceptions

Ability perceptions provide a further source of information for adults to distinguish their own inherent power frames underpinned by 'finding it hard', finding it difficult, finding it doable, and 'finding it easy'. Within the realities of what they do it is through their own ability perceptions that they make judgements of their ability to comply with what they are being told to do and they derive an understanding of the power they in choice situations:

FNID01.02.12.P8.1.1.57.1:04:45 finding it hard

P8 identifies herself as having a learning disability. She appears to have a low self-esteem and says that she gets used to people putting her down and that she is finding it hard to say nice things about herself. She knows that she will have to live the rest of her life with her learning disability. She is finding it hard to accept that she has a learning disability

FNID.01.02.P8.1.4.3:45 finding it difficult

P8 has access to a computer in the house but has difficulty in reading, writing and using the computer. She depends on others to help her with computers, reading and writing. She depends on staff and on peers to take notes or sit beside her and type on the computer. She experiences lessened self-esteem and self-confidence as she is not able to keep up with the others when she finds it difficult to fit in with expectations.

FNID25.01.12.P5.1.10.2:30 finding it doable

Having a boyfriend is an important choice for P5. She has the freedom to visit her boyfriend at arranged times but she reports to staff when she is going and when she returns to the community residential house. She develops a routine of visiting her boyfriend twice a week and at weekends and is continually reporting her whereabouts to staff. Having time to get to know her boyfriend is important to her and she does not want to rush into things. She is satisfied with her reporting mechanisms to staff (in case anything would happen to her)

FNID06.02.12.P6.1.47.56:18 finding it easy

P6 loves cleaning and takes pride in being tidy. She knows that she does this very well and finds it easy. She remembers cleaning and tidying from growing up in the residential service. She recalls that she has always been very tidy and particular. It is important for her to be clean and tidy and to do things right.

Ability perceptions are a solid base from which they determine positivity or negativity in power frames. And the combined nature and extent of power frames and identity frames influence how they frame control, and when compared to the general population, can vary from being close to or far from the ideal. In the context of their ability perceptions they predict the extent to which they can match the ideal, functional diversity provides a solid source of information for which to determine support. Experiences of achievements, inadequacies or failures affect their level of acuity with regard to ability perceptions which in turn exerts influence on their frames of reference. Ability perceptions can be as close to the ideal as possible as adults who perceive they are high in their abilities find it easy to engage in daily activities of living (personal hygiene, eating and drinking, grocery shopping, clothes shopping, cooking, baking, accessing public transport), maintain relationships, are successfully employed, live in the community and get married. Ability perceptions can be further away when they perceive a divergence between what they actually do and what adults in the general population do, when they find it difficult to engage in the daily activities of living and are more dependent on others, or when they find it hard to do what they are being told to do and become oppressed. Whatever the spectrum of the dependent-independent continuum then, they can still experience a high degree of satisfaction and/or dissatisfaction with regard to choice arrangements.

When ability perceptions are more satisfactory than initially predicted frames of reference are more positive and expectations of what can be achieved in the future are increased. It is the balance of power inherent in their ability perceptions that effects how they engage. For example, a goal may have initially been set for an adult to go to the day service on the day service bus, and the adult now gets the bus independently or vice versa. In this way the actual success of set goal outcomes are indicative of adults who have higher ability perceptions and are more in control and failure of set goal outcomes are indicative of adults with lower ability perceptions and are have less control over what they do.

5.4.1.3 Mind-set frames

Mind-set frames refer to the inherent mind-sets of the adults. Positive mind-set frames comprise pragmatic mind-set and independent mind-set, while negative mind-set frames comprise dependent mind-set and oppressed mind-set. The level of mind-set harmony ranges from mind-set disharmony, mixed mind-set harmony aligned with negativity in mind-set frames, and mind-set harmony aligned with more positivity in mind-set frames. Examples of a memo and field notes regarding mind-set frames are available in Appendix 10.

5.4.1.4 Frames of reference and framing control

Essentially frames of reference are respectively grounded in past and current experiences of what works well and what does not. Regardless of when frames of reference are formulated they are always specifically situated. Across time frames of reference generates a cumulative perspective as adults assimilate and learn more about how they ‘fit’ with their environment. Initial frames formulated are situated in the interactions of what adults are being told to do and their actual doing, and through the continuation of these interactive experiences, can become entrenched.

Frames of reference are ideas about one-self and those in power positions which have consequences for how adults frame control. Adults have learnt over time that aspirations of achieving an adult status and being in control in relationships, work, etc. are not necessarily indicative of the final choice outcomes that they achieve or obtain. They have also learnt that how they emotionally respond and adjust to comply with what they are being told may increase their chances of having more freedom to

choose and ultimately more control. Thus frames of reference based on prior experience, though significant in some cases, are not irrevocable and remain open to renegotiation.

They continually draw from frames of reference based on the interactions between what they are being told to do and what they actually do. Whether agency enacting practices are more or less intensified, whether their own functional diversity is low or high, or whether optimal engagement exists, they draw on frames of reference to increase contextualization of framing control.

Aligning with the flow of control is conditional upon frames of reference, which is further contingent on whether adults can change what they are told to do to their wishes while adjusting to fit within its boundaries. Frames of reference drive adults to persist in framing control. The more positivity in frames of reference formulated within the boundaries of what they do the higher their levels of interpreting and positioning control with regard what they are being told to do. They experience varying degrees of certainty in their frames of references, as support is not always predictive and the opportunities for negotiation are often minimal. Certainty in frames of references is validated based how they emotionally connect and make adjustments to comply with what they are being told to do. Nonetheless, they are incorporating the pre-existing complex and reinforcing sets of frames formulated while they continually make interpretations and determinations on their control positions.

5.4.2 Interpreting

Interpreting refers to their levels of knowledge and thinking which impinges on positioning control. Interpreting has properties of identifying powerlessness, bounded understanding, tracking transparency and targeting set practices.

5.4.2.1 Identifying powerlessness

Identifying powerlessness denotes adult understanding that they are powerless and not knowing how to combat this. Identifying powerlessness is underpinned by powerless knowing and non-productive thinking:

FNID19.01.12.P2.1.49.31:00 overwhelm

P2 works in xxx initially stacking shelves and watering plants. When another employee goes out sick she covers for the girl who was out sick as well as doing her own work. She works in two separate areas. She feels under pressure from customers hassling her all the time what price is this etc., or get me somebody who knows about plants. While being unhappy, she remains in this job for 7 months and becomes more stressed, until eventually she walks out of the job and does not return

In powerless knowing, the very knowledge that they have renders them powerless. Non-productive thinking is explained as powerless thinking, negative thinking and obstructive thinking. Powerless thinking occurs when adults think they have no power to make choices. Negative thinking occurs when they continually think about negative experiences which can lead to obstructive thinking. Obstructive thinking occurs when they become inordinately critical of themselves and others, and refuse to move out of their comfort zone of obstructive thinking to try new choice options. They view offers of support negatively and where possible, opt for non-engagement.

They are identifying powerlessness when what they are actually doing is incompatible with what they are told to do. The level of powerlessness identified is conditional on their oppositions to what they are told to do or on how compatible their functional diversity is with what they are told to do. For example, the greater the incompatibility of their functional diversity with what they are being told to do, the greater the degree of powerlessness they identify with. When their ability perceptions are underpinned by finding it hard to comply they are identifying powerlessness. Alternatively, identifying powerlessness occurs when they are either knowingly excluded from or opposing to support which may result in low levels of engagement. Those identifying powerlessness have more experiences of making choices to rules, (which are contrary to the wishes of adults) conveyed as directives, and accompanied with expectations of compliance, which adults comply with as they do not know what else to do. Those identifying powerlessness are not in control and do not know what to do about it, and make choices to rules as their actual doing interacts with being told.

5.4.2.2 Bounded understanding

Bounded understanding explains limiting levels of knowledge and thinking when interpreting, and is underpinned by discriminatory knowing and selective thinking. Discriminatory knowing has properties of illogical knowing, dependency knowing, and routine knowing, knowing rules exist, and knowing problems exist. Selective thinking has properties of limited thinking, limited questioning, naïve thinking, not thinking, and problematical thinking:

FNID19.01.12.P2.1.20.11:15 illogical knowing

It is within the structure of the organisation that arrangements are made so that those in community residential houses access the services of the doctor in the residential setting. When asked about accessing services in the community P2 considers that as she accesses the doctors in the main house of the residential setting she is accessing community services.

FNID18.01.12.P3.1.32.37:40 limited questioning

The weekly routine is based on the organisational rules that govern group managed care provision. The houseparent picks P3 up from the day-service each evening and drops her to the day-service each am. This is seen as part of the houseparent's job in supporting her and she complies with the rules and subsequent routine. When the researcher asks her if she could get the public transport to her community residential house she replies that she is not sure, she hasn't thought of this being an option. Having her care provision organized by others (management) and being part of a group managed care system results in her having little control over choices about transport as these choices are made at a higher management level to accommodate group service provision. As she abides by the rules she does not consider what other possible options might be available for her to get to and from the day-service on an independent basis. She travels independently on the public transport when she goes home from the service

Adults who are challenged to understand what they are being told to do have bounded understanding. Such limitations in knowledge and thinking are conditional on their functional diversity, support and engagement. When bounded understanding occurs adults are making choices with rules, (which may or may not be contrary to the wishes of adults) which are conveyed through agency enacting practices and accompanied with expectations of compliance. Bounded understanding can contribute to more negativity in ability perceptions underpinned by finding it difficult to comply. Those who make choices with bounded understanding and select a choice option can be disappointed with the choice outcomes once the realization of the choice implications is actualized. Continuous engagement with set rules and routine generate less responsibility and accountability for choices contributes to bounded understanding. And conversely a lack of consultation has consequences for bounded understanding.

5.4.2.3 Tracking transparency

Tracking transparency denotes sufficient levels of knowledge and thinking when interpreting is underpinned by vigilant knowing and vigorous thinking. Vigilant knowing has properties of root learning/knowing, practising, and self-telling, knowledge repeating, and verbalising. Vigorous thinking has properties of visualising, planning and organising, futuristic thinking, anticipating consequences, insightful thinking, reasoned thinking, and reflective thinking:

FNID18.01.12.P3.1.3.3:37 visualising and verbalising

P3 has a 'new rule' that she has to get to and from the public transport service to the day service on her own from Monday for each Monday morning and Friday evening. She visualises and verbalises her actions as she pre plans how she will negotiate the choice, stating that she will walk down by the XXXX and onto XXXXX and articulates the actions of her rules on how to stay safe when making the choice "I won't talk to anyone" and "I will mind myself crossing the road".

Those who have a clear knowledge and understanding of what they are being told to do have greater certainty in tracking transparency and make choices according to rules. Tracking transparency occurs as a consequence of higher levels of consultation, engagement and functional diversity. While the transparency of what they are being told to do is conditional on the awareness and understanding of the adults, knowing the rules influences their knowledge and facilitates how they anticipate outcomes. For example, one adult verbalizes the rules to cross the street as she performs the task, and is therefore satisfied with her achievements and is engaging in self-control. Additionally, they are rationalizing the impact of the choice actions on themselves and others. They are estimating behaviour not on impulse but according to set rules and regulation. They are self-obligated in their knowing as they make choices by rules. Tracking transparency is indicative of emotional self-protecting and functional complying and thus what they actually do is meeting the requirements of what they are told to do.

5.4.2.4 Targeting set practices

Targeting set practices refers to high levels of knowledge and thinking when interpreting is underpinned by automatic knowing and self-determined thinking. Automatic knowing underpinned by competent knowing, experiential knowing and factual knowing explains the nature and extent of instantaneously knowing what they are being told to do. Determined thinking explains how they instantaneously think about what they are to do, and is underpinned by inquisitive thinking, meticulous thinking, and procedural thinking:

FNID06.02.12.P6.1.15.18:06 knowing

P6 regards eating well as a significant choice in life. Having a level of awareness and knowledge impacts on the choices made. She buys fresh vegetables as fresh vegetables are better than frozen vegetables and it is important to cook fresh vegetables each day. She engages in listing the fruit and vegetables that she eats and that are recommended as being good for you. She knows all of these off by heart.

Targeting set practices occurs as a consequence of higher levels of consultation, engagement and their functional diversity. Those who have a full knowledge and understanding of what they are being told to do have confidence in how they are targeting set practices and are using rules to make choices by. Instant knowing occurs when they immediately know what to do with regard to choice arrangements and perform the task without having to think about it. They engage in mastering know-how of using rules to make choices. Mastering know-how occurs when while using rules to make choices, they have the confidence to execute choices which are embedded in rules. They have rules for healthy nutrition, alleviating stress, assertiveness, money management, friendship and marriage, privacy, and

also use refer to wise maxims as rules. There is congruency between what they are being told to do and their functional diversity. Targeting set practices occurs as a consequence of higher levels of consultation, engagement and functional diversity.

When ability perceptions are underpinned by adults finding it easy to do what they are told they avail of opportunities to be independent and have the confidence to perform the associated actions without having to think about them. Self-determined thinking occurs when they engage in procedural thinking and astute thinking. Here they engage in preplanning, premeditating and deliberating as tactical and intentional thinking skills regarding being told. Procedural thinking occurs when they have an established way of approaching and undertaking choice arrangements, or where they undertake a series of actions in a certain way. They concentrate on thinking about the required procedures involved when estimating the task at hand. Procedural thinking leads to planning in advance and having good organizational skills. Harmony exists between what they do and what they are told to do. And they frequently make comparisons with what they are doing themselves and what others do. When they intuit good choice arrangements they seek continuity. By using purposeful thinking they are focusing on the task at hand and become absorbed in accomplishing it. Astute thinking is undertaken to ensure that they are fully apprised of what they are told to do. Targeting set practices leads to being in control.

5.4.3 Positioning control

Positioning control denotes their perceptions of the control they have in what they actually do taking into consideration what they are being told to do and based on their assumptions of being self-directed or externally directed. Positioning control comprises not in control, greater external control, engaging in self-control and in control.

5.4.3.1 Not in control

Not in control are conditions relating to individual adult circumstances in which they are not in control of choices underpinned by lacking self-direction, ineffectual actions, and lacking control:

FNID23.01.12.P1.1.15.28:50 not allowed

PI is not allowed to have keys to the house as it is 'house policy'. She believes that this house policy comes from the directives of health board policies in Dublin, and the organization has to comply with these policies and they subsequently require the adult to comply with the house policy. She believes that she does not have control over the choice to have a key to the house she lives in.

Not in control occurs when they do not have control over choice arrangements. When what they do is oppositional to what they are being told to do and when they are unwilling or unable to comply, they are not in control. For some, not only are they opposed to what they are being told to do, but in identifying powerlessness are doubly disadvantaged, as they do not know how to contest it. Ultimately, not in control links to a sense of lacking independence and in control is strongly linked with having independence, all of which feed back into how they formulate frames of reference.

5.4.3.2 Greater external control

Greater external control are conditions relating to their individual circumstances which comprises being externally directed, having less influence, accepting external control, and externalising control:

FNID19.01.12.P1.1.45.28:07 they just tell us
The house parents set the rules of the tasks to be completed in the community residential house and by whom, “they just tell us what to do” and P1 accepts that this is the routine and does as she is told

Agency has greater control, and adults are accepting of this or willingly externalise control of choice arrangements to agency. Those who over time become accustomed to the presence of external control with regard to choice arrangements, routinely accept external control and externalise control, often explained in ‘it’s the rules’. In making interpretations with bounded understanding they make choices with rules. In doing so, they can become passive or indifferent to what they are being told to do and experience mixed mind-set harmony. Additionally, greater external control is more likely to strongly link with experiences of greater dependence, all of which feed back into negativity in formulating frames of reference. Greater external control occurs when being directed by others and having less influence in self-directing choices. They become accepting of being directed by others, lack opportunities for self-direction, have more experiences of others controlling choices, and are less influential in choice situations.

5.4.3.3 Engaging in self-control

Engaging in self-control are conditions relating to individual adult circumstances and underpinned by increasing self-direction, influencing choices gaining control:

FNID.P10.25.09.13.2.7. engaging in self-control

P10 reports the actions, which she does in walking to and from the day service each day and it is obvious that this is increasing a sense of control and independence for her which she appreciates. She adheres to the fixed protocol and does exactly as she is expected to do each day.

When engaging in self-control they experience the liberty of their freedom to choose, and feel authorized to use their autonomy with regard to choice arrangements. This increases autonomy as it becomes accompanied with lesser restrictions and greater freedoms. When engaging in self-control they are aware of what they are being told to do, and experience more mind-set harmony. When engaging in self-control those with higher functional diversity are tracking transparency and taking responsibility for the choice option and associated expectations of compliance and thus what they actually do meets the requirements of what they are being told to do. Additionally, as engaging in self-control is strongly linked with greater opportunities for independence, they are aware of the existence of external control but also are aware of the opportunities of increasing control, all of which feeds back into positivity within frames of reference. When engaging in self-control they are increasingly self-directed and influencing choices, and ultimately gaining control.

5.4.3.4 In control

Being in control are conditions relating to individual adult circumstances and underpinned by being self-directed, effecting actions, and self-controlling:

FNID06.02.12.P6.1.35.35:00 self-directing personal choices

P6 states that she wants to be on her own when buying underwear. She believes that buying underwear is something which is very personal and she likes to do it in private. She likes to go shopping on her own especially when shopping for underwear. She has control over when and whom she shops with so she goes on her own when shopping for clothes and underwear.

When in control they have a sense of ownership and competence with regard to the choice arrangements. Enacting practices are less intensified and adults have the authority and autonomy to direct choice arrangements. Structures are set up so that they experience more personal control in an agreed routine and timely way. When what they actually do is congruent with what they are being told to do, the frames of reference they formulate are more positive. Making interpretations, they target set practices and being in control is strongly linked with experiences of independence, all of which feed back into positivity in formulating frames of reference. They are in control when they have a sense of influencing choices, which iteratively feeds back into positive aligning cycles when balanced with emotional stabilizing and model complying. When they are in control they are self-directing and effecting actions influencing choices. They have more experiences of being self-directed and are self-controlling.

5.4.4 Framing control and aligning with the flow of control

In framing control adults set the direction of aligning with the flow of control. They weigh up the compatibility between what they are being told to do and the realities of their actual doing in order to select an approach to aligning that is pertinent to their individual context, and cognizance of the requirement for compliance with what they are being told to do. Framing control determines the nature and direction the aligning cycle which is counterbalanced by emotional connecting and adjusting compliance.

Aligning with the flow of control is thus a responsive action to fairly consistent, yet potentially changeable situational realities. Being told and actual doing set the agenda which is relatively fixed, meaning adults are continually aligning with the flow of control in response to the cumulative perspective of framing control. As situational realities change with choice arrangements, framing control occurs in new contexts. They are continually reflecting on frames of reference formulated. By formulating frames of reference in the context of what they are being told to do and how it interacts with their actual doing they make interpretations and position the control they have and enact the direction of aligning in either a positive or negative direction. Weighing up what they are being told to do and the realities of their actual doing ultimately determines the influence of one or the other, leaning more towards being person-driven or externally driven. Once framing control sets the direction of the aligning cycle the equilibrium is either guided by what they are being told to do or moves towards the remit of their actual doing promoting self-direction. They respond to the interaction of what they are being told to do and what they do by framing control which is contextualized by how they position the control they have, and the nature and direction of aligning is set in motion. Not in control or greater external control instigates a negative aligning cycle while engaging in self-control and being in control instigates a positive aligning cycle. While, framing control influences the direction of the aligning cycle, framing control is both indicative of and counterbalanced by, emotional connecting and adjusting compliance.

The interaction of what they are being told to do and what they actually do has consequences for how they frame control. And, while their experiences of being told can be either restricting or empowering, how they are interpreting in the context of what they actually do becomes the main driver for framing control. For example, agency enacting practices can have consequences for but is not necessarily indicative of how they frame control. The level of variation in their functional diversity is also indicative of how they frame control, as those with lower functional diversity are

more likely to be not in control or have greater external control in their lives, whereas those with higher functional diversity are more likely to be engaging in self-control or to be in control. Therefore, the greater the divergence between their functional diversity and what they are being told to do the more likely a negative aligning cycle is instigated. Similarly, while external influences can have consequences for how they frame control, it is often engagement which forms the crux of framing control, as for those who are excluded from choice arrangements are not engaged and subsequently not in control.

Framing control is conditional on engagement instigating the dynamics of the aligning cycle. Freedom to choose, while prescribed by the agency, is not completely controlled by the agency or adults, but rather each party reacts and responds to the presenting realities. Adults draw from frames of reference, but the direction of the aligning cycle is also contingent on their engagement and their functional diversity which progresses choice outcomes.

Framing control is conditional on engagement and has consequences for aligning with the flow of control being a dynamic process. What they are being told to do is at one extreme, mostly relayed by the agency in differing layers of a hierarchical structure, and while at the other extreme, adults are self-directed in what they actually do. They instigate the direction of aligning with the flow of control, which may or may not include the presence of a logical plan of action. But without support, choices made can be haphazard, would not move forward and choice outcomes could not be achieved. The nature and direction of aligning with the flow of control is influenced by support. Continual negotiation occurs when confronted with enacting practices and adults compromise to find a balance between the different aspirations, preferences and opinions interfaced in adult-agency interaction.

Support is embedded in the need for agency to tailor support to meet individual needs while providing a group-managed service delivery. Ultimately, consultation is a condition which has consequences for engagement. While agency can promote some opportunities for engagement, other opportunities remain outside much of their control. However, they know from drawing on frames of reference that the more willing and able they are to engage the more they can seek their own aspirations.

5.5 Emotional connecting

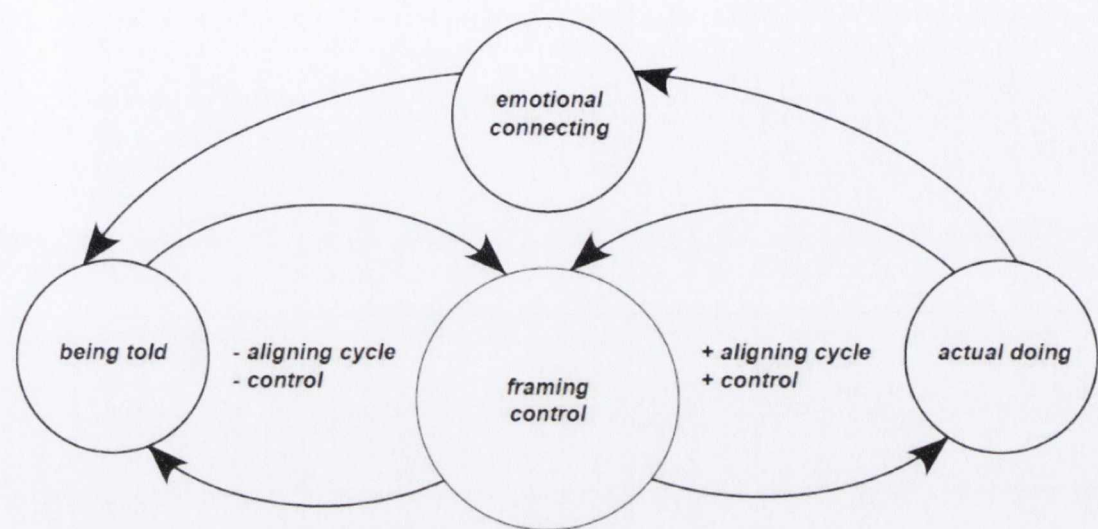


Figure 5:7 Diagrammatic representation of *emotional connecting*

Emotional connecting explains the nature and extent of their emotional response to how they frame control and influences how they adjust their behaviours to comply with what they are being told to do. Emotional connecting counterbalances the equilibrium as they emotionally connect with how they frame control and is underpinned by emotional de-stabilizing, emotional self-preserving, emotional self-protecting, and emotional stabilizing.

5.5.1 Emotional de-stabilizing

Emotional de-stabilizing denotes how adults who stress, continually revisit stress and become yet more stressed and is underpinned by stressing, ruminating and despairing:

FNID25.09.13. P10.2.4 emotional de-stabilizing
P10 relays that she is not getting on at home with her mum, that her mum has a drinking problem. She says that she fights with her mum while at home. She comes to the day service and is visibly upset. The staff ask her if she is ok and she says that she is. She asks to go to the bathroom. She stays in the bathroom. The staff ask a peer to go and check on P10. The peer asks her if she is ok and she says that she is. She shows visible signs at being stressed as she appears to cry. The staff confront her saying to her that it is obvious that there is something wrong. She still persists to say

that there is nothing wrong. Staff see that she has blood on her arms and highlights this to her. She admits to the staff that this is self-inflicted. Staff tell her that she has to report this and contact somebody. Staff (x2) go to her house. Her mother blames her for bringing staff around the place and another argument ensues. She becomes more stressed and overwhelmed with the situation and runs away.¹

FNID30.01.12.P9.1.23.23:15 desperation

P9 has no control over her money. She also feels that she has no choice over the clothes she wears as the house parents buy the clothes for her. She says she has no choice over when she gets her hair done as the house parents do these things for her. She goes home at the weekend and her aunt gives out to her for looking like a mess and having ill-fitting clothes. She believes that the house parents have bought her the wrong size clothes. She recently moved from community to community residential services and feels that her space is invaded by another service user following her around the house. She feels controlled and lacks personal control in her life. She is aware that there is conflict between family and house parents with regard to how her money is spent. She feels picked on by everybody. She continually revisits experiences of lacking choice and control.

Stress occurs when the adult experiences general unhappiness, anxiety, strain, worry, hassle and/or pressure with regard to the current choice situation. One adult who feels she is being unjustly treated and lacks the problem-solving skills to cope with the situation, continually repeats, 'its' not good for me'. The greater the stress the adults experience and the more they continually re-visiting stress, and the more they dwell on the stress in their lives. This gives rise to ruminating and despairing as they become overwhelmed and desperate. Finding it hard to comply with what they are being told to do, they identify powerlessness, as they are aware that they disagree with what they are being told to do and yet are unable to do anything about it which emphasizes they are not in control, and, by continually re-visiting stress they subsequently become increasingly upset and distressed. The greater the stress they internalize, the more likely the equilibrium will move negative aligning cycle counterbalanced by dissentious complying.

5.5.2 Emotional self-preserving

Emotional self-preserving denotes how adults who are continually experiencing uncertainty seek safety which is underpinned by accommodating obscurity and keeping fear at bay.

Adults engage in accommodating obscurity by generalising:

FNID19.01.12.P2.1.23.12:45 generalising

The houseparent controls the money. When P2 goes out/home the houseparent "tells" "just gives" her money. The houseparent decides how much money to give her and she takes the money and does not question. She does not express an opinion on how much money she should be getting or asking for. She does not speak in explicit terms regarding the money she gets, but rather generalises as "the money"- She leaves it up to/depends on the houseparent to make the choice of how much money to give to her.

Adults also engage in accommodating obscurity by accepting uncertainty:

FNID19.01.12.P2.1.24.13:50 Accepting uncertainty

P2 has difficulties in making sense of sizes (numbers). She accepts that this difficulty has consequences in how she shops for clothes. She is dependent on the houseparent to assist her to buy clothes. She depends on houseparent to support her to make choices when buying clothes. She is happy that she makes her own choices about the clothes and accepts the support of the houseparent when making the choice.

Adults also engage in keeping fear at bay:

FNID23.01.12.P1.1.4.5:57 Keeping fear at bay

P1 is not allowed to carry medication on her person. She believes that this is due to the environment and safety policy. She accepts external control of the houseparents who keeps her tables, locks them away and holds the key. She accepts that she is not being in control of her medication. She does not question that she should control/be supported to control her medication? She demonstrates awareness that others may take the medication by mistake and fears that others might take the medication while she is not looking and she fears the blame which would be attributed to her if this did happen fear of consequences and blame attribution increases compliance with rules and subsequent greater dependency and lesser self-control.

In keeping fear at bay they engage in avoidance:

FNID15.01.12.P4.1.4.6:22 don't rock the boat

Things are good for P4 in the house now so she doesn't want to rock the boat by taking on a friend's argument. She declines supporting her friend by disassociating with the argument and verbally claiming that she does not know what really went on. A housemate does not comply with the orders of the houseparent to get the community residential services transport home and is subsequently subjected to the wrath of the houseparent. The housemate comes to her seeking support. She wants to stand up for her friend but sees standing up for her friend as making life difficult for herself so avoids taking on her friend's argument. Her house mate gets into a huff with P4 because she feels that she is not supporting her and they are meant to be friends. Getting involved in the argument may mean that things in the house will get worse for her that she will rock the boat. She states that things are good for her at the moment.

Greater external control is balanced by emotional self-preserving. This occurs when they are aware that they are being told what to do, but are challenged to understand and/or adhere to the requirements, which has implications as they seek self-safety and security while negotiating a challenging environment. Emotional self-preserving explains how they seek safety in uncertain environments underpinned and is by accommodating obscurity and keeping fear at bay.

Finding it difficult to comply with what they are being told to do and with greater external control they counterbalance by emotional self-preserving. They are counterbalancing their bounded understanding with emotional self-preserving so as to strive for self-preservation in the context of uncertainty.

Those who are continually experiencing uncertainty learn to negotiate any qualms by emotional self-preserving. Such examples of how they engage in generalising when accommodating obscurity are, when they have difficulty remembering time-frames they substitute phrases like, “it was a while ago”, and when they have difficulty remembering names they substitute the terms, “staff” or “houseparent”, and when they have difficulty remembering names of courses or places they substitute, “something like that”. Another example of accepting uncertainty is when they become accustomed to greater external control when changes are made regarding the houseparents coming to work in their houses. Additionally, bounded understanding helps them realize that they are finding it difficult to break down the elements of what they are being told to do and they often engage in wondering what they should be doing. In the face of uncertainty they focus on trying to establish and maintain self-safety. Those who continually experience challenges and uncertainty become more fearful and concentrate efforts of self-preservation through keeping fear at bay. Emotional self-preserving occurs when they have bounded understanding and strive for self-safety in the context of greater uncertainty. The more fear and uncertainty they experience the less likely the direction of the equilibrium is to move to the positive aligning cycle. Those who engage in emotional self-preserving are more likely to engage in selective complying.

5.5.3 Emotional self-protecting

Emotional self-protecting denotes how adults who are continually gaining confidence ensure sustainability and promote opportunities for further advancement of control. They appreciate how well they are doing and are careful to protect themselves so as to promote further opportunities for control. Emotional self-protecting is underpinned by emotional gratifying, emotional shielding, and emotional rationalising:

FNID25.01.12.P5.1.1.0:00 seeking clearance

P5 lets staff know about what she does - She initiates the routine choices which have been previously agreed with the community staff and lets the houseparent know where she is by phone. This results in her having greater autonomy in relation to the choices she makes.

FNID25.01.12.P5.1.12.4:20 living by safety rules

“it would be dangerous walking home in the dark...it’s about 2 miles out”when there is lack of accessible public transport P5 depends on the community residential staff and bus to bring her home. She knows that it may be dangerous to walk home in the dark so she phones the staff for a lift. She is depending on the staff to give her a lift home in the community residential bus

Emotional gratifying occurs when they are grateful for how well they are doing. Emotional shielding occurs when they focus on seeking clearance, seeking reassurance, while guarding and emotional rationalising occurs when they rationally weigh up factors influencing the choice being made. For example, when one adult who is afforded the opportunity to move in with her boyfriend needs more

time to think about it, she engages in emotional rationalizing and makes choices by rules so as to ensure her rights in the choice she makes. Tracking transparency is a driver for emotional self-protecting, as in the context of greater certainty they ensure security. For example, the adult who is vigilant in knowing the rules is more likely to abide by them, and being grateful for the liberating opportunities for freedom to choose, ensures their own security while being more self-directed and responsible for choice arrangements. When engaging in self-control they balance the equilibrium by emotional self-protecting. By emotional self-protecting they make choices by rules and continue to be conscientious but cautious in their application. Those who are emotional self-protecting are more likely to engage in functional complying. Those 'doing as told' as a consequence of tracking transparency, balance engaging in self-control with emotional self-protecting. Emotional self-protecting occurs when they are making choices by rules.

5.5.4 Emotional stabilizing

Emotional stabilizing denotes how they are ensuring continued confidence in their emotional well-being and is underpinned by alleviating stress and feeling optimal performance:

FNID06.02.12.P6.1.40.41:40 articulating safety rules

P6 feels safe in the community that she lives. She feels safe in accessing transport. P6 states that she has no fears, that she is not afraid of anything. She says that it is important to be safe and not to be afraid. She articulates the safety rules as that "don't give out your details, mind you bag, as long as you can keep to yourself" and "if they engage in conversation and if you don't know them be polite and say I have to go now, and walk away".

FNID06.02.12.P6.1.52.1:07:45.rules for managing stress

P6 relates rules for managing stress in her life: "you sit down and think about what's causing you the stress; go for a walk; go for a bath; play nice music; light a candle; go to somebody and talk about it; don't hold it in; go and get help". She recognises the signs of stress e.g. that some people can get rash. She sympathises with a girl who threw herself into the river on Christmas morning and rationalises that you can't suffer in silence in this world so you may need to go to a doctor. She recognises that there is always help out there but unfortunately there are people out there who are not able to express themselves. She is accepting that people might not want to talk if she were to do counselling. She accepts that she is willing to wait until the person is willing to talk and would sit in silence for that time.

Alleviating stress comprises of securing health and safety, focusing on controllable, seeking validation and feeling optimal performance. It comprises revelling in success, maintaining connectedness and exercising devotion.

Emotional stabilizing counterbalances the equilibrium when in finding it easy they are targeting set practices and are in control, comply with and sustain compliance with what they are being told to do. This has consequences for being in control and emotional stabilizing. The more frequently they are in control, the more likely they are to continually re-visit positive experiences and become more confident and competent with regard to what they are being told to do. Emotional stabilizing happens when they are using rules to make choices by. When the equilibrium is counterbalanced by emotional stabilizing the perceived risk associated with choice arrangements is less, choice ownership and responsibility is greater, and they subsequently engage in more self-directed behaviour. Those who engage in emotional stabilizing are more likely to engage in model complying.

5.5.5 Emotional connecting and aligning with the flow of control

The manner in which they frame control impacts on how they emotionally connect which is indicative of how they adjust in what they actually do to comply with what they are being told to do. Both emotional connecting and adjusting compliance are counterbalancing concepts, which direct the nature and extent aligning with the flow of control.

Compatibility of what they actually do with what they are being told to do set the conditions for emotional connecting. What they actually do is weighed up against what they are being told to do and frames of reference based on their ideas of the current 'fit' between both. By comparing what they are doing with what they are being told to do, they select the nature of aligning with the flow of control, considering the extent to which the realities of what they do is containable within the boundaries of what they are being told to do.

Emotional connecting essentially weighs up how they are aligning with the flow of control. The more emotionally stable they are, the lesser demands by agency for them to comply with what they are being told to do. They accept or make compromises or adjustments to align with acquired levels of control, by emotional connecting; they create, sustain or change the equilibrium which continually counterbalances the divergence or congruence between requirements and realities. The direction of the aligning cycle is balanced either in a positive or negative way by emotional connecting. How they frame control and emotionally connect influences the extent of their engagement in choice arrangements. Emotional connecting within the boundaries of what they actually do forms the basis for a predictive correlation between their functional diversity and engagement. The potential for achieving satisfaction with choice arrangements in line with congruence of functional diversity and what they are being told to do is indicative of their full engagement. Therefore, both engagement and functional diversity are counterbalanced by how they are emotionally connecting.

External influences and engagement are ongoing, dynamic variables that contextualize where they position control meaning that emotional connecting is not a distinct stage at either the start of choice arrangements or at the final choice outcome, but rather continues throughout. Positioning control about choice arrangements can be aligned positively or negatively in response to what they actually do. While a positive aligning cycle promotes acceptance a negative aligning cycle questions their functional diversity. Frames of reference drive them to be persistent in positioning control while emotionally connecting. Those who experience greater negativity in frames of reference tend to frame control negatively, which is a driver for, and counterbalanced by, lower levels of emotional connecting. Those with lower levels of emotional connecting frequently move between emotional destabilizing and emotional self-preserving and are thus unlikely to be successful in achieving and sustaining optimal levels in emotions. Consequently, those who are either very sure or very uncertain about the presence of intractable disharmony are more likely to be non-accepting of enacting practices of those in power positions.

While they seldom think about the validity of how they frame control they nevertheless know that it is those in power positions who direct support. This has consequences for increases or decreases in their freedom to choose and so they feel compelled to comply. Those with higher functional diversity are more emotionally stable and so are more rational in weighting their emotions with what they are being told to do, and those with lower functional diversity is low, are less emotionally stable and so too are more challenged in their efforts of emotional connecting.

Conversely, emotional connecting can ensure an acceptable balance between being self-directed and being externally-directed, without their functional diversity being significantly compromised. Adult emotional wellbeing can be a pre-regulator in aligning with the flow of control, as, by agency ensuring the most appropriate choice arrangements are facilitated, adults are the more satisfied with what they are being told to do.

Emotional connecting allows for positive aligning cycles, wherein they engage with potentially new choice arrangements which afford opportunities for greater control. Thus emotional connecting provides an ongoing protective and emotionally stabilizing functions and vice versa. If they align the requirements of what they are being told to do too far, a negative aligning cycle can begin to redress the presenting evidence of stress. For example, an adult who is put on a diet and exercise plan due to increased weight gain and high blood pressure initially disagrees with the amount of exercise and extent of diet, but once accustomed to the new regime makes the necessary adaptations to comply with what she is told to do. However, over time she is losing too much weight, doing too much exercise and becoming stressed and choice arrangements are revisited.

In ongoing choice-making interactions framing control and emotional connecting maintain differing levels of equilibrium between what adults are told to do and what they do. Emotional connecting is

conditional on functional diversity. Functional diversity and emotional connecting are ongoing, dynamic variables which contextualize where they position the control they have, meaning that emotional connecting is not a distinct stage at the start of the choice-making or at the final choice outcome but continues throughout. How their ability perceptions are counterbalanced by their emotions have implications for how they make adjustments and compromises in their behaviours. For example, in sensing internal distress, those who proactively re-stabilize the equilibrium through resituating what they are being told to do, off-set emotional de-stabilizing. For instance, when one adult prescribed with anti-psychotic medication recognises that she is 'hearing voices' become concerned for her own welfare and approaches the relevant staff to voice her concerns, she is moving the position of control from engaging in self-control to greater external control. And for those who enjoy greater freedom to choose it is important for them that they can contact someone when needed for advice and support. Conversely, others may continue progressing through negative aligning cycles counterbalanced by emotional de-stabilizing. For some adults who become distressed agency intensify enacting practices and those with lower functional diversity are more likely to move from emotional stressing to emotional self-preserving, managing to do what they are being told to do while maintaining a negative aligning cycle.

Emotional connecting is about feeling good, okay, indifferent, or not okay, when what adults are told to do is interactive with what they actually do. Being told tells them what they should be doing, how, and within what scope. Through their experience of 'feeling okay' with some or all of the conditions of their freedom to choose and the support they receive, they are able to reflect on the extent to which they can comply with what they are told to do. Emotional connecting is psychologically based. For instance, their thoughts regarding agency enacting practices which are accompanied with expectations of compliance regulate their feelings and emotions with in line with what they are being told to do. Emotional connecting typically evidences processes rather than outcomes. Even if the ideal outcome has not been achieved, it is their emotional responses to particular requirements along the way which is the evidence for how they are emotionally responding. Emotional connecting thus assures a degree of engagement regardless of functional diversity.

5.6 Adjusting compliance

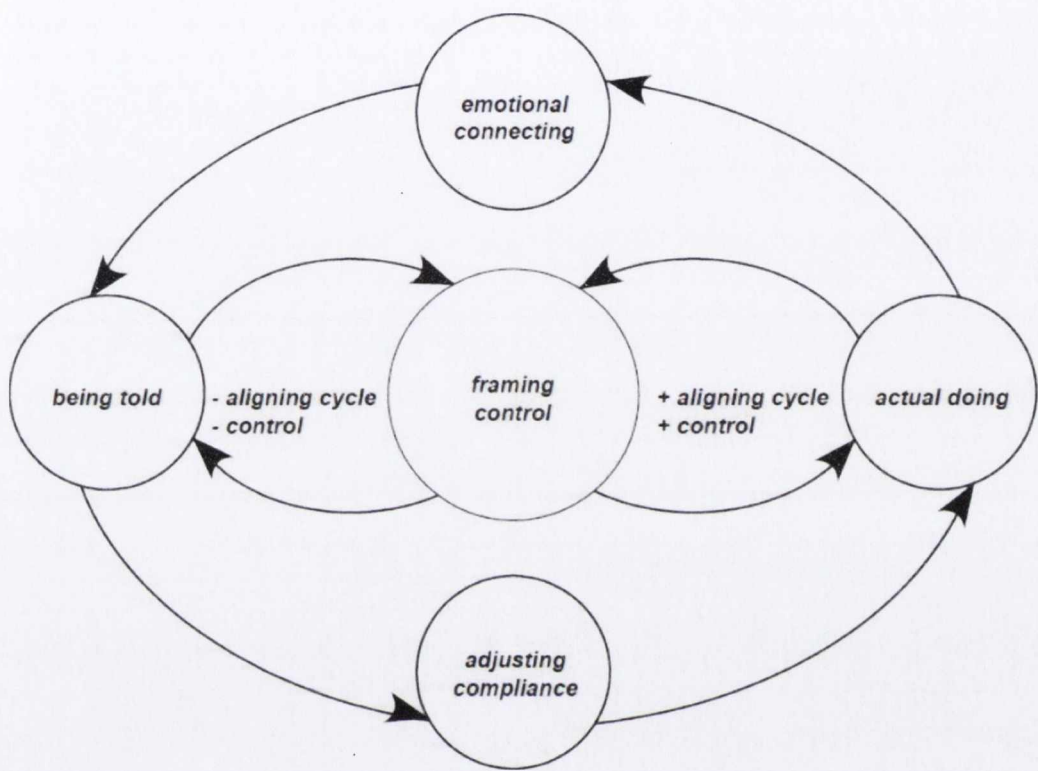


Figure 5:8 Diagrammatic representation of *adjusting compliance*

Adjusting compliance explains the nature and extent of which adults comply with what they are being told to do and is underpinned by dissentious complying, selective complying, functional complying or model complying.

5.6.1 Dissentious complying

Dissentious complying makes reference to behaviours of adults who are mentally opposed and stressed by what they are being told to do and respond by resistant complying and non-complying. In some choice situations adults will physically comply while being mentally opposed to what they are being told to do, engaging in resistant complying displaying resistance or defiance. The greater the

psychological opposition to what they are being told to do, the more likely the chances are that they engage in non-complying behaviour:

FNID19.01.12.P2.1.51.32:00 non compliance

P2's father dies in 2002. She is in a job where she feels stressed (father dying...job going badly). She runs away from the service. A staff member recognises her stops her and brings her back to the community residential services where (the manager) "she took the head off me". As she relays the story she admits that she was going through a really bad time and now appears ashamed of her behaviour. She demonstrates regret fullness for her actions. Rules were broken under the duress of stress and when this happened reprimanding occurred and shame is inflicted, and lessons of conforming are learned. As regret sets in and she provides excuses for her behaviour at the time, she has also learned that she needs to be obedient –the shouting is used to shape the behaviour of compliance in the future.

The more negative they are in how they frame control the more likely they are to engage in dissentious complying. For example, those who draw from negative frames of reference while finding it hard to comply with what they are being told to do are more likely to identify powerlessness and make choices to rules and are not in control. Not in control, counterbalanced by emotional destabilizing is both indicative of and counterbalanced by dissentious complying, which ultimately feeds back into negatively framing control and the equilibrium is maintained at a negative aligning cycle.

5.6.2 Selective complying

Selective complying explains their behaviours when they somewhat comply, passively comply, or are submissive in their behaviours, when confronted with being told what to do as underpinned by partial complying and submissive complying. Partial complying occurs when what they are being told to do match their own aspirations but their actual doing deviates and they are finding it difficult to comply with what they are being told:

FNID30.01.12.P7.9.11:29 lacking words to explain, getting stuck for words

P7 tries to relay to the researcher about the cuts to respite and changes in service provision. P7 has a general idea of the changes but finds it difficult to get the words out to explain what is happening "you have to pay and I think you've to pay by.... you know.....by you know by.....(x4)...what we'll say (x2)" [can't think of words to explain what he wants to say fragmented sentence interferes with the flow of the sentence formation conversation gets lost] P7 takes a long time to produce what he wants to say, difficulty in making sentences creates difficulty in getting message across and having a conversation

Submissive complying happens when they do what, how, and when they are told because they are told. Those who negatively frame control are more likely to engage in selective complying. For example, those who draw from negative frames of reference while finding it difficult to comply with what they are being told to do are more likely to have bounded understanding, make choices with

rules and make determinations of greater external control. Greater external control, counterbalanced by emotional self-preserving, is both indicative of, and counterbalanced by, selective complying, which ultimately feeds back into negatively framing control and the equilibrium is maintained at a negative aligning cycle.

5.6.3 Functional complying

Functional complying refers to their behaviours when they sufficiently and cautiously do what they are told to do and is underpinned by tentative complying and sufficient complying:

FNID18.01.12.P3.1.16.18:00 pre-choice arrangements

P3 lives in community residential services and attends a day service on a daily basis – on Wednesdays she does voluntary in a nursing home for a couple of hours. She gets a taxi from the day service to the home and is collected by the houseparent once her hours are completed. She enjoys doing this work. She enjoys the work and speaks clearly about the expectations of the job. The work that she does is to help older people to bingo and to tea break and to singsongs. She also articulates how she gets to the job and how she is collected by the houseparent to come home. She phones the taxi company and orders the taxi herself to go to her voluntary work on Wednesdays. She walks from the taxi drop off to the voluntary work placement and undertakes her voluntary work. She is familiar with the routine and enjoys the work that she does. Issues around the choice are less stressful when routine exists, when she understands clearly what she is expected to do, when she understands her responsibilities and adheres to these.

Functional complying happens when they know what to do, how and when to do it, take responsibility for doing it meeting the requirements of what they are being told to do. Those who positively frame control are more likely to engage in functional complying. For example, those who are drawing from positive frames of reference while finding it doable to comply with what they are told to do are tracking transparency, making choices by rules and engaging in self-control. Engaging in self-control, counterbalanced by emotional self-protecting, is both indicative of, and counterbalanced by, functional complying, which ultimately feeds back into positively framing control and the equilibrium is maintained at a positive aligning cycle.

5.6.4 Model complying

Model complying refers to their behaviours when they comply fully and confidently with what they are told to do and is underpinned by committed complying and compliance seeking:

FNID06.02.12.P6.1.50.59:50 Pre-planning

P6 articulates her rules for planning holidays. Both herself and her husband have travelled to England to see his sister. She articulates places in Ireland where herself and her husband have been on holidays and states that "we sit down andsit downsee what finances you have and then where you want to go..... you can't book anything if you can't afford it" "Dublin not a place for holidays, it's more a place for concerts,Galway or Killarney is for holidays". She thinks if you plan it around now you might get it cheaper. "You have to sit down and see if you can afford it".

Model complying occurs when they instantly know and do what they are to do, have full responsibility for doing it and do it. Those who have full positivity in framing control are more likely to engage in model complying. For example, those who draw from positive frames of reference while finding it easy to comply with what they are being told to do are targeting set practices and using rules to make choices by so being in control. Being in control, counterbalanced by emotional stabilizing, is both indicative of, and counterbalanced by, model complying, which ultimately feeds back into positively framing control and the equilibrium is maintained at the ultimate positive aligning cycle.

5.6.5 Adjusting compliance and aligning with the flow of control

Adjusting compliance is influenced by framing control and emotional connecting and occurs within the boundaries of what they are actually doing and vice versa. Furthermore, what they actually do and how they adjust compliance are ongoing, dynamic variables that influence how they frame control meaning that adjusting compliance is not a distinct stage at the start of the choice making or at the final choice outcome, but continues throughout. While what they actually do is conditional on how they engage, adjusting compliance is not necessarily indicative of functional diversity. Rather, how they frame control and make emotional connections are more indicative of how they are adjusting compliance.

Adjusting compliance conceptualizes the nature and extent to which they comply with what they are being told to do within the boundaries of what they actually do. As they develop a sense of independence, they frame control making determinations about the extent of control they have to direct choices, and about the extent to which support is assisting them to move towards the desired independence. When framing control, they identify congruencies or discrepancies between actual and desired choice outcomes. Adjusting compliance stabilizes the equilibrium between what they are being told to do and the realities of what their actual doing. Each adult is adjusting compliance when making choices, regardless of the level of emotional stability or whether or not choice outcomes are achieved.

What they actually do provides a solid evidence base for adjusting compliance. The closer their actual doing is with what they are being told to do the lesser the requirement for compliance sought. Conversely, the greater the divergence between what they actually do and what they are being told to do, the more requirement for compliance. Thus for, one adult who becomes overwhelmed, stressed and walks out on a job, the degree of adjusting compliance required is immense because the divergence between the actual outcome and the desired outcome is extreme. While for another who is tracking transparency, emotional self-protecting and engaging in cautious complying while accessing support the degree of adjusting compliance required is minimal, as she progresses to live with more independence in the community.

Framing control is contextualized not only by what has gone before and what is currently happening but also engage in futuristic thinking about what is to come. For instance, the more positivity they have regarding current and future experiences of choice and control, the more motivated they will be in seeking and sustaining momentum. This can involve simply repeating simple tasks such as, making their own lunches and putting milk in tea or organising their own healthcare appointments. By ensuring that they have something to progress onto support can maximize optimal levels of adjusting compliance which feeds back into how they frame control. However, though service agency dictates the distribution of support for those in the community residential services, agency have less influence over what happens to those who leave the community residential service and move into the community. For these adults how well they adjust to comply with what they are being told to do is conditional upon their functional diversity which will direct where they will move onto, and whether they continue to engage with what they have learned from the choice experience.

Depending on engagement in choice arrangements, adults will be more or less positive in framing control about their power to initiate choices, sustain momentum or transfer their new understandings into other choice situations. They want to feel confident that they are prepared for moving on, and that they will not inevitably falter in the real world and revert back to where they started. Therefore, what they actually do is bound by their functional diversity. By increasing and repeating opportunities for control and by reaching consistency in completing tasks, and so on, they satisfy the agency that they are making the necessary steps towards being ready for further opportunities for greater control and independence.

In common with emotional connecting, adjusting compliance promotes the positive aligning cycle when they are being told what to do and its regulatory nature ensures that directives are always present. Adjusting compliance is a corrective and stabilizing process, as high levels of adjusting compliance afford adults who have greater opportunities for control to be more accepting of restrictive choices when they occur, widening the net for emotional connecting. In reconciling actual choice outcomes with ideal choice outcomes, they feed back into frames of reference, even if the actual outcome is significantly far from the ideal.

Compliance is indicative of how well the realities of what adults actually do meet what they are being told to do. Being told tells them what they should be working towards, how, and within what scope. Being told is conceptualized as telling them what they are to do, and their behaviours are directed through the remit of agency enacting practices. Compliance is task-based, for example; the physical action of behaviour, and when complying with some or all of what they are being told to do, they are able to reflect on the extent to which their behaviours match what they are being told to do.

Compliance is optimized when their actual doing equalizes what they are being told to do, and positive aligning is a consequence of their interpretations of what they are being told to do so as to become increasingly self-directed. Compliance strives to ensure that the boundaries of being told though stretched are never meant to be breached, and typically evidences processes rather than outcomes. Even if the ideal outcome has not been achieved, they continually evaluate their levels of compliance to particular requirements of what they are being told to do along the way.

What they actually do is determined by multiple factors of which the adult is only one. What is actually achieved is highly dependent on the individual themselves, their aspirations and levels of engagement and the external influences shaping choice arrangements.

5.7 Being told and actual doing

The purpose of this section is to further elucidate the related categories of what adults are being told and the realities of their actual doing, as the conditions in which aligning with the flow of control takes place. Continually being told emerges as a substantial issue in their daily realities of choice opportunities. The concept of being told is outlined first, explicating the properties of external influences and enacting practices. The category of actual doing is then presented, underpinned by functional diversity, support, and engagement and their lower level properties.

5.7.1 Being told

Being told comprises of external influences and enacting practices. Being told refers to a set of political, social and cultural conditions which set the expectations and direct adult behaviours in the society they live and services accessed. While external influences are mostly outside the control of either adult or agency, enacting practices are communications from agency in power positions which direct adult behaviours as the nature and extent of external influences roll out in the realities of choice arrangements, thereby effecting how adults frame control.

5.7.1.1 External influences

External influences are explained as policy and legislation and social norms which set expectations for their behaviours.

External influences are the influencing factors that are not within the immediate control of the agency or adults and underlie how they are aligning with the flow of control. External influences underlie the decision-making practices of those in power positions and have consequences for setting policy and legislation as well as standards and norms. Policy and legislation impacts on choices:

FNID01.02.12.P8.1.33.26:60 cutbacks

P8's weekly allowance of 22 euros has been stopped due to government cutbacks. She reports that lacking money results in lacking independence (being able to have a coffee with a friend) and she explains with annoyance and anger, that these cutbacks have been introduced by the government.

FNID 30.01.12.P7.1.0:00

P7 has a local newspaper article which has a picture of his dad and himself standing outside their house "tough times for parents of disabled children". The tough times referred to are the free bus service now being cut which results in P7's parents having to pay 70-100 euros per week for transport. Additionally, a charge is now being installed for respite care of 22 euros, and P7's states that his weekly allowance of 13.60 has been cut. Funding to the service provider has been cut, which means that the service provider, has to review allocation of funding which impacts on choices.

While policy and legislation does strive to accommodate difference, within the daily realities of making choices these adults are a minority group in an environment where majority rules. Irish policy and legislation, influenced by the international agenda, is outside the control of agency or adult. External influences, driven by policy and legislation governing disability allowance, funding, transport, all act as barriers or enhancers to choice arrangements which underlie support. Healthcare policy and legislation promoting health and safety impacting on choice arrangements can have

consequences for imposing restrictions on their freedom to choose. Disability assessments and requests for appliances and aids frequently result in adult and agency submitting requests for and waiting for funding or equipment. Policy and legislation can create increased dependence, such as, when policy and legislation has consequences for a lack of resources, choice arrangements are revised, and original outcomes can be achieved by placing extra pressure on their families. For example, an adult who routinely travels using service buses transport, to get from home to the day-service finds that when the bus service is cut, he is more dependent on his family to transport him to the day-service. When a lack of staff resources at the weekend means that they cannot meet friends for coffee, such restrictions in their freedom to choose impacts negatively on their control of choices as they realise that their aspirations are unattainable. Whereas, in other instances when resources are lacking, revised choice arrangements can increase opportunities for independence, such as when an adult who routinely travels using service buses transport, travels on public transport when service buses are not available.

Policy and legislation can also have a positive impact on increasing their freedom to choose. For example, policy on integration of people to community living affords opportunities for them to move from residential settings to community living. Policy and legislation is a contextualising factor for framing control as they continually weigh up their aspirations against the possible reality of these achievements.

Social norms set the standards for how the general population in that society live and these are the standards from which adults make determinations on how they 'fit' with the society they live in. For example, for the majority of adults, satisfaction in attaining achievements in education, occupation and generation are the norm, and deviation from obtaining a satisfactory sense of achievement can be regarded as failure. Social norms impact on choices:

FNID01.01.12.P8.1.65.1:04:46 comparing

P8 is finding it hard to accept that she has a disability. She is aware that her siblings and other relatives do not have a disability. She knows that she is slow in picking up stuff. She knows that people stare at her because she has a disability. She continually compares herself to other family members, what they have and what they do.

External influences are variable in their influence and changeability. For example neither agency nor adult can control the political, cultural, social and economic climate or the enormous impact of the current rising trend in the use of technology. In comparison, external influences can be relatively immovable, posing significant restrictions to engagement. For some adults, external influences may be the most significant barrier to achieving control and thus cannot be addressed within the remit of agency.

While external influences can compel adults to behave in certain ways, it is often the diversity in their domains and levels of functioning that are the maintaining factors which stipulate what they are told to do. For example, those with lower levels of functional diversity who speak of moving house, moving into the community and having independence, find adjusting to such external influences as insurmountable. As intellectual disability is inherently limiting, the extent to which those with lower levels of functional diversity can actively achieve independence is severely impeded, and for some choices may never be realised.

Moreover, when external influences and subsequent choice arrangements can promote opportunities for independence, the level of intervention required may not be within the scope of agency to support adult aspirations and thus they are unable to achieve desired outcomes. Conversely, the enacting practices of agency can direct them to move outside the boundaries of the external influences in order to achieve a greater sense of independence.

5.7.1.2 Enacting practices

Enacting practices explain the communications of agency in power positions which direct the behaviour of these adults in subordinate subservient positions, and to which these adults respond by setting their agendas for framing control. Enacting practices comprise of respectful or disrespectful approaches, verbal directives, non-verbal directives and rules. Enacting practices may be influenced by but are not necessarily consequences of external influences or support. Adults surmise the compatibility of enacting practices of those in power positions based on their perceptions of whether or not agency are likely to or actually supportive of their functional diversity:

FNID.28.06.12.P2.2.10:40 disrespectful attitudes

P3 walks from her own community residential services house to another community residential service house to get a bus to the day service in the mornings. While waiting for the bus a houseparent in the other house, which she says that she doesn't even live in gets her to do housework. She feels that this is unfair treatment and that she should not be asked to do this.

FNID06.02.12.P6.1.12.15:00 respectful attitudes

P6 explains that she meets a community nurse for lunch, she regards the staff as a friend. If she is in difficulty she calls this staff member. She states that she has high regard for this staff member and feels that she is treated respectfully by the staff. She knows that if she gets into any difficulty she can call this friend and relay any issues of concern to her. She has great praise for XXXX and believes that she is respected by her so she regards the relationships as a friendship.

Adults perceive enacting practices as disrespectful, providing examples of 'not being listened to', not having opportunities to complain', being told that one 'looks like a gollywog', or when one's

‘healthcare information is shared with others in the hairdressers without permission’. Perceptions of enacting practices as respectful are explained as ‘being able to talk about issues of concern’, ‘approachability’, ‘listening’ and ‘like a mother’. Enacting practices have consequences for how adults frame control.

Verbal directives explain a range of verbal language used by agency which directs adult behavi ours. The following is an example of how in the context of functional diversity agency verbally directs adult behaviour:

	+ verbal directives -	
+ functional diversity -	Doing as <i>being told</i> Leads to less <i>being told</i> Through more <i>options</i>	Doing without <i>being told</i> Leads to less <i>being told</i> Through more <i>advising</i>
	Not wanting to do or not doing as <i>being told</i> Leads to more <i>being told</i> through Directive ordering	Not Doing without <i>being told</i> Leads to more Need for <i>being told</i> through Instructional Telling

The verbal directives communicated by agency can trigger either a positive or negative aligning cycle. When adults are not doing as told or need to be told what to do, agency intensify how they verbally direct adults to comply with what they are told to do. And, when adults are doing as told or doing without being told, agency minimalizes how they verbally direct adults to behaviour.

Adults often seek changes to the requirements of verbal directives, so as to make them more compatible with their own aspirations. When agency denies adult requests for changes some agency use their power status to gain adult compliance by intensifying enacting practices:

FNID25.09.13.P4.6.18:10 ordering
Perceptions of being denied control of privacy happens when P4 gets a phone call and the houseparent asks her “who are you on the phone to?” “you are not to ring your sister again” She defiantly replies: “why not she’s my sister?” She feels that she is denied control over the choice as she states “I can’t ring xxx (my sister) because house staff are stopping me I don’t know why” “I did feel like crying I don’t stop her from ringing her family I have my own phone but I don’t understand and that’s really getting to me”

Enacting practices are underpinned by a system of regulation regarded as rules which come in multivariate formats. Rules are usually fixed, but can be flexible. While some rules are influenced by bodies external to the service, rules are formulated mostly internal to the service and are usually communicated with the requirement for compliance. Within the context of service provision, rules

aim to sustain the efficiency of the service operations facilitating group managed care provision, promoting protection and providing opportunities for empowerment, while limiting the prospects for error, harm or neglect. But such limitations can have consequences for restricting adult freedom to choose and can escalate into negatively framing control. Over time this creates mind-sets of dependency and oppression and expedites to shape the trajectory of a negative aligning cycle.

Rules can trigger positive or negative aligning cycles, for example, when continually making choices to rules, or choices with rules adults frame control more negatively. Those who are making choices to rules or making choices with rules retreat within the remit that they are continually being told what to do and within the boundaries of what they actually do a negative aligning cycle happens. The following is an example of where one adult makes choices to rules:

FNID23.01.12.P1.1.9.12:30.rules

P1 believes that the policies of the health board are to blame for the rules which govern her choices. She believes that these rules are 'over the limit'. Fitting into the system she complies with the rules of the organisation and moves house as directed when she is sick. She does not agree with moving house but does not articulate her disagreement and physically complies. In the presence of physical compliance and in the absence of questioning or statements of saying no, she reluctantly complies with the pre-arranged directives of the service. She believes that "there is too much policy over us"

However, when adults frame control more positively and are more self-directed in choice arrangements they are making choices by rules or using rules to make choices, and a positive aligning cycle occurs. Rules set the expectations of their behaviours and direct requirements for compliance with being told. Rules are more intensified when conveyed through the verbal directives of orders and less intensified when conveyed as advice.

Agency when united in giving orders intensifies enacting practices and adults are driven back into their subordinate status. Additionally, inconsistencies in enacting practices lead to negatively framing control and lower levels of emotional connecting and adjusting compliance. For example, when an adult asks a houseparent how is she doing with her epilepsy and the houseparent tells her she is doing excellently. She contends that in this case she should have greater freedom to choose and be allowed into town on her own, but house parents do not allow it. She therefore believes that they are holding her epilepsy against her. Meantime she is told by another houseparent she is independent and by another that she cannot stay on her own as she might burn down the house. Conversely, when what adults are being told to do is congruent with their aspirations, enacting practices can also be a driver for increasing functional diversity and creating positivity in how they frame control.

5.7.2 Actual doing

The essential constituent factors which set expectations for and direct adult behaviours are rooted in being told. However, in response to the multiple and diverse realities of their actual doing, choice experiences are different for each adult. Actual doing conceptualizes diversity in domains and levels of adult functioning, the support they receive, and opportunities for and how they engage, so pertaining to what actually happens in choice situations, rather than what they are required to do.

5.7.2.1 Functional diversity

Functional diversity refers to their domains of functioning identifying strengths and needs in these domains. Functional diversity as a contextualising factor in framing control provides a basis for their ability perceptions which can be either positive or negative. Functional diversity effects their realisation that for them some of their aspirations will not be reached within the scope of what they are being told to do. For example, initial choices may no longer be achievable within the limits of support.

Engagement is a necessary condition for optimising functional diversity. They know from framing control that the more willing and able they are to comply with what they are being told to do, the more likely their chances of sustaining or increasing levels of control.

Maximising opportunities for engagement reciprocates the likelihood of optimising functional diversity while complying with what they are being told to do. As such, while a positive aligning cycle acts by assimilating what they are being told to do into what they do, it can also revert back on it-self to promote compliance attainment through improving functional diversity. For example, one of the adults is currently doing a money management training programme and initially her houseparent accompanies her to the bank instructing her on what to do, but over time she goes to the bank alone to withdraw her money. Conversely, when what they are being told to do 'fits', what they actually do, functional diversity can be either maximized or minimized. While many strive to achieve optimal control in what they actually do, their functional diversity is essentially outside much of their control. Functional diversity is facilitated or restricted by the impact of what they are being told to do and is driven by support. And while functional diversity can be maximized or minimized conditional to support, their engagement will influence the outcomes of what they do.

Functional diversity is a solid source of information for their ability perceptions which contribute to how they frame control. Based on ability perceptions they continually assess their own performances,

providing a basis for how they consider moving forward when aligning with the flow of control and has influence on how they emotionally make connections and adjust compliance behaviours. They draw on frames of reference so as to choose what to concentrate on regarding their assumptions and possibilities for control, and by testing the possibilities and reflecting they either maintain or change their approach in aligning with the flow of control. This is a dynamic approach also influenced by engagement as they comply with what they are being told to do, review progress, and consider how to increase, decrease or maintain perceived levels of control. When what they are told to do is tailored to their functional diversity, and appropriate support ensures satisfaction with choice outcomes, what they do is more likely to be in compliance and they frame control more positively. For example, when an adult with limiting physical mobility needs more time than others in the group to get to the service bus in the evening, she is instructed by day service staff to make her way to the bus earlier than the others. Furthermore, sustaining levels of engagement with what they are told to do, have consequences for developing self-confidence and skill mastery effecting higher levels of emotional connecting. Although being unable to sustain high levels of engagement with what they are being told to do is counterbalanced by reduced levels of emotional connecting and adjusting compliance it can have consequences for adults bursting the boundaries of what they are being told to do.

5.7.2.2 Support

Support refers to the nature and extent of conditions which impact on how they make choices comprised of choice arrangements, consultation and resources. Support is multivariate in nature and occurs in a variety of contexts and is conditional on functional diversity and external influences:

FN16.01.12.P12.1.1.0:00 being supported

P12 talks to the houseparent about her difficulties getting onto the community residential service bus which is due to a physical limitation in mobility. It appears that the houseparent observes what was happening and talks to her about her physical mobility needs and possible interventions such as the need to get some equipment to help her to get on the bus. The houseparent also stipulates that she will ask XX or XX to get a stepper so that it will be easier for her to get onto the bus. The houseparent talks to her about her difficulties getting on the bus, implicitly she depends on the houseparent to observe, listen and advocate for resources within the community residential service to meet her needs. When the houseparent initiates the opportunity for talking it creates more opportunities for her to explain her difficulties of finding it hard to get onto and off the bus and to access public transport. Talking results in more explaining of needs. Talking results in more discussion. Talking results in opportunities for voicing opinions and subsequently the houseparent is helping out with the needs she has regarding getting on the bus. The houseparent discusses her needs with other staff who will get the necessary resources for her e.g. the stepper to get on and off the bus. This stepper can be kept on the bus. Talking is focused on a physical need and factual solution

Choice arrangements explain the structural conditions of choices underpinned by pre-arranged, arranged and self-arranged. Choice arrangements are organised inclusive of, exclusive of, or by the individual adult themselves within the requirements of what they are being told to do. Many choice arrangements are pre-arranged and communicated to adults when in place. Ultimately, regardless of when choice arrangements are communicated to them, it is in deducing the compatibility between what they are being told to do and what they do that they determine whether choice arrangements meet their aspirations and so are indicative of how they frame control. Choice arrangements are heavily influenced by service provision being run primarily as a group-managed service provision in a hierarchical management structured system.

Consultation refers to the level to which they are consulted when choices are made, and comprises of lacking consultation, limiting consultation, reasonable consultation, and full consultation. While external influences direct that consultation is a necessity for some choice arrangements, adults report a lack of consultation with regard to many choice arrangements. In the realities of what they do, many of their choice arrangements are operationalized in the continuous application of rules and in the context of available resources.

When it does happen consultation facilitates engagement. The more the agency consults these adults about what to expect with regard to choice arrangements the more they are able to interpret the conditions for engagement. When present consultation clarifies aspirations, requirements, addresses misconceptions, alleviates fears, and vice versa. In its absence, consultation can be a trigger for lower levels of emotional connecting and vice versa when what adults are being told to do is interactive with what they do.

Consultation provides opportunities for engagement, but once informed of choice arrangements, how adults frame control is counterbalanced by how they emotionally connect and how they adjust compliance behaviours. Furthermore, when consultation is not only directed at adults themselves, but also at agency involved in relevant choice arrangements, it is a driver for maximising engagement and minimising the occurrence of failures and unnecessary risks. Consultation when facilitating support contributes to functional diversity, enabling adult compliance with what they are being told to do.

While some external influences legitimize the need for consultation in the context of some choice arrangements, much of the support for other choice arrangements is arranged prior to the inclusion of the adult, and so an arena is created where consultation is often lacking. As a consequence of consultation, engagement will be either maximized or minimized.

Resources comprises of information, supervision, time, equipment, funding to explain the available provisions supporting choice. Regardless of the availability of resources, consultation is variable in the context of support, such as when within a hierarchical management style system which facilitates group-managed care provision, choice arrangements are often made at the higher management level of the organisation and the information is passed down through the levels of hierarchy to the adult. Therefore support has consequences for their levels of engagement in choice arrangements.

Supervision underlies support, but moreover, it is how adult aspirations for supervision align with actual supervision has consequences for how they frame control. When supervision is perceived as being assistive they express more positivity in framing control, whereas when supervision is perceived to be intrusive they express more negativity in framing control. And whether control is framed positively or negatively it consequently feeds back into how frames of reference are formulated as adults weigh up the fulfilment of their own individual needs and aspirations with what they are being told to do.

Support when individually tailored, is facilitated by their consultation in choice arrangements which are heavily influenced by functional diversity and accommodative resources assist them in overcoming or working around limitations and promoting strengths. Support can be conditional on external influences, such as, policy and legislation, authorising resources and agency to oversee the distribution of resources impacting on choice arrangements within the context of a group managed care facility. Functional diversity can also be a driver for support, for example, where choice arrangements are made to accommodate those with greater health needs, often when resources are limited. Support is increased at times of crisis. For example, one adult who lives in the community with family is finding it hard to cope at home where enacting practices from family member's conflict with her aspirations and she is not in control. While she does not want service employees to get involved in her family situation, the enacting practices of service employees confront her and her initial response is not to comply with what she is being told to do. As she opts for non-engagement with support, what she does deviates from what she is being told to do and in struggling for control she pushes the boundaries of her own functional diversity too far, lowering levels of how she emotionally connects and adjusts her behaviour. This ultimately feeds back into negatively framing control and she is challenged to negotiate support. However, when support is congruent with aspirations, engagement is facilitated. And, when required, support from additional services, such as counselling or psychology, can maximise the potential for adults to engage in choice arrangements.

Support construed with or without adult presence, can be restrictive or empowering in nature and their perceived freedom to choose has consequences for how they frame control. How they adapt and adjust to the nature and extent of information shared forms the basis for aligning with the flow of control. But the degree to which they are prepared or willing to cope with sustained routines or changes determines their level of engagement and ultimately what they actually do. Support is a condition which has consequences for how they frame control, as by having access to resources which assist them in achieving their aspirations; it ultimately assists them emotionally and in making adjustments in their behaviours. For example, if they are satisfied that their aspirations are being met through choice arrangements and have continued access to specific resources, they frame control more positively. Conversely, lacking access to specific resources also contributes to how they frame control. For example, information is a resource, which aids how they make choices. Those lacking information can make assumptions about what their main issues are and how these can be addressed. Lacking information consequently contributes to negatively framing control, lacking information can also increase emotional stability enabling them to be more focused on what they are actually doing. For example without access to information about impending cuts to disability allowance, transport restrictions, or imminent moves, they are more able to concentrate on what they actually do as they are less stressed about impending restrictions or changes with regard to external influences and subsequent resource distribution. They thus continue to align their approach within the context of each choice and available information.

5.7.2.3 Engagement

Engagement explains the nature and extent of conditions which impact on their engagement in choice arrangements. There are different levels of engagement ranging from non-engagement where the choice is pre-arranged by agency to full engagement, where they are central to choice arrangements:

FNID30.01.12.P9.1.3.1:00 non-engagement

P9 is deprived of the opportunity to participate in the discussions about the choice of where she lives and whom she lives with. She is deprived of her freedom to live in the community with her family. She is deprived of personal control to make a choice about where she lives. She is deprived of the opportunity to have personal control over her belongings as another adult who shares a room with her takes her clothes and slippers without her permission and wears them. She lives in a foster home with her aunt. It is decided by others that community residential services would be a better placement for her rather than the home environment she currently has. She initially understands that she is in community residential services to give her aunt a break not to be there full time. She is stressed and unhappy when she finds that she is in community residential services full time, and that she shares a room with another person who takes her clothes and slippers without asking her and wears them. She is upset that she is placed in full time community residential services

FNID01.02.12.P8.1.9.8:00 full engagement

P8 has a lump on her breast and has an operation to have it removed. She says that makes her own choice to do this. She speaks about it being her own decision to make the choice to have the

lump removed- it appears that she is empowered to make the choice to have the lump removed. She talks to the nurse manager. She meets with the doctor and talks about her condition as she is embarrassed over enlargement in size and leakage from her breast. She says that the doctor explains everything to her. She tells the nurse manager that she wants to get the lump removed. She appears to be present at all meetings and consulted with regard to the choice being made

Enacting practices influence engagement. At a very basic level if adults are excluded from decision - making, and not aware of what is going on, then, they are not able to engage and this has consequences for non-engagement. However, inasmuch as what they are being told to do can stipulate the perceived need and opportunity for engagement in different contexts and for different choice situations, it is often the compatibility between agency enacting practices and what adults actually do, with regard to choice arrangements that is paramount in how they will engage. They are less engaged in choice arrangements that are not significant to or opposing their aspirations, and there is therefore more likelihood of dissentious complying and ultimately opting for non -engagement and vice versa.

Conversely, when one adult who was excluded from choice arrangements, made attempts at increasing engagement by trying to contact the manager via verbal requests and written letters given to house parents to air her complaints, she found her requests ignored. This became a source of frustration and a trigger for negatively framing control, especially so, when the agency did not respond at all. For adults, less certainty about their ability perceptions and their own aspirations trigger negativity in framing control. Those who are lacking information about other possible options and are unaware of negotiations regarding choice arrangements passively comply what they are being told to do. Ultimately adults are more engaged in choice arrangements that are significant to, or match their ability perceptions and aspirations, and they engage enthusiastically.

While positively framing control is arguably predictive of higher levels of engagement, this is not necessarily so, as adults may have more positivity in framing control, but their functional diversity in combination how they frame control is ultimately indicative of engagement. Conversely, engagement is a necessary condition for optimising their functional diversity and by complying with what they are being told to do, they increase and sustain engagement. When enacting practices have consequences for choice arrangements being increasingly directed by the adults themselves, their engagement is maximized, which in turn increases the likelihood of them becoming more self-directed in what they actually do, so reaching their ultimate outcomes while doing as told. Thus, while a positive aligning cycle acts to break down the fact that adults are being told what to do, it can also double back on itself to promote the attainment of compliance behaviours though engagement. Enacting practices can guide maximization of engagement, so providing opportunities for optimizing functional diversity with regard to choice arrangements and vice versa. Adults can maximize engagement by 'fitting' what they do with what they are being told to do.

5.8 Conclusion

Control in controlling environments emerges as a main issue of concern for the adults in this research study. As the emergent theory demonstrates they respond to this main issue of concern by aligning with the flow of control as underpinned by framing control, emotional connecting and a djusting compliance when being told within the boundaries of their actual doing. The emergent theory aligning with the flow of control determines that continual feedback typically demonstrates how adults respond with different patterns of behaviours, namely; resisting the flow of control, getting carried by the flow of control, going with the flow of control and embracing the flow of control.

Framing control determines that their past experiences and current understandings of choice situations impact on their general beliefs and specific perceptions of the possible and actual control they have with regard to their choices. Being told sets the requirements for and directs their behaviours while actual doing determines what they actually do when choices are made. Based on framing control, and taking into consideration how they emotionally respond and make adjustments as they make choices within the boundaries of what they are being told to do, and within the remit of their actual doing, these adults are aligning with the flow of control.

6 Aligning with the flow of control and relevant literature

6.1 Introduction

The previous two chapters have outlined the emergent-grounded theory of aligning with the flow of control, presenting the main theoretical concepts and key emergent choice issues of this thesis. The purpose of this chapter is to explore the relevance and utility of this grounded theory within the context of how adults make choices; the substantive area from which it was empirically derived. As already explained in the methodology chapter, rather than conducting a review of literature in the substantive area prior to data collection and analysis, extant literature has not been incorporated within the research process until the theory has emerged. The chapter commences with a scoping review of 'choice' in intellectual disability literature followed by an overview of the tenets of rational choice theory as referenced in behavioural economics and sociological theory. The underpinnings of self-determination and control theories are illuminated followed by specific discussion of Glasser's choice theory (1998) as these theories are inextricably linked with choice behaviour as emergent in this thesis. Extant literature on emotions and compliance are compared to the emergent theory of aligning with the flow of control, discussing its practical implications within the current contexts. Similar to evidence in the literature the emergent theory demonstrates that issues of choice and control are inextricably interlinked for this group of adults with intellectual disabilities.

6.2 Choice in intellectual disability literature

Traditionally, choice opportunities were severely restricted in the lives of adults with intellectual disabilities (Mithaug 2005), whereas nowadays, choice is construed as a valued and ideal entitlement in their lives (Webber and Cobigo 2014; Brown and Brown 2009; Agran et al 2010).

Webber and Cobigo (2014) undertook a sweeping review of English-language literature published between January 1st, 1991 and December 31st 2011 in an attempt to establish what service providers for the intellectually and developmentally disabled people need to know when measuring how they impact consumers' freedom to make choices. They identified four components of choice, advocating that the following components should be used as measurements to evaluate services: (1) the availability of choice opportunities; (2) the provision of choice options; (3) informed cognitive processes and act of choosing, and (4) a supportive environment. Webber and Cobigo (2014) found

that evidence of methods to promote choice among persons with intellectual disabilities is limited and that service providers are ill-equipped to develop services which promote choice, recommending that further research be undertaken to assist service providers evaluate their services, demonstrate accountability, and to maintain a balance between promoting choice and protecting vulnerable adults. Notably, Brown and Brown (2009) identify a five step strategy for integrating choice into the lives of these individuals: (1) assessment of choice acceptance in the environment; (2) clarification of methods for broadening familiar choice opportunities; (3) clarification of methods to increase individual's freedom, initiative, and skills in choice-making; (4) increase skills of relevant support persons; (5) development and assessment of specific methods for recording choice in practice which link choice with other key quality of life concepts.

The above provides for a mandate whereby service providers and supporters are now obligated to ensure that choice is evident in the lives of people with intellectual disabilities. The following presents a scoping review of choice from the evidenced based experiences of adults with intellectual disabilities.

6.2.1 A scoping review of choice inclusive of people with intellectual disabilities

This section presents a scoping review of 'choice' inclusive of adults with intellectual disabilities. The PICO Tool (Wakefield 2014) was helpful in clarifying the aim of the scoping review which was to identify how qualitative or quantitative evidence can assist an understanding of choice reflected in the perceptions and experiences of these adults. Literature was sourced from Academic Search Complete, OMNI Full Text Mega, Psych Info, Cinahl Plus Full Text, Eric, and Medline databases. Limiters of full text and search dates which ranged from 2008-2014 were applied. The applied selection criteria was; (i) research design to be inclusive research, intervention, experimental, descriptive, qualitative, or quantitative; (ii) population inclusive of adults with intellectual disabilities; and (iii) topic focus to include choice.

As set out in Table 6.1 this search strategy included BOOLEAN and Truncation word searches of "intellectual disab*" OR "learning disab*" OR "developmental disab". Combined individual searches were undertaken with AND "adult*" AND "choice*". Combined individual searches with the results were then undertaken with "option*" OR "support*" OR "strat*" OR "resource*" OR "guideline*" OR "intervent*" OR "experience" OR "perception" OR "view*". This search strategy was combined with NOT "child*" OR "adolescent*" OR "teenager*". Articles were judged to be relevant based upon their title. Following initial searches, screening of abstracts was undertaken and studies

excluded which referred to people with general disabilities and people with acquired brain injury, as well as opinion papers. Articles were discarded which did not have any relationships with the research aim, which were not research papers or lacked clarity with regard to research methodology.

Table 6.1 presents the search strategy:

Table 6-1 Search strategy: ‘Choice’ evidence base inclusive of adults with intellectual disabilities

		Academic Search Complete	OMNI Full Text Mega	Psych Info	Cinahl Plus Full text	Eric	Medline	Total
1	“intellectual disab*” OR “learning disab*” OR “developmental disab*” AND “choice*”	(n =344)	(n=59)	(n=170)	(n=191)	(n=124)	(n=102)	(n=866)
2	combined with NOT “adoles*” OR “teenager*” OR “youth*” OR “child*”	(n=223)	(n=89)	(n=127)	(n=88)	(n=148)	(n=52)	(n=737)
3	combined with AND “adult*”	(n=57)	(n=3)	(n=31)	(n=47)	(n=28)	(n=34)	(n=200)
4	Combined with “option*” OR “strat*” OR “guideline*” OR “support*” OR “resource*” OR “intervention*” OR “experience” OR “perception” OR “view”	(n=33)	(n=3)	(n=22)	(n=30)	(n=20)	(n=21)	(n=129)
5	Minus Duplicates and articles which did not meet the inclusion criteria or lacked clarity with regard to research methodology or were opinion papers.						Total (n=33)	

The intention of this review was to select research articles which provided an evidence-base portraying how adults with intellectual disabilities experience choice. A data extraction tool was used to extract structure and organise key information from the research articles (Wakefield 2014), under the following headings Article No.; Country of study; Author(s); Title; Year; methodology and methods; findings and limitations.

Of the 33 articles sourced, represented a variety of countries from the United Kingdom, Sweden, Netherlands, Taiwan, United States of America, Canada, Australia and New Zealand. The studies differed in the following areas: a) population; adults as research participants, (self-reports and/or proxy reports or observations), co-researchers (member of a research team), or undertaking a dual role (co-researcher and research participant), b) intervention; survey, interview, conversation analysis, inclusive research, and c) type of choice; living arrangements, (change of residence, roommate selection), d) productivity, (vocational activities, employment), e) health (accessing and attending health check appointments, hydrotherapy, contraception, planned pregnancy and parenting) and social arrangements (eating).

The findings are represented in the themes of: choice making exercises (being motivated, identifying and selecting preferences and goal setting and problem solving), support for choice making (having opportunities to make choices, a supportive network with good support and education and skill development) and challenges to choice making (limiting choice availability and opportunity, limiting resources and attitudes). Implications of the scoping review are discussed and conclusions drawn.

6.2.1.1.1 Choice making exercises

Choice making exercises were underpinned by being motivated, identifying and selecting preferences and goal setting and problem solving.

Choice making was a significant exercise for adults with intellectual disabilities, as Agran et al (2010) found that 90% indicated that making choices was important, 77% indicated the support person wanted them to make choices, 87% were sometimes asked if they liked their job, and 74% felt that support staff took their suggestions seriously. These authors reported that making choices was associated with being independent, being happy, learning, and having pride in being able to decide for themselves. There was a dearth of research which specifically aimed to identify adult perceptions and experiences of factors which motivate them to make choices, but from research undertaken on the topic of choice adults did report 'attaining social recognition and connection', 'a sense of pride and satisfaction', and 'feelings of competence', which culminated in intrinsic motivation to make choices, and 'money', 'food' and 'library books' which capped external motivating factors (Lysaght et al 2009). The emergent theory explains that it is how adults frame the control they have in choice situations is the greatest motivating factor in their choice behaviour.

Adults participated in an exercise which facilitated identification of their preferences and compatibility with regard to the choice of roommate selection (Wiltz and Kalnins 2008). But when staff did not have this knowledge or use methods to assess preferences accurately, discrepancies arose between proxy opinion and actual individual choices (Cobigo et al 2010). For example, some of the adult women while not being afforded the opportunity to choose specifically expressed a preference to consult a female doctor with gynaecological healthcare concerns (McCarthy 2010).

The emergent theory explains and makes comparisons regarding choice situations where individuals are either facilitated or denied opportunities to identify preferences. Further in-debt analysis is undertaken to explain choice behaviours when choice making exercises are either congruent or oppositional to their aspirations.

Conversely, in the context of a choice regarding employment, Donnelly et al (2010) found that reaching a true understanding of preferences and interests required long-term engagement with adults and respect for the knowledge and views of their family and other members of their support network. Lysaght et al (2009) found that although the titles of volunteer jobs mirrored those of paid jobs the descriptions of such jobs provided to workers with intellectual disabilities varied in levels of responsibility. Similar to the importance of adult aspirations in the emergent theory this finding highlights the necessity to identify preferences of adults in the context of job responsibilities so as to further enhance their choice experience in the context of work or employment opportunities. Furthermore the emergent theory identifies the need for recognition of compatibility between adult functional diversity and what they are being told to do.

The exercise of goal-setting as well as further on-going skills of problem solving and valuing work performance, were also linked to choice-making skills (McConkey and Collins 2010; Agran et al 2010). But for some, even when methods for making choices were in place, this did not necessarily indicate that choice-making was effective as Ferguson et al (2010) reported that individuals did not recognise the choice to attend a hydrotherapy programme as a choice-making opportunity. Nonetheless, Brown and Brown (2009) claimed that exercising choice should be recognised as an important aspect of support for people with intellectual disabilities.

Similarities were evident in the emergent theory as those with clarity in goals and plans tended to have better problem solving skills while those who demonstrated less clarity in goals and plans lacked problem solving skills.

6.2.1.1.2 Support for choice making

Support for choice making were found to be; having opportunities to make choices, a supportive network with good support and education and skill development.

Having opportunities to make choices was clearly endorsed as a requirement in policies of providers of services for adults with intellectual disabilities (Stancliffe et al 2011). And in practice Jensen et al (2012) found that when an adult who engaged in self-injurious behaviour was afforded the opportunity to choose working staff, there was a significant reduction in the time spent in mechanical restraint. Interestingly, the most significant decrease of time in restraint occurred after the choice was made, rather than after the chosen work staff arrived (Jensen et al 2012).

While adult participants in this research study accepted that they got on with some staff and not others, they did not have any control in the employment of staff or in staff turnover.

Having a supportive network was pivotal to successful choice outcomes. For instance, McConkey and Collins (2010) found support staff played a crucial role in goal attainment. Some adults emphasized that having a support person who knew them well was particularly advantageous when attending health checks (Michell 2012) or General Practitioner appointments (McCarthy 2010). The role of advocacy support from people working within and outside services who knew the person well has been acknowledged (Chapman et al 2011). And those who were successful parents reported that caring, responsive and supportive agencies to be a significant element (Conder et al 2010). Similarly in this research study adults depended on others for support, but levels of support were variable across individuals and choice situations. Significantly in this research study it was the congruence or incongruence between the needed support, desired support and support given which were indicative of the levels of satisfaction of the adult with the choice situation.

Good support was reflected in adults' reports of skills support staff required were 'a show of respect', 'support for choices', 'friendliness', 'offers of advice' and 'support to speak up', (Williams et al 2009). These authors recommended that a focus on strategies, such as 'stepping back, listening and observing', 'body language', 'time', 'team work' and 'personal knowledge', would enhance proper support for adults when making choices. Similarities exist in this research study with the attitudes and practices (enacting practices) of those in power positions which impact on how adults determine the control they have in choice situations but also these enacting practices are a driver for adult feelings which impact on their emotional wellbeing.

Drawing data from an ethnographic study using conversation analysis Antaki et al (2009) observed how five varieties of offering choice could enhanced choice-making for adults: (a) two-option simple alternative in one question; (b) open question and understanding check of answer; (c) open question and immediate single option; (d) open question repaired to one-at-a-time alternatives; and (e) closed (yes/no) question. Similarities exist in this research study of communication directives which are on a continuum from directive orders, orders, single option, two-option, telling, instructing and advising.

Other important resources to support choice making were regarded as education and skill development. For example, education improved understanding of options for support of adults and those who assisted (Lysaght et al 2009). Education combined with the principles of applied behaviour analysis for an adult with a dual diagnosis of mental illness and intellectual disabilities resulted in increased opportunities for the adult to make choices and subsequently develop more self-control (Benedick and Dixon 2009). Another resource regarded effective, was facilitation of skill

development for financial matters in pre-vocational programming, which aimed to enhance options for productive involvement of adults enabling them to participate meaningfully in life decisions (Stancliffe et al 2011; Chou et al 2011; Lysaght et al 2009).

In this research study the more adults were able to comply with what they were being told to do the more opportunities they were afforded creating opportunities to phase choice experiences for short term and longer term choice arrangements, so continually engaging in experiential learning. Furthermore in this research study peer support in choice arrangements occurred informally where those with necessary skills or less impairment assisted their peers creating opportunities for greater empowerment and/or less presence of supervision.

6.2.1.1.3 Challenges to choice making

Challenges to making choices arose as limiting choice availability and opportunity, limiting resources (consultation, information, expertise, transport, financial support) and attitudes.

Evidence suggested that while choice was evident in the policies of service provider's access to greater life choices with regard to community-based residential options was still limited for service users (Stancliffe et al 2011). Limiting choice availability was reported with regard to a wide range of activities of living and in some instances those with more severe levels of intellectual disability had lesser choice than those with a milder degree of intellectual disability, whereas others in institutions and group homes had little choice regardless of their level of disability (Stancliffe et al 2011). And the absence of evidence regarding factors that influenced employment-related decisions of adults with intellectual disabilities raised concerns about how such choices were offered (Ciulla et al 2011).

Similarly in this research study those with lower functional diversity reported they had less control over choices and vice versa. Those in group managed service provision had less opportunity to make individual choices but interestingly the adult who lived in the community while having the freedom to choose engaged in set structured choice arrangements.

Stancliffe et al (2011) reported that even though effective methods were available for choosing where, and with whom to live, these approaches were too rarely implemented. Some adults reported that choices of where and with whom to live were not made by themselves (Chou et al 2011). Others reported being often limited in choosing their companions at meals, and when such choices were

made, they were dependent upon staff support to realise them (Adolfsson et al 2010). Conversely, some who lived independently were more likely to eat alone, either voluntarily or involuntarily, and many expressed dissatisfaction with eating alone (Adolfsson et al 2010).

Other challenges to making choices were regarded as lacking resources such as consultation and information to make choices. For example, women with severe intellectual disability lacked consultation and information when they were excluded from discussions or formal meetings about their individual futures, such as being transferred from a locked ward to community-based settings (Owen et al 2008). Additionally, some adults with intellectual disabilities lacked awareness about risk management (Kilcommons et al 2012).

Similarities existed for adults in this research study for adults who reported moving day service, community residential house or transitioning from community to residential services.

Decisions to attend healthcare hydrotherapy programme appointments were for the most part made for, and in lesser instances made with, the adults (Ferguson et al 2010). With regard to work positions, a number indicated that their work position had been secured by relevant others, and evidence was limited to determine the level of choice they had actually exercised in the placement process and in some cases their description of the work they actually did reflected lower levels of responsibility than as assumed in the job title (Lysaght et al 2009). Decisions to start using contraception were reported by some women to have been mostly made by others rather than by themselves (McCarthy 2010).

While similar to reports from participants in this research study choice arrangements appear to be more organised for the person by relevant others, but compatibility with choice arrangements e.g. job and job situation appeared to be more significant for research participants rather than who instigated or arranged choices. Conversely, for one adult in this research study who was employed part-time found that while her job title remained the same her workload doubled as she covered for another employee who was out sick which highlights the significance of ongoing information sharing and support.

Lack of information and consultation was evident for some adults as they did not recall discussion regarding the choice to become a parent, the associated implications of making such a choice, and were subsequently shocked with the removal of their child (Conder et al 2010). Others found limitations in the accessibility of information regarding reminders to attend General Practitioner (GP) for health-check (Michell 2012) and material to take away from such appointments (McCarthy 2010). Lack of on-going information-sharing was highlighted as many women could not remember what the

doctor had told them about contraception (McCarthy 2010). Moreover, Cardol et al (2012) found that adults who had diabetes had received information about the condition which none of them could understand. While the presence of accessible information is significantly important for adults with intellectual disabilities there needs to be a greater emphasis on on-going information sharing and consultation. The lack of accessible on-going information sharing contributes to a lack of consultation.

While a variety of information sharing was reported by the adults participants in this research study more significant to the accessibility of the information shared was the opportunity and receptivity of consultation.

Additional challenges reported were limiting support from staff and relevant others; for example, when care staff lacked practical skills in communicating information to those with more severe intellectual disability (Owen et al 2008). Some adults reported that their lives were still under the control of the staffs' expectation rather than themselves and Chou et al (2011) claimed staff competence and staff training needs to be influencing factors. Staff's failure to share information compounded levels of uncertainty and stress for adults, at times of major transitions, such as moving house (Owen et al 2008). McCarthy (2009) found that only 5 of the 23 women used available options of family planning services and cited lack of knowledge of both the women and their carer's as a possible factor which influenced the low uptake. Other adult women felt that they were not supported to maintain relationships with families and advocates over time (Owen et al 2008). And some frequently experienced disparities between their self-interests and choice opportunities (Donnelly et al 2010). Adults were cautious when voicing complaints against support staff and drew on repertoires of competence and incompetence, staff as being directive and controlling and the right to free choice, tempering their dissatisfaction by making contrasts between good and bad supporters and practice (Jingree and Finlay 2013).

Other resources such as transport and financial disincentives were also cited as challenges to participation in meaningful activities (Haigh 2013; Lysaght et al 2009). Some reported experiences which reflected how the attitudes of relevant others impacted on their choices. For example when staffs perception of intellectual disability continued to be informed by a medical model, rather than a more social model, adults with intellectual disabilities who had limitations in speech tended to be perceived by others as essentially knowable based merely by type and level of impairments, basic needs and presentation of challenging behaviours (Owen et al 2008).

Furthermore, drawing data from an ethnographic study using conversation analysis, Antaki et al (2009, p. 261) demonstrated how the discourse of choice was utilised by staff, to promote institutional

managerial objectives: (a) choice about matters important to the organisation, (b) choice as a format for a running commentary, (c) choice as reactive to misfires, (d) choice as a format for refusing an expressed preference and (e) choice about abstract, unfamiliar or underspecified alternatives. This indicated that staff commitment to service objectives over the aspirations of adults with intellectual disabilities affected the choices made by these individuals.

Adults with a dual diagnosis of mental illness and intellectual disability who presented with impulsive behaviour were often dismissed by clinical staff as having impulsive personalities, or lacking self-control (Benedick and Dixon 2009). Furthermore, attitudes impacted on how adult women experience support with regard to sexuality. For example, their sexual needs were often ignored, curtailed or actively denied by professionals, as well as the general community. These women had greater experiences of being sexually regulated and subsequently struggled to develop positive sexual identities (Fitzgerald and Withers 2011). How society in general viewed these adults had a knock-on effect for how these adults were treated. For example, General Practitioners had varying attitudes to undertaking health-checks for these adults who reported varying experiences with regard to feelings of being welcomed in the GP surgery (Michell 2012).

6.2.1.1.4 Implications from the scoping review

The findings that over a span of 6 years just 33 articles incorporating research inclusive of adults with intellectual disabilities on their views and experiences of 'choice' is indicative of the assumptions of this researcher that little research has been undertaken from the perceptions and experiences of adults with intellectual disabilities. Key implications from the scoping review centred on service policies, accessible literacy and the necessity for appropriate forums to air grievances.

From a service perspective discourse in philosophies, policies and mission statements need to be embedded in the daily realities of how and what choices are made available to adults and how choice is continually reflected in the interactional reality of the person - professional contacts even in circumstances where limited choices are actually offered (McCarthy 2010; Antaki et al 2009). While Chou et al (2011) suggested improved resource allocation Ferguson et al (2010) contended that provision of choice opportunities alone is insufficient to enable active choice-makers. More specifically Haigh (2013) recommended service policies to ensure there are places for adults with intellectual disabilities to socialise and meet friends and romantic partners, support to access and enjoy valued roles at work or at home and be enabled to develop effective coping mechanisms, especially in managing feelings like anger and sadness. Evident in the emergent theory was the diversity in needs and aspirations of the individual research participants with regard to choice. And

policy guidelines need to ensure that evidence is made available as to what a person wants and how the individual communicated this information.

Ferguson et al (2010) believed that information was key to effective choice-making, and although accessible information is becoming more available, it is important for future research to consider the nature of the information provided and the ways in which this information is used. Lack of accessible information can have consequences for adults having limited awareness of the available opportunities for health-check choices (Michell 2012). Limited awareness can lead to lack of engagement and when women with intellectual disabilities experience lack engagement with regard to a choice, they ultimately experience a lack of a sense of personal agency (McCarthy 2009). While such protective practices may be appropriate for some women, women with intellectual disabilities need to be enabled to exercise as much choice and control over their health as they possibly can. General Practitioners need to improve communication with their patients and easy read materials should be available for doctors to use with their patients (Michell 2012). In recommending that information be made more accessible to people with intellectual disabilities and diabetes, the University of Queensland, Australia, developed an accessible diabetes website which provided additional information about living with diabetes that did not focus solely on medical aspects (Cardol et al 2012). Evident in the emergent theory was not only the diversity in accessible literacy needs of the individual research participants but the significance of repeated explanation and reminders to support individuals understand information and communicate choice. A crucial step in integrating choice into daily practice was seen to be embedded in increasing skills of support personnel and family members (Conder et al 2010; Cobigo et al 2010). McConkey and Collins (2010) proposed the need for a more detailed examination of the knowledge and skills for support staff in relation to person-centred working and how support could be tailored to reduce or remove the perceived barriers to social inclusion. Michell (2012) averred the significance of the level of expertise of professionals who supported these adults and advised that General Practitioners, surgery staff and carers required assistance from other professionals and regular training so as to facilitate best support. Michell (2012) recommended that it is adults with intellectual disabilities who should be the experts in advising doctors and other support persons on how best they can be supported. McCarthy (2010) recommended specialisation of GP practices, that is, some GP practices to become 'locally enhanced'. Adults and their support network require assistance to enable them appreciate their role in the choice-making process and fully recognise and utilise choice options and opportunities (Ferguson et al 2010). Evident in the emergent theory was not only the diversity in support needs of the individual research participants but also the differing levels of consultation made available. Moreover, along with what information was communicated or how it was interpreted, it was also the way adults were made feel by those in power positions was a significant factor in how these adults experienced choice.

The provision of opportunities for these adults to air their expressions of satisfaction or grievances is a prominent issue but the facilitation of such opportunities raises further concern (Jingree and Finlay 2013). It is critical that input is sought from these adults on the value of choice making (Agran et al 2010), specifically with regard to health-care (Michell 2012), the social aspects of meals (Adolfsson et al 2010) and the way advocacy services facilitate them to have more opportunities for choice and control in their lives (Chapman et al 2011). The variety in individual expressions of satisfaction and dissatisfaction across a multitude of choice situations was evident in this theory but the lack of evaluation of their perceived levels of satisfaction was a common thread among all research participants.

This scoping review demonstrated research findings similar to the issues arising for the adult participants in this research study therefore giving credence to the emergent theory. While Chapter 2 demonstrated that choice is a valued concept, it is evident from this scoping review that there is a dearth of information on the perceptions and experiences of adults with intellectual disabilities with regard to choice. The emergent theory while expanding on the current research evidence of issues of concern for adults when making choices provides scope for further research into choice behaviour of adults with intellectual disabilities.

This scoping review demonstrated research findings that living arrangements, productivity and health were the focus of research on choice in the lives of adults with intellectual disabilities, the emergent theory advocates that money, transport, relationships and many activities of living, such as putting milk in tea held the same were as significant to adults as the choice of where and with whom to live. The emergent theory demonstrated that these adults wanted to live lives as similar as possible to those in the general population. And it is by understanding the person's world, the compatibility of their functional diversity and the opportunities afforded that choice behaviour will be better appreciated.

Many of the adults in the research study still experience restrictions in choice situations and there is a dearth of research on the impact of such choice restrictions on the individual, the complexities of why choices are being restricted and the impact of such choice restrictions on the person.

6.3 Rational choice theory

Rational Choice Theory (RCT) asserts that a rational choice or action is one in which the individual considers their preferences and beliefs so as to choose the best available action (Satz and Ferejohn 1994). It has three major interpretations: normative (articulating conditions regarding how individuals/groups ought to choose); predictive (postulating a set of claims predicting actions of individuals/groups); and descriptive (illustrating the psychological decision-making processes of individuals/groups) (Schulz 2011; Bermudez 2009). Taking the normative interpretation RCT hypothesizes that when individuals make choices they are influenced by the culture and norms of the societies in which they live, which has implications for their patterns of behaviour, and as a result these patterns of behaviour develop within their societies (Grune-Yanoff 2010). The predictive interpretation of RCT proposes that the behaviours of individuals or groups in certain choices situations are predictable (Bermudez 2009). The descriptive interpretation of RCT proposes that the actions individuals take are underpinned by their beliefs about their realities and chosen so as to maximize their desire-satisfaction (Schulz 2011; Bermudez 2009) while they simultaneously balance costs against benefits so as to arrive at an advantageous decision (Peter and Charlotta 2008). Sequentially Rational Choice theorists claim that in complex choice situations, individuals categorize alternatives rather than compare prior to choosing (Apesteguia and Ballester 2013), individuals exhibit cycles of choice over some sets of alternatives sequentially using two rationales of 'short-listing' and 'selecting' to discriminate among the available alternatives (Manzini and Mariotti 2007, p.1824). Furthermore, rationalizability of choice functions by game-trees theorists claim that without having knowledge of individuals, of collective groups, or of the specific decision-making processes they use in making choices, potential cycles of choice which are collective in nature can be rationalized by extensive games (Xu and Zhou 2007). Conversely, boundedly rational choice theory seeks to accommodate choice behaviour that rational decision-makers do not exhibit, for example those individuals/groups who make choices without the full consideration of or realisation of an alternative set of options (Masatlioglu et al 2012).

In providing an evidence base for rational choice theory choice models are a family of statistical representations have been developed to explain how individuals/groups make choices when faced with a range of different options by describing, explaining and predicting specific choices which they make at specific times (Horsky et al 2010; Amartya 2008; Briesch et al 2010; Goldfarb and Xiao 2011).

Choice sets generally determine the nature and number of options available, and whether or not the selection of one option rules out choice of alternatives (Weinstein 2000). The variability of choice

sets is dependent on each individual's choice situation; for example, the choice set of an individual living in a rural area is different from an individual who lives in an urban area (Beard and Dasgupta 2006), or on whether or not an individual can choose one or more options from a set of alternatives (Charles 2008). Choosing from one or more options can create confusion, whereas when an individual can only choose one option the chance of confusion lessens, which accounts for the commonality in use of such instruments as Discrete Choice Experiments (DCEs) used for quantitative elicitation of individual preferences in healthcare interventions, services or policies (de Bekker-Grob et al 2012); in drug treatment options (Hilgsmann et al 2013); lifestyle programmes (Veldwijk et al 2013) and travel and transport (Yan et al 2013). Generally individuals are presented with a set of choices and their responses are collected and evaluated (Lohmann 2008).

The collection of such data, while identifying and facilitating the preferences of individuals, also enables a wide range of policy questions to be identified and subsequently addressed, ultimately improving the economic state of service providers (Ishaq et al 2013; Krabbe 2013). The use of choice models facilitates the identification of defining attributes in choice making such as gender, age, race, financial status, bio-psychosocial experience, and individual preferences (Lui et al 2010). Choice models are able to estimate the probability of an individual making a particular decision by choosing a particular alternative from a given choice set (Jackson 2005).

Critics have long debated the value of rational choice theory for social sciences, centralising arguments on the pervasive but elusive concept of rationality (Martinus and Reguly 2013). For example, by making the assumptions that all individuals are logically knowledgeable persons who have nearly unlimited memory powers critics allege that the theory lacks legitimacy (Hausman 1992). While the critical discussions of choice theory have shifted the debate from the rational decision making practices of individuals to observed choice behaviours reflected in the debates of boundedly-rational choice theory, these theorists are criticised for paying scant attention to the social context in which people act and interact, as well as for neglecting to address individual's rationality in following social rules, their habits, and the tacit aspects of institutions (Dequech 2001). It is simply not possible to empirically test or falsify the rational assumption that patterns of behaviour in society are created by and create choice behaviour (Hodgson 2012). Furthermore, there is a dearth of research evidence to support the theory in the context of explaining individual goals, limited choice availability, or indeed the vast array of human motivations and desires (Dietrich and List 2013; Kapeller et al 2013; Scott 2008; Basov 2013). Here, individuals who are fully rational are supposedly completely free from emotions. Therefore the presence of emotions is perceived as a threat to rationality (Basov 2013).

As evidence demonstrates, individuals tend to choose options from alternatives with which they are more familiar. Subsequently, choice models can also be used to predict how a person's choice will change under different circumstances. While choice models aim to explain the underlying decision-making processes of individuals when choosing from different options, choice theory focuses on explaining behaviours. The above demonstrates similarities with the emergent theory in that choice models explain the underlying decision-making process of individuals but in this research study some individuals have access to a greater choice set for others access to choices are limited or severely restricted. Therefore both choice models and rational choice theory are challenged to explain the total behaviour of the individuals in this research study. Similar to the underpinnings of rational choice theory the choices of the adult participants in this research study are influenced by the culture and norms of the service provision in which they live but these choices are different from those of the general society, which has implications for their patterns of behaviour in choice making which is not accounted for in this theory and while these patterns of behaviour develop within their segregated communities they are different from those of adults in the society in which the individual/group lives. Similar to the predictive interpretation of RCT the emergent theory proposes that the behaviours of individuals or groups in certain choices situations are predictable; however in the emergent theory there are other factors such as emotions and compliance behaviours which are factors which influence the predictability of patterns of behaviours. Similarities also exist with the descriptive interpretation of RCT proposes that the actions individuals take are underpinned by their beliefs about their realities and chosen so as to maximize their desire-satisfaction while they simultaneously balance costs against benefits so as to arrive at an advantageous decision but how these adults are limited in making choices which maximize their desire satisfaction and the costs that they balance with the benefits are at a different level than those of the general population. How the adults in this research study are motivated to make choices is as significant if not more so as the choice made. The following provides an overview of self-determination theory.

6.4 Self-determination theory

Self-determination theory focuses on human motivation and personality, placing emphasis on the motivation behind people's choices (Van Petegem et al 2012; Markland et al 2005). The principles of self-determination theory have been widely applied in various fields of life, such as, teaching, social work, health, employment, parenting and sports (Kosmala-Anderson et al 2010; McDermott and Edwards 2012). As prominent theorists in self-determination theory, Deci and Ryan (1985, 2000, 2002) view motivation from a multi-dimensional perspective, which has three general strands: amotivation, extrinsic motivation (which is itself multi-dimensional in nature), and intrinsic

motivation. These types of motivation vary along a self-determination continuum, wherein a person’s perception of whether the origin of their reasons for engaging in a behaviour is internal (done willingly and of free choice), or external (done because they are compelled or required to do so, either by external pressure from others or because of self-imposed pressures motivation), or depending on their ‘perceived locus of causality’ (Deci and Ryan 1985, 2000, 2002). Table 6-2 presents a continuum of self-determination:

Table 6-2 A continuum of self-determination

Amotivation	Extrinsic Motivation				Intrinsic Motivation
Non Regulation	External Regulation	Introjected Regulation	Identified Regulation	Integrated Regulation	Intrinsic Regulation
Impersonal	External	Somewhat External	Somewhat Internal	Internal	Internal
Non-intentional Non valuing Incompetence Lack of control	Compliance External Rewards and punishments	Self-control, ego- involvement Internal rewards and punishments	Personal importance Conscious valuing	Congruence Awareness Synthesis with self	Interest Enjoyment inherent satisfaction
- Self Determination +					

Based on Ryan and Deci (2000) Self-Determination and the Facilitation of Intrinsic Motivation, Social Development, and Well-Being American Psychologist. 55(1), 68-78.

As shown in figure Table 6-2 a state of amotivation exists where an individual has little or no motivation to attempt the behaviour involving beliefs of helplessness (Vallerand 1997), and feelings that one has inadequate ability, effort and strategies. The state of extrinsic motivation exists when an individual performs activities for known external rewards, whether these rewards are tangible or psychological in nature. The four main types of extrinsic motivation are external, introjected, identified, and integrated regulation. Intrinsic motivation exists when an individual is mostly self-directed and partakes in activities for reasons of enjoyment, learning, or task accomplishment, which result in important outcomes for the individual (Ryan and Deci 2000), and an increase in intrinsic motivation contributes to successful results in the named fields (Jang 2008). For example, in terms of sports, sportsmen and women who are self-determined are those who are most successful as, due to their self-motivation, they are able withstand the very difficult times in training, and their time to exhaustion will also be longer compared to sportsmen and women who are externally motivated (Moller et al 2006). Additionally, Vallerand (1997) propose three types of intrinsic motivation: “to know”, “to accomplish” and “to experience stimulation”.

Deci and Ryan (1985) argue that an individual’s regulation can be found at any place in the continuum ranging from amotivation, through extrinsic motivation, to intrinsic motivation, and can vary in different situations or contexts. This continuum represents “the degree to which the regulation of a non-intrinsically motivated behaviour has been internalised” (Deci and Ryan 1991, p.254).

Miller and Rollnick (2002) purport that while external rewards have an immense impact on intrinsic motivation; they also have the potential to decrease intrinsic motivation. This can be clearly explained via positive reinforcements (Knee and Neighbors 2002). According to self-determination theory, there are three main psychological, universal and innate needs, namely, autonomy, competence and psychological relatedness. When these needs are fully satisfied a person obtains an optimal sense of well-being (Villacorta et al 2003). There are similar interpretations of these psychological needs in the literature as presented in Table 6-3:

Table 6-3 Interpretations of psychological, universal, innate needs of autonomy, competence and relatedness

	Autonomy	Competence	Relatedness
Chin (2012)	defined as freedom of choice	when one feels capable, such as when receiving positive and informational feedback	The need to feel sense of belonging and connectedness with others
Verstuyf et al (2012)	The need to feel volitional as the originator of one' actions in carrying out an activity	Competence reflects the need to feel efficacious and capable of achieving desired outcomes	The need to feel close to an valued by important others to have a sense of belonging with peers, family and community
Jacobs et al (2011)	The need for autonomy refers to the need to experience oneself as an initiator and regulator of one's actions	The need for competence refers to the need to master one's environment	People's innate need to seek close and intimate relationships with others
Ntoumanis et al (2009)	Autonomy reflects a desire to engage in activities of one's choosing and to be the origin of one's own behaviour.	individuals' need to interact effectively with their environment, to experience a sense of effectance in producing desired outcomes and preventing undesired events.	The need to feel connected to and accepted by others in a social milieu.
Sheldon and Schuler (2011)	autonomy (feeling ownership and internal causation of one's behaviour).	Competence (feeling effective and efficacious in one's behaviour)	Feeling close and connected to important others,
Thogersen-Ntoumani et al (2010)	Autonomy reflects a desire to engage in activities of one's choosing and to be the origin of one's own behaviour	individuals' need to interact effectively with their environment and to experience a sense of effectance in producing desired outcomes and preventing undesired events	The need to feel connected to and accepted by others in a social milieu
Patrick et al (2007)	feeling uncoerced in one's actions. The need to feel volitional in one's actions to fully and authentically endorse one's behaviours, and to act as the originator of one's own behaviour.	Competence feeling capable The need to feel effective in one's efforts and capable of achieving desired outcomes	The need to feel connected to and understood by others
Villacorta et al (2003)	The cause agent in one's own life and act in harmony with one's integrated self	Competence the need to control the outcome and experience of one's life	The need to be connected to interact and care for others.
Ryan and Deci (2000)	Independent and in harmony with one's self	Feeling that one is in control	Being connected to and caring for others
Biddle (1999)	Autonomy is related to self-determination and similar to the notion of being the originator and feeling that actions emanate from one-self	Competence refers to striving to control outcomes and to experience mastery and effectiveness	Relatedness refers to striving to relate to and care for others; to feel that others can relate to oneself; to feel a satisfying and coherent involvement with the social world (Deci and Ryan 1991, p.345).

While the above presents interpretations of the psychological needs of self-determination theory as sourced in the literature, some theorist's notably place competence and relatedness prior to autonomy and vice-versa creating a lack of clarity as to how these concepts relate to each other.

Self-determination theory suggests that the social environment can be either adaptive or maladaptive in meeting the psychological needs of the person. For example, when the social environment facilitates psychological need satisfaction, behaviour is usually self-determined and psychological well-being is experienced (Ntoumanis et al 2009). Yet when social environments are perceived as controlling by being coercive and by using monitoring, surveillance and task -contingent rewards, the social environment undermines the psychological needs of the person and lower levels of satisfaction are reported.

In self-determination theory, Deci et al (1994) purport three drivers in the social environment which influence the extent to which an individual's basic psychological needs are satisfied. The first is autonomy support, which refers to opportunities for choice facilitated fairly from those in a position of authority who acknowledge the perspective of those they interact with. The second is the provision of clear expectations, optimal challenges, and constructive feedback by those in authoritative positions (Reeve 2002). The third element of the social environment is regarded as interpersonal involvement, and the willingness of those in a position of authority to dedicate psychological resources, such as time, energy, and affection to those with whom they interact (Deci and Ryan 1991). Obaldiston and Sheldon (2003) underscore the fact that individuals differ in their sense of urgency and desire for satisfaction, and therefore experience variable senses of fulfilment and overall satisfaction in the context of psychological needs incorporated in self-determination theory. In testing the unique relations of each satisfied need with a wide range of positive outcomes self-determination theory is explicated (Ryan and Deci 2008). The assumption is that satisfied needs support processes that bring about psychological health and growth (Ryan, 1995). Much research supports the importance of the proposed needs for autonomy, competence, and relatedness, as they have been found to independently predict a thriving well-being within multiple time-frames, multiple cultures, multiple age groups, and in experimental manipulations of need-satisfaction and deprivation (Ryan and Deci 2008; Sheldon 2004).

6.4.1 Shortcomings of self-determination theory

Self-determination theory does not explicitly outline proximal factors like beliefs, perceptions of control, planning and commitment and how these influence the actual execution of behaviours (Hagger and Chatzisarantis 2009). Additionally, while intrinsic motivation is ultimately recognised as the most self-determined form of behavioural regulation because the behaviour has been fully “integrated” into one’s self or identity (Deci et al 1994, p.121), it can still be extrinsically motivated to some degree, as it may be an instrumental action, performed by the person to achieve personal goals rather than the person performing the behaviour for the pure joy of the activity itself (Deci and Ryan 1991).

6.4.2 Self-determination and the experiences of people with intellectual disabilities

In the intellectual disability literature the concept of self-determination is understood in the context of the frequency and types of choices available to and made by people with intellectual disabilities (Smyth and Bell 2006; Agran et al 2010; Conder et al 2010). Promoting self-determination for and with people with intellectual disabilities is recognized to be an essential element of disability service provision (McDermott and Edwards 2012). Wehmeyer (1998) conceptualizes the actualisation of self-determination as the ability of people with intellectual disabilities to determine their own fate or course of action, as well as the freedom of this group of people to determine their own political status and independence. Self-determined behaviour is that which is intentional or conscious, self-initiated rather than initiated by others, and impacts on one’s quality of life (Wehmeyer 2005, p.117). The actualisation of self-determination as a defining factor in enhancing quality of life for persons with intellectual disabilities has been empirically confirmed (Wehmeyer et al 1996; Lachapelle et al 2005). While much of this literature centres on younger people with disability who are transitioning between school and work (Wehmeyer and Palmer 2003; Laragy 2004) there is less evidence of self-determination of adults with intellectual disabilities who are transitioning from work to retirement (McDermott and Edwards 2012). For example, with regard to employment, self-determination is regarded as a good indicator of positive work outcomes in lives of persons with intellectual disabilities (Wehmeyer and Schwartz 1997; Wehmeyer and Plamer 2003), and people with intellectual disabilities who are more self-determined are more likely to strive to achieve better employment opportunities (Wehmeyer and Bolding 1999). Additionally, competitive employment and community-living settings can enhance self-determination, when offering opportunities to make choices and possibilities of greater personal control (Stancliffe et al 2000; Stancliffe 2001; Wehmeyer and Bolding 2001). However, normative development in regard to self-determination can be

described as a trend of increasing self-determination with age, and theoretically, a maximum level of self-determination should be attained at some point during late adolescence or early adulthood. However, for those with intellectual disabilities the developmental trajectory of self-determination can be severely compromised (Burton et al 2005). While, Rossow-Kimball and Goodwin (2009) draw attention to the importance of promoting self-determined leisure for those approaching retirement, McDermot and Edwards (2012) found that older adults in supported employment are not currently enabled to make self-directed choices about retirement. Interestingly, in seeking the views of people with intellectual disabilities regarding their perceived quality of life, Strnadova and Evans (2012) found the strongest theme identified in self-reports of the participants was the lack of control participants perceived they had over their lives.

6.4.3 Self-determination theory and control related properties

Wehmeyer (2004) conceptualises self-determination as an individual's right and capacity to exert control and direct their lives. While self-determination theorists believe that although the self-determination continuum uses language similar to that of control (e.g. intrinsic, extrinsic), it is essentially about motivational reasons for initiating behaviours which vary in degrees of self-determination (autonomy). Deci and Ryan (1985) distinguish between a need for autonomy and a need for competence, stipulating that autonomy concerns freedom in initiating behaviours, so having a person-means focus, whereas competence concerns a person's perception of contingency between behaviour and outcome, so having a person-ends focus, and therefore being more control related. Deci (1992, p.168) proposes that self-motivated, personally initiated behaviours differ in the extent to which they are self-determined as opposed to controlled specifying that motivational orientations provide a means of explaining different qualitative aspects of human functioning. For example:

"the need for self-determination is an important motivator that is involved with intrinsic motivation and is closely intertwined with the need for competence.... It is important to emphasize that it is not the need for competence alone that underlies intrinsic motivation; it is the need for self-determined competence"

(Deci and Ryan 1985, pp.31-32)

In other words, intrinsically motivated states must involve competence and autonomy. Competence and autonomy are therefore part of a wider picture of control, but there is a need to understand the differences between these major concepts. If intrinsically motivated behaviour is the ideal, then both competence and autonomy are necessary but not sufficient, since controlling competence or autonomous incompetence will not lead to self-determination. Nonetheless, with integrated regulation

of behaviour almost certainly come heightened feelings of competence and control and internalised reasons for acting come to be experienced as self-regulated.

The emergent theory in many ways agrees with self-determination theory in that past experiences can influence current motivations to make choices, but for the researcher the adult participants in this research study all of the adults in this research study were motivated none were found to be amotivated, but rather for some their greatest challenge was knowing they were powerless in some choice situations and not knowing what to do about it. All adults were motivated to be interactive in their environment and to have a satisfactory sense of control in environments that were controlling of them.

6.5 Control theories

Control theories have been embedded in mechanistic and humanistic systems which examine human behaviour in a diverse number of fields, such as management, engineering, applied mathematics, economics, and healthcare (Miles 2012). Control theorists fundamentally believe that all human beings psychological needs are encapsulated in their fundamental desire to be effective in their interactions with their social and physical worlds whereby they are motivated to exert control or mastery (Heckhausen and Schulz 1995; Schulz and Heckhausen 1996; Skinner and Greene 2007; White 1959; Elliot and Dweck 2005). The effects of the construct of control are closely linked with well-being (Ryon and Gleason 2014; Ganster and Fusilier 1989) in all domains of life, including work (Spector et al 2004), health and illness (Mardiyono et al 2011), across the life span from childhood (Mittal and Griskevicius 2014), adolescence (Meldrum and Hay 2012); Boman and Krohn 2012), to adulthood (Michie et al 2013) and older adulthood (Swift and Tate 2013). Many constructs, models and theories have inspired the maturation of the nature and functioning of the construct of control, including, helplessness (Seligman 1975); locus of control (Lefcourt 1976); self-efficacy (Bandura 1997); perceived control (Rothbaum et al 1982); affect control theory (Heise 1985); attribution theory (Weiner 1985); identity control theory (Anderson and Mounts 2012; Burke 1991); perceptual control theory (Powers 1973); and behavioural investment theory (Henriques 2011). The following section initially focuses on locus of control and perceived control theory, and more specifically discusses perceptual control theory and internal psychology of control providing discussion of the relevance of this literature with the emergent theory.

6.5.1 Locus of control

The locus of control construct stems from a social learning theory approach to personality (Rotter, 1954; Rotter, 1966). The construct locus of control has been clarified as the difference in the way individuals perceive rewards and punishments (Rayane and Achterberg 1997; Kormanik and Rocco 2009) determining their beliefs in the intrinsic aspects of their actions (Ignat and Clipa 2010). It is described as a continuum ranging from 100% internal locus of control to 100% external locus of control, with no individual operating at either end, but rather lying between the two extremes and balancing the needs of the two (Rotter 1966; Neal et al 2014). A multi-dimensional nature to the locus of control construct was added by Levenson (1974) who subdivided the external control orientation beliefs into two: (a) chance expectations (fate or luck) and (b) control by powerful others. Levenson (1974) proposed that individuals who believe that their lives are unordered and occur because of chance or fate may behave and think differently from those who believe that powerful others control their lives.

Locus of control is often regarded as internal control orientation wherein individuals have general beliefs in their abilities to control the outcome of their actions (Berglund et al 2014; Lee 2013; Khan 2011). The basic assumption of internal control orientation is individuals' belief that they have control over what they do and so influence outcomes (Rotter 1966). Internal locus of control is regarded as something stronger individuals possess, through which they are capable of setting up, taking responsibility for, and work towards achieving their own goals within a short period, while not being unduly influenced by others' opinions of them (Neal et al 2014). Additionally, they possess self-efficacy having strong beliefs in their intrinsic abilities to mitigate arising problems and develop solutions (Neal et al 2014). Furthermore, individuals regarded as having a greater sense of internal control have consistently been found to be adaptable, optimistic, to engage in more positive health behaviours, and are less prone to depression (Ryon and Gleason 2014). Ultimately, such individuals tend to be physically and mentally healthier, happier and have higher achievements at the workplace as compared to their colleagues (Ryan and Francis 2012; Khan et al 2012). Internal locus of control has been found to be age associated (growing stronger as individuals age), and gender associated as the internal locus of control tends to be higher in men compared to their female counterparts (Kasilingam and Sudha 2010).

Individuals with external locus of control are more likely to depend on others to intervene (Gillibrand and Flynn 2001), have negative attitudes towards factors that influence their life, (Lee 2013) and as a result, tend to blame external forces for the circumstances they are confronted with (Lefcourt 1982). And in cases of success such individuals are more likely to attribute their success to luck or fate rather

than to their own efforts and abilities as they have less trust in their internal abilities to change circumstances, and instead are resigned to believing that everything happens due circumstance. This creates a strong feeling of hopelessness and powerlessness whenever they face challenging situations (Pals and Kaplan 2013). Studies have consistently linked the external locus of control with psychological distress (Carter et al 2014), dysfunctional behaviour, as well as poorer mental and physical health (Lauer et al 2008). Indeed high levels of external locus of control are frequently implicated in depression and anxiety disorders (Remster 2014; Kennedy et al 1998). The cultural norms of independence especially in western societies have a major impact on control beliefs and experiences of individuals living in such societies, and it is important to note that external locus of control does not carry the same negative connotations across cultures (Cheng et al 2013).

Locus of control is a construct that has been conflated with self-efficacy, but self-efficacy is task specific and locus of control is domain specific (e.g., health domain, social domain, which is much more general (Rayane and Achterberg 1997). Additionally, autonomy can be differentiated from locus of control in the sense that it is possible to distinguish individual's perceptions about the control they have in the workplace such as their level of autonomy, from their more general beliefs about control as reflected in locus of control (Spector et al 2004). And, while locus of control is stable neither across time nor different domains it has been regarded as an important construct in choice-making (Paulhus 1983; Lachman 1986). Furthermore the assumption that a strong internal locus of control always means good, and strong external locus of control meaning bad, is not necessarily true in certain situations (Kasilingam and Sudha 2010). Extensive research has been undertaken on control as a trait-level predictor, but there is a conspicuous lack of research undertaken to address the construct at the state level, and further research is needed to determine how control is operating at the within-person level (Ryon and Gleason 2014). Goldstein et al (2011) noted that locus of control can be limiting in the context of how individuals with an internal locus of control make choices possibly overestimating the feedback effect. This means that the locus of control perception may overestimate how much an individual is in control in a given area of life, while underestimating the strength of external disturbances or overestimating the person's own ability to act as required whereas individuals with an external locus of control could be overestimating the disturbance effect. The individual may incorrectly accept the idea that the environment will probably win and so determine the individual's experiences. From an older adult perspective, successful ageing over time, has been attributed to indicators of primary and secondary control beliefs (Swift and Tate 2013). When responding to crisis situations, individuals with a strong internal locus of control prefer varying response strategies as compared to their counterparts with an external locus of control, and subsequently individuals with strong internal locus of control can make working decisions in such a situation as compared to the others (Goodman et al 2007). Nonetheless, numerous scales measuring the locus of control construct

have been developed with the relatively recent publication of a compilation of twenty-eight control scales (Halpert and Hill 2011).

Having a sense of control is said to be a critical element in successful psychological adjustment, not only work but also to other domains of life (Kobasa et al 1982; Skinner, 1996; Spector et al 2004). It has been noted that internal control beliefs are an important component of emotional adjustment and ability to handle stress in general life (Kobasa et al 1982) and at work (Spector 1982). When people encounter stressful events, emotional regulation enables them to evaluate the emotional impact of the situation and help determine what types of emotional reactions are appropriate, as well as when and how they express emotions (Wang and Saudino 2011). Both control beliefs and perceptions have been prominent in research on stress and well-being in the work place (Spector et al 2004).

According to Spector's (1998) control model of stress, control helps filter perceptions of situations, affecting their appraisal (Lazarus and Folkman 1984) as being benign or threatening. A person who perceives low control is more inclined to appraise situations as job stressors, which is likely to lead to job strains (Spector et al 2004). Locus of control has been shown to influence the degree to which individuals experience stress such that individuals who believe that they have control of their own lives experience less stress and, conversely those who believe that their lives are out of their control experience greater levels of stress and the subsequent adverse effects of stress (Lefcourt et al 1984; Sandler and Lakey 1982; Shapiro and Shapiro 1983). Ryon and Gleason (2014) found daily variation in locus of control was predicted by daily problems and anxiety such that high same day and previous-day anxiety and problems were associated with reports of lower levels of control. Furthermore, daily locus of control was positively associated with positive health behaviours and predicted negative health symptoms. These results provide evidence for a social learning perspective on the development and maintenance of individual's sense of control and these authors suggest that locus of control should be considered both a state-and trait-level construct in future research.

Frames of reference has similarities with the control orientation of the individual in locus of control theory as individuals hold general beliefs and specific perceptions of the control they have with regard to the choice being made. Frames of reference underpinned by identity frames, mind-set frames and power frames are foundational factors in how adults frame control, from which they continually draw upon as they make interpretations and position the control they have in the conscious realities of choices made. Drawing on frames of reference, making interpretations and positioning control are properties of the emergent category framing control. Additionally, the emergent theory explains that how individual frame control is counterbalanced by their emotions and how they make adjustments in compliance behaviours.

6.5.2 Perceived control

Rothbaum et al (1982) present a two-process model of perceived control suggesting that control can be classified into two categories – primary and secondary. Rothbaum et al (1982) theorized that individuals gained feelings of control: by taking direct action to change the environment to align it with their wishes (primary control); and by psychologically adapting to negative situations and events such as age-related decline so as to come to terms and accept them (secondary control). Perceived control theory is regarded as having two major elements which assist in describing human behaviour; a cognitive element and an affective element (Carver and Scheier 1981). In the cognitive element individuals have goal standards for their performance and gauge how well they are currently executing their task by making comparisons between their actual performance and their goal standard, and in the affective element if individuals perceive a divergence between their actual performance and their goal standard they make behavioural changes motivated by their desire to resolve the performance discrepancy (Miles 2012).

Primary control consists of actions taken by a person to change the world, or in other words is the attempt to adapt the world to the person and can be thought of as taking direct action to change the world in accordance with one's wishes (Swift and Tate 2013; Spector et al 2004). Secondary control involves changing oneself to fit the external environment and consists of four different forms of predictive, illusory, vicarious and interpretive control (Swift and Tate 2013; Spector et al 2004). Secondary control comes about when attempts at primary control fail, and individuals switch between primary and secondary control in response to changing life circumstances (Rothbaum et al 1982) psychologically adapting when faced with uncontrollable situations and events (Swift and Tate 2013). It is closely related to external locus of control which was originally assumed to entail a perception of uncontrollability. However, numerous research findings have disconfirmed this assumption, attesting that 'externals do not feel powerless, but simply pursue rewards in different avenues' (Cherulnik and Citrin 1974, p.404).

While Rothbaum et al (1982) model of perceived control adds to the concept of control it does not explain all aspects of aligning behaviour when discussing the construct in the context of control theory. Furthermore, while illuminating secondary control Rothbaum et al (1982) does so at a cost, as confining secondary control to severely limited ability is restricting for the theory in its own right. For adults in this study lowering perceptions of control is not viewed as a failure, but rather a clever strategy to maintain a satisfactory sense of control in challenging circumstances. The word align is referenced strongly in explanations of Rothbaums et al (1982) model of perceived control.

Table 6-4 presents the Rothbaum et al (1982, p.12) Model of Perceived Control, Primary and Secondary Processes:

Table 6-4 A model of perceived control: primary and secondary processes

Model of Perceived Control Primary and Secondary Processes (Rothbaum et al 1982 , p.12)		
Type of control	Salient Processes	Description
Predictive	Primary	Attempts to predict events so as to succeed at them. Active behaviour and individuals are likely to credit their own effort and ability, especially in tasks of moderate difficulty
	Secondary	Attempts to predict events so as to avoid disappointment. Passive and withdrawn behaviour, especially in tasks of moderate difficulty. Active, persistent behaviour in extremely easy or difficult situations. Individuals are likely to attribute severely limited ability.
Illusory	Primary	Attempt to influence change-determined outcomes. Active behaviour in change and skill situations and individuals are likely to credit their own efforts and abilities
	Secondary	Attempt to associate with change. Active behaviour in change situations but passive and withdrawn behavior in skill situations and attributions to change are likely
Vicarious	Primary	Attempt to manipulate powerful others or imitate their power or ability. Instrumental submissive behavior or manipulative behavior and individuals are likely to credit their own efforts and abilities
	Secondary	Attempt to associate with powerful others. Non-instrumental, submissive behaviour and attributions to others are likely.
Interpretive	Primary	Attempt to understand problems so as to be able to solve them or otherwise master them. Active behaviour and individuals are likely to credit their own efforts and abilities
	Secondary	Attempt to understand problems so as to derive meaning from them and to accept them. Passive, withdrawn, and submissive behaviour and attributions to severely limited ability change and powerful others are likely.

Individuals engage in predictive control when they find comfort in being accurately able to foresee uncontrollable events, so avoiding unrealizable expectations (i.e. disappointment) that fuel their perceptions of uncontrollability. In explaining predictive control as a construct of secondary control Rothbaum et al (1982) purport that when individuals are attributing outcomes to low ability combined with behaving in a passive and withdrawn manner, their behaviour is often associated with the term ‘helplessness’. Yet this combination may often represent the individuals attempt to inhibit unfulfillable expectations, thus preparing oneself for future events and thereby gaining predictive control. Aligning with the flow of control goes further providing the explanation that adults who frame the control they have more positively (in control/engaging in self-control) have higher levels of emotional well-being (emotional stabilizing, emotional self-protecting) which ultimately feeds back into how they frame control.

Individuals engaging in illusionary control display passivity and withdrawal, tending to seek out chance situations and are more reactant when adverse events occur. In explaining illusory control certain individuals will neither seek out skill situations nor strive to manipulate the environment, but instead attempt to align with and rely upon the powerful forces of chance (Rothbaum et al 1982). The attribution of outcomes to chance, luck, or fate combined with passivity in or withdrawal from certain competitive skill situations is frequently taken as evidence of relinquished control (Weisz et al 1984). Individuals engage in vicarious control when they associate with powerful others, and where the association is desired for its own sake. And in explaining vicarious control Rothbaum et al (1982) purport that by individuals aligning themselves with more powerful others, individuals can share the victories and accomplishments of powerful others; in short these individuals can share the control experience of others (Rothbaum 1982). But in order to share in the control of powerful others the individuals must first become aligned with those who are more powerful and this is achieved through submission. When individuals attribute outcomes to powerful others and show submissive behaviour, they are often thought to have abandoned the pursuit of perceived control (Weisz et al 1984). Individuals engage in interpretative control when their search for meaning is particularly intense under conditions in which only minimal primary control exists (Rothbaum et al 1982).

Other definitions of perceived control can be found in the research of Mardiyono et al (2011) who undertook a concept analysis of perceived control and found it to be composed of two dimensions: belief about controllability and belief about ability to control threats or events. And further multiple dimensions have been associated with the term perceived control; for example, its cognitive (personal efficacy), personality (locus of control), and motivational (motivation to control) and domains (Zimmerman 1990). Zimmerman found that these domains formed a single discriminate function that distinguished between individuals who scored low or high on a measure of helplessness or alienation, including indicators of powerlessness and social isolation. Thus according to this author, through continually learning, using problem-solving skills and determining perceived or actual control, individuals who develop perceptions of psychological empowerment, are better enabled in achieving their desired outcomes such as social inclusion and involvement in their communities, through positive perceptions of control are outcomes of learned hopefulness, and vice versa. He defined learned hopefulness as the “process of learning and utilizing problem-solving skills and the achievement of perceived or actual control” (Zimmerman 1990, p.72) which “suggests that experiences that provide opportunities to enhance perceived control will help individuals cope with stress and solve problems in their lives” (pp.72-73).

Zimmerman and Rappaport (1988) proposed a construct of psychological empowerment to account for the multi-dimensional nature of perceived control, which, according to them, had been previously treated as if it were a univariate construct. Nonetheless, perceived control has been measured with

various tools based on different theories (Wallhagen and Lacson 1999; Moser et al 2007; Chapman et al 2009; Kempen et al 2005; McColl et al 2000; Johnston et al 1999; Faller et al 1995). The major difference between perceptions and control beliefs concerns the specificity and stability of the target of control. A control perception concerns whether or not the person can influence a particular event at a specified time, whereas control beliefs or locus of control concern whether or not a person believes he or she generally can control certain types of events (Spector et al 2004). Research has shown the importance of not only perceptions of control in the immediate work environment, but also of a person's more general beliefs about control (Spector et al 2002).

Aligning with the flow of control challenges these ideas as in framing control adults draw ideas from frames of reference and project these ideas onto how they make interpretations and position the control they have in choice situations. Those who have greater positivity in frames of reference perceive they have higher levels in positioning control. In the emergent theory individuals never abandon the pursuit of perceived control but rather their perceptions of control are ongoing powerful factors which set the direction of the aligning cycle.

6.5.3 Perceptual control theory

Perceptual control theory originated in the writings of a first paper published in 1960 (Powers et al 1960) and subsequent work over the next thirteen years, which culminated in 'Behaviour: The Control of Perception' (Powers 1973). With the addition of more recent revisions (Powers 2005; Powers et al 2011), it is regarded as one of few theories which expresses the sense of how an expectation actually influences behaviour in functional terms (Carey et al 2012).

Powers (2005, p.299) defines perception as "A neural signal that is a continuous analog of some aspect of the environment". By defining perception in terms of nervous system activity, perceptual control theory allows the definition of concepts of sensation, perception, cognition, and meta-cognition as perceptual signals (Goldstein et al 2011). Khan (2011) refers to perceptual control theory as a theory that provides for a general theory of functioning for organisms and at the conceptual core of the theory is the observation that living things control the perceived environment by means of their behaviour. Powers et al (2011) believes that the control system of perceptual control theory exists inside individuals who learn based on their experiences, and who control their experiences by their behaviours as they adjust their behaviours to changing circumstances (Goldstein et al 2011). The most powerful aspect of perceptual control theory is that it extends the concept of homeostasis to

include the psychological domain of experiences rather than just being derived in the context of biological control (regulatory) systems (Goldstein et al 2011).

The perceptual control theory presents a conceptual framework of a negative feedback control system which, allows for the integration of biological, psychological and social worlds, most of which have changeable set points concerning the importance of experiences (inputs) and the control (regulation) of experiences by behaviours (outputs), implying that control of inputs rather than outputs is how individuals organize themselves (Goldstein et al 2011). Perceptual control theory takes the negative feedback control system as being very different to cause-effect (input-output, stimulus-response, open loop) systems (Powers et al 2011; Marken and Horth 2011).

The emergent theory also has some similarities to how perceptual control theory uses reference signals, as adults are drawing on frames of reference and interpreting choice situations leading to positioning control. Similar to perceptual control theory (Powers 2007) in framing control the sub-core category their control beliefs and perceptions of controllability are most crucial in setting the direction of the aligning cycle when their actual doing interacts with what they are being told to do and vice versa. But unlike control theories, the emergent theory of aligning with the flow of control accounts and provides explanations for four differing aligning cycles, the direction of which is set by how adults frame control the nature and extent of which is counterbalanced by their emotions and the adjustments they make.

Perceptual control theory regards cognitive processes as interpretations of sensory inputs which act as reference signals. It is the result of a closed loop effect of causes and effects in which an action is varied to make its perceived results match a specific state. Aligning with the flow of control is in agreement with the perceptual control theory in that an individual's perceptions are fundamentally important, but unlike perceptual control theory which purports that organisms control their perceptions, aligning with the flow of control explains that what individuals are feeling and doing are major counterbalancing factors in the individuals control experiences. Perceptual control theory demonstrates that both internal locus of control and external locus of control are always operating. Although external factors determine what behaviour a person must perform to control a perception in any specific way, it is the organism, not the environment, which determines what specific state of the perception is wanted and, if possible, adjusts the behaviour in the way external factors make necessary to control it in order to bring the perception to match the current setting of the reference signal.

In perceptual control theory the explanation of emotions require considerable clarification as Powers (2007, p.40) questions whether an emotion arises before the action it seems to demand, or after the action and because of it. Emotions present as challenging to Powers (2007) as they seem to be both

cause and effect, and so are difficult to explain in the negative feedback loop theory, whereas as explained in aligning with the flow of control adults are continually making emotional connections. Powers (2007) believes that emotions are one aspect of the whole integrated hierarchy of control where, basically, the identification of emotions exist any time there is an error signal, but when the degree of error is minimal, individuals do not use emotion-words, so it appears that there is a small amount of error that must be exceeded so as to qualify a state of being emotional. Positive emotions (e.g. joy, anticipation) involve the individual's control of perceptions which s/he wants to experience or to approach. The error signal in this case decreases when a person is experiencing the positively valued experience (Goldstein et al 2011). Powers (2007) also purports that in most circumstances in which the actions take place, the error is addressed before it enlarges, and the physiological state returns to normal with no noticeable emotional state being seen. Perceptual control theory takes the view that individuals experiencing a satisfactory sense of control in important areas of their lives subsequently enjoy psychological well-being, while individuals who do not experience a satisfactory sense of control can experience more psychological problems (Goldstein et al 2011, p.12). Yet there are no specific lists of emotions or feelings provided by perceptual control theory, as reference to emotions is explained mainly in terms of the value of the goal, and whether one wants to obtain more of (positive emotions) or less of (negative emotions) the experience, and it is the goal that gives the cognitive meaning to an emotion (Goldstein et al 2011).

Goldstein et al (2011) believe that the feeling and emotion could be a momentary one or a lasting as a mood, but nonetheless feeling and emotion which flow from the control of experiences and errors in any control system could potentially result in an emotional experience. Similarly, as explained when what adults actually do occurs in the conditions that they are being told what to do, from the outset in framing control they are also make emotional connections which is a counterbalancing factor in how they frame control. Goldstein et al (2011) believe that as a result of experiencing distress for a long period of time, the supply of neurotransmitters of brain circuits may become chemically un-balanced and the physician prescribes medication for re-stabilization enabling the individual to engage in therapy and change in order to solve the life problems. The perceptual control theory perspective is that restoring the individual's ability to control effectively eliminates the source of distress, and the symptoms will diminish or disappear (Goldstein et al 2011).

Aligning with the flow of control provides further explanations of emotional connecting which is viewed as a crucial counterbalancing factor in the nature and extent of the aligning cycle. Unlike perceptual control theory the emergent theory view emotional connecting as continual individual responses to what adults are being told to do and happens within the boundaries of their actual doing which influences and has influence on how they frame control and is indicative of how they adjust to comply with what they are being told to do. Additionally the perceptual control theory does not fully

account for those adults who continually live either satisfactorily or unsatisfactorily within the remit of being controlled by others.

According to perceptual control theory when error signals continue unabated in important control systems, the person experiences physical distress in his/her body. The perceptual control theory explanation of impaired functioning for a person with a psychological problem hypothesizes that the larger the error signals and the longer they remain present, the faster the rate of reorganization. When the reorganization is running at a rapid rate, many control systems are being changed, which functionally removes them from normal use in everyday life, at least temporarily. Perceptual control theory conceptualizes that successful reorganisation depends on evaluating the results of changes, so as to know whether more reorganization is needed. Continuous reorganization may result in a person not recognizing a solution to a problem when it appears and not pausing to see the results (Goldstein et al 2011).

Similar to perceptual control theory and the theory of aligning with the flow of control, the primary concern is perceptions, but in perceptual control theory the primary interest is with perceptions and the control of these perceptions. Furthermore, perceptual control theory provides little account for perceptions of not being in control when the focus is on determining that individual perceptions control their behaviours.

6.5.4 Control theories in intellectual disability literature

In intellectual disability literature the locus of control theory is evidenced mostly in educational and criminal justice literature. Students with intellectual disabilities who generally believe that their academic successes are a result of factors within their control are said to possess a strong internal locus of control, while students who attribute academic failures to external factors have a strong external locus of control (Shogren et al 2010). Generally students with a strong internal locus of control believe that their actions will influence their success and therefore engage in studying for exams, thereby improving their skills and ability to meet the educational level expectations and finish educational programs (Karbalaie et al 2013; Furnham and Steele 1993). Students, who have a strong external locus of control, tend to have lower intelligence levels, lack motivation to concentrate, put little effort into learning and ultimately fail academically (Rojewski et al 2012). Influencing factors have been reported as the actions of peers, attitudes towards the learning process, teachers and school systems (Rutkowska and Klimczak 2012). Such students develop the external locus of control as a survival tactic, so as to avoid their frustrations. Instead of taking responsibility for their failures and

success, they often gain solace in apportioning blame to the educational system and the teachers (Lee 2013). Ultimately, students failing in their educational endeavours increase their external locus of control orientation in responding to academic failure by losing hope and failing to put more effort in their work so as to improve their current performance (Möller et al 2009). Goodman et al (2007) devised an accessible locus of control scale and results on the locus of control scale suggested that like the general offender population, convicted offenders with learning disabilities are likely to have a higher external locus of control than their non-offending peers. However, there is a dearth of accessible locus of control scales available for use with such offenders (Hulme and Middleton 2013).

6.6 Glasser's choice theory: an internal control psychology

Choice Theory (Glasser, 1998) an internal control psychology, has been developed as a theory to replace external control psychology. Originally Dr. William Glasser an American Psychiatrist developed Reality Therapy as a counselling mechanism while working with patients diagnosed with mental illness and subsequently founded the Institute for Reality Therapy. Reality therapy is a method of counselling which teaches people how to direct their own lives, make more effective choices, and how to develop the strength to handle the stresses and problems of life. As his theoretical thinking around the underpinnings of Reality Therapy developed Dr. Glasser based its' philosophical underpinnings on a theory named Choice Theory and changed the name of the Institute from Reality Therapy to the Choice Theory Institute.

Choice theory purports that all individuals engage in purposeful behaviour as they continually strive to close the gaps between their needs, wants and what they are actually getting out of life (Corey, 2013). The choices individuals make are driven by genetic needs of survival, belonging, power, freedom and fun (Glasser 1998). In the practice of Choice Theory while the most important need is love and belonging, all individuals will have differing requirement of need. Choice theory also stipulates that each individual possesses what s/he considers to be their quality world; that being that based on past experiences and future aspirations and aligned with current needs each individual stores a mental set of pictures which make up their 'quality world' (Corey 2013). Understanding each individuals 'quality world' is a necessity so as to facilitate the process of learning to form satisfying relationships (Corey 2013).

According to Glasser (1998) behaviour is made up of thinking, feeling, acting and physiology, where thinking and acting greatly impact on feelings and physiology when choices are made. Glasser (1998) purports that a person's total behaviour can be represented using Choice Theory Total Behaviour Car

as a metaphor (Wubbolding 2011). Behaviour occurs as four distinct, but inseparable components of acting, thinking, feeling, and physiology happen simultaneously, and are represented as the four wheels on the Total Behaviour Car which symbolizes the human motivational system (Glaser 1998). Understanding choice behaviour through the Ten Axioms and taking into consideration the Seven caring Habits, avoiding the Seven Deadly Habits, Glasser (1998) believes that individuals will find satisfaction in their relationships with relevant others and accommodate individual requirements of genetically driven needs so engaging in more internal control psychology which is beneficial to the development of satisfying relationships and avoiding external control psychology which is destructive to relationships. An overview of Glasser’s Choice Theory (1998) is presented in Table 6-5:

Table 6-5 Choice theory (Glasser 1998)

Glasser’s (1998) Choice Theory Ten Axioms: 1) The only person whose behaviour we can control is our own 2) All we can give another person is information 3) All long-lasting psychological problems are relationships problems 4) The problem relationship is always part of our present life 5) What happened in the past has ever to do with what we are today, but we can only satisfy our basic needs right now and plan to continue satisfying them in the future 6) We can only satisfy our needs by satisfying the pictures in our Quality World 7) All we do is behave 8) All behaviour is Total Behaviour and is made up of four components: acting, thinking, feeling and physiology. 9) All total behaviour is chosen, but we only have direct control over the acting and thinking components. We can only control our feeling and physiology indirectly through how we choose to act and think 10) All total behaviour is designated by verbs and named by the part that is most recognisable. Seven Caring Habits: supporting, encouraging, listening, accepting, trusting, respecting and negotiating differences Seven Deadly Habits: criticizing, blaming, complaining nagging, threatening, punishing, bribing/rewarding to control
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As a counsellor, Glasser came to believe that insight was not enough to make the long-lasting changes the clients needed (Robey et al 2011). Glasser began to believe that taking personal responsibility for one’s behaviour while avoiding putting blame on others leads to more effective lives. Understanding people as undetermined free creatures who choose their behaviour is foundational to choice theory (Lojk and Lojk, 2012).

While Glasser’s choice theory originated in the treatment of people with mental illness more focus has been placed on “quality school” an instructional model that focuses on teacher-student interaction and classroom enrichment (Logan and Plumlee, 2012). And as the scope of the theory expands Choice Theory provides excellent guidelines for the development of a healthy mental life and Glasser sees the

promotion of this as one of the strengths of the William Glasser Institute. The techniques, theory and wider applications of Choice Theory and Reality Therapy continue to evolve.

There is a gaining momentum for the usefulness of Choice Theory in practice (Wubbolding 2011; Seta et al 2014; Jusoh et al 2015). For example Watson and Arzamarski (2011) asked past participants from an interdisciplinary graduate course of their perceptions of what worked in their experience. Results indicated that 88.6% of the participants who responded to the survey used CT/RT to better their personal lives and 100% used CT/RT professionally. Watson et al (2014) conducted interviews to elaborate more in-depth insights regarding professional interdisciplinary graduates regarding their attitudes and impressions about using RT concepts personally and professionally. All participants found the theory and process relevant both personally and professionally independent of their health profession. Practitioners valued CT/RT and felt professional fulfilment in using these concepts with clients. And from the perspective of clients one of the main values of RT was that they were asked what they wanted, something that hadn't happened previously.

6.6.1 Criticisms of Glasser's choice theory

Glasser's choice theory has been criticised as being extreme in the promotion of choice theory as an alternative to conventional psychopharmacology and with such claims demonizing medical professionals who prescribe medication for patients with psychiatric illness (White 2005). Without sufficient evidence base Glasser purports that these patients present as a result of the individual's brain creatively expressing its unhappiness and in doing so misrepresents that many psychiatric illnesses have no biological basis (White 2005). Additionally Bourbon and Ford (1994) have challenged inherent contradictions in Glasser's choice theory that when a student misbehaves, the teacher is responsible for failing to meet the needs of the student, which contrasts the implicit assumption of the theory which posits that a student chooses his own behaviour. Even though Glasser has advocated for the need for more research to validate the theory, such evidence base to date is limited.

6.6.2 Comparison of Glasser's choice theory with theories of control

While control theorists have developed the concept of control from binary opposites of individuals either having control or not having control, to the development of more unified theories of control incorporating the biological, psychological and social as individuals interact with their environments. Glasser (1998) choice theory places emphasis on the need to focus individuals on internal control

psychology rather than external control psychology. Table 6-6 presents a comparison of theories of control with Glasser’s (1998) choice theory:

Table 6-6 A comparison of theories of control with Glasser’s (1998) choice theory

Self determination theory	Locus of control	Perceived control	Perceptual control	An internal control psychology
Self-determination propose that individuals are motivated to make choices based three main psychological innate needs, namely, autonomy, competence and psychological relatedness	Control theorists fundamentally believe that all human beings psychological needs are encapsulated in their fundamental desire to be effective in their interactions with their social and physical worlds whereby they are motivated to exert control or mastery			Choice Theory propose that individuals make choices which are driven by genetic needs of survival, belonging, power, freedom and fun developed as a theory to replace external control psychology (Glasser, 1998).
	Locus of control concerns a person’s beliefs of whether or not a s/he generally can control certain types of events (Rotter1966; Spector et al 2004)	Perceived control describes how people are motivated to fit with their environments and gain feelings of control (Rothbaum et al 1982)	Perceptual control theory proposes that living things control their perceived environment by means of their behaviours (Powers1973; 2005;2008; 2011)	
A continuum of amotivation, extrinsic motivation (which is itself multi-dimensional in nature), and intrinsic motivation.	A continuum ranging from 100% internal locus of control to 100% external locus of control with no individual operating at either end (Neal et al 2014)	A two process model 1) primary control-actions individuals take to adapt the world to the person; 2) changing the self to fit the external environment	A closed loop theory – A negative feedback loop whereby individuals have experiences (inputs) which they control (regulation) by their behaviour (outputs).	Total Behaviour Car metaphor - All behaviour is made up of four distinct, but inseparable components: acting, thinking, feeling and physiology which happen simultaneously, and symbolizes the human motivational system
Needs based	Reinforcement based Locus of control is clarified as the difference in the way people perceive rewards and punishments (Kormanik and Rocco 2009). Domain specific - Locus of control is domain specific (e.g., health domain, social domain, which is much more general (Rayane and Achterberg 1997). Variable - Locus of control is neither stable across time nor different domains (Paulhus1983; Lachman 1986). Age related - Internal locus of control grows stronger as people age (Kasilingam and Sudha 2010). Society Dependent - exercising control over one’s life is consistent with the cultural norms in individualistic societies (Cheng et al 2013).	Perception based Primary Control Happens when individuals take direct action to change the environment to align it with their wishes. Secondary Control Happens by psychologically adapting to negative situations and events such as age-related decline so as to come to terms and accept them. Secondary control consists for four different forms; predictive control, illusory control, vicarious control and interpretive control (Rothbaum et al 1982).	Perception Based Hierarchical Reference System Intensity level (awareness threshold) Sensation level (quality of sensory event) Configuration level (patterns of sensation) Transition level (changes in configuration) Events level (continuity in experience) Relationship level (recognition of association between events) Concept Levels Category level (classification of events) Sequence level (complex ordering of events) Program level (system that leads to choices about actions) Principles level (general standards) Systems level (beliefs about how things out to be)(Powers, 2011)	A needs based internal control psychology An internal control psychology focused on accommodating individual requirements of genetically driven needs Choice theory purports that all individuals engage in purposeful behaviour as they continually strive to close the gaps between their needs, wants and what they are actually getting out of life (Corey, 2013). Choice theory, incorporates Seven Caring Habits (supporting, encouraging, listening, accepting, trusting, respecting and negotiating differences), Seven Deadly Habits (criticizing, blaming, complaining nagging, threatening, punishing, bribing/rewarding to control) and Ten Axioms.

The above presents a table of the depicting differing theoretical perspectives of control. Many aspects of control theories have similarities to the explanations of this emergent sub-core category of framing control; for example, identity control theory, locus of control, perceived control and perceptual control theory. As explained the sub-core category of framing control sets the direction of the aligning cycle.

6.6.3 Comparison of Glasser's choice theory and aligning with the flow of control

The fundamentals of Glasser's choice theory of thinking, feelings and actions have similarities with the categories of framing control, emotional connecting and adjusting compliance in aligning with the flow of control. And the identified component of physiology in Glasser's theory is similar to the notion of equilibrium in the emergent theory. Conversely similar to Glasser's choice theory the emergent theory illuminates and explicates that for the adults in this research study their thinking focused on their beliefs and perceptions of the control they had in choice situations, their emotions outshot their feelings and their actions were relentlessly reflected in their compliance behaviours as they interacted with what they were being told to do. And furthermore inherent in those interactions the emergent theory accounts for differences in individual's psychological homeostasis. The emergent theory identifies that an individual thoughts of control are fundamental to how they make choices but while Glasser acknowledges thinking, feelings and actions and physiology as four distinct but inseparable components of choice behaviour, the emergent theory not only purports that how an individual thinks, emotionally connects and adjusts have influence on each other but are also driven by interactions between what adults are being told to do and what they are actually doing. In Glasser's choice theory individuals are driven by the genetic needs of belonging and love freedom and fun, in the emergent theory adults primarily draw on a bank of ideas they form on their identities, abilities and mind-sets while interpreting choice situations and making determinations regarding the level of control they have. The essence of the emergent theory highlights the significance of when being told what to do adults frame control, connect emotionally and make adjustments and be it positive or negative create maintains or changes an equilibrium in the realities of what they actually do.

6.7 Integrating literature on emotions

Glasser's choice theory (1998) purports that individual's control their acting and thinking and feelings and physiology follow. Inherent in the theory of aligning with the flow of control is the significance that emotions which stem from individuals states of feeling good or bad are part of an ongoing crucial element in the theory. The emotional state of adults has more prominence in the emergent theory as rather than following an individual's acting and thinking it is both influences and is influenced by their thoughts of control and their compliance behaviours. The choices made by adults in this research study were hugely influenced by their emotions.

Emotions have been conceptualised as a dimensional construct (Wundt 1896). Emotions comprise of valence (pleasure), arousal (autonomic arousal) and dominance (the level to which the individual feels influence over a situation) (Jerram et al 2014). Emotions arise when an individual's attention is drawn to a choice situation, appraising the relevance of the situation with regard to his or her values, needs or goals, and responding to that situation by making adjustments (Scherer 2000). The regulation of emotion is regarded as productive as is contextually appropriate action by individuals in response to the intensity of their emotions (McClure et al 2009). Emotion deregulation happens when individuals are unable to control their emotional responses to produce contextually appropriate actions due to deficits in recognizing, understanding, and accepting emotions, and engaging in goal directed behaviours which result in experiences of negative emotions (McClure et al 2009; Gratz and Roemer 2004). Whether positive or negative, emotions are reflected in individual basic states of feeling good or bad, energised or enervated. Core affect which is the heart of all emotional states (Wilson-Mendenhall et al 2013; Russell 2003) is determined by the ways by which individuals regulate specific emotions, moods and stress (Koole 2009).

Emotion regulation is one of the most far-ranging and influential processes at the interface of cognition and emotion (Koole 2009). Importantly, it is the individual's interpretation of a given situation that potentially triggers an emotion, rather than the situation itself (Lazarus 1991).

Emotional regulation is a control process whereby individuals monitor and adjust with reference to given standards (Carver and Scheier 1998) which primarily focus on the modulation of internal emotional changes so as to meet the external needs (Wang and Saudino 2011). Emotion regulation has been found to occur proactively, for instance, when people avoid an upcoming situation that is expected to elicit an undesired emotion (Aspinwall and Taylor 1997; Zeelenberg and Pieters 2007). Emotion regulation has been found to subjectively precede the onset of emotion and the extent to which individualized ability to proactively regulate emotions successfully is reflective of the fact that

some individuals may never experience any unwanted emotion at all (Koole 2009) as individuals vary in their capacities to regulate emotions and cope with stress (Wang and Saudino 2011).

The Quoidbach et al (2015) process model of emotion regulation, which is open to modification through a feedback loop, suggests that people can regulate their emotions by (a) choosing situations to enter (or not) based on their expected emotional outcomes, (b) modifying those situations once they are in them, (c) directing their attention to specific features of them, and (d) changing their appraisals and altering their physiological, experiential, and behavioural responses. Individuals typically engage in three broad types of processes; anticipating positive future events, experiencing present positive events, and reminiscing about past positive events. This before-during-after distinction also aligns well with behavioural economics, decision-making, and consumer behaviour literatures. Researchers in this area have identified three distinct sources of pleasure: the pre-experience utility from anticipation, the utility from the experience itself, and the post experience utility gained from reminiscence (Quoidbach et al 2015).

As a unified approach Henriques (2011, p.46) acknowledges in Behavioural Investment Theory the importance of control theory, while also underscoring the need for control theorists to devise an emotion-focused approach.

As with the emergent theory, Burke (1991) found there to be positive emotional consequences to identity verification and negative emotional consequences to the lack of identity verification. But while identity control theory has focused mostly on the positive consequences of identity verification (Burke and Stets 1999; Cast and Burke 2002), little research has been done to elaborate the variety of negative emotions that arise from discrepancies between meanings held in the identity standard and meanings perceived in the situation (Stets and Burke 2005). The emergent theory highlights how individual concepts of identity inform their perceptions of control. This emergent theory elaborates the nature of existing congruencies or discrepancies between societies expectations of adult status and the actual experiences of adulthood of the research participants, whereby the variety of positive or negative emotions that arise are contingent upon the identity frames formulated by the adult, the extent of the discrepancy as perceived by the adult, and the relative power and status of the adult and others in the choice situation. For those in this research study, the identity verification or identity non-verification of adulthood is shown to depend upon the context of the social structures in which the verification or non-verification occurs has consequences for their emotional wellbeing and subsequent behaviour, which subsequently feed back into how they are framing control.

In the emergent theory, those who are in control have greater tendencies for emotional stabilizing. Their emotions are consequently more positive, and they enjoy a sense of utmost confidence. As became clear in this research study, those who have a greater sense of confidence regarding choice

situations have greater perceptions of being self-directed. This contributes to their framing control by being in control and the associated tendency for them to respond emotionally to choice situations with certainty is more prominent. In doing so they experience satisfactory choice situations while enjoying a greater sense of control and have higher levels of emotional stability. Having a sense of control over personal life choices, when enhanced by the realisation of the anticipated outcomes, contributes positively to their subjective sense of identity as an adult.

Yet more research consistent with the emergent theory has shown a positive correlation between traits of self-control and current level of positive emotions (Hofmann et al 2014) and happiness (Cheung et al 2014). Each of these studies confirm that individuals with greater beliefs of control in the context of the choice being made experience greater levels of emotional stability. Bastian et al (2014) further suggest that the experience of positive emotion is closely linked to subjective well-being, demonstrating that in countries where positive emotions are highly valued people report more life satisfaction, and that in countries where there is less emphasis on positive emotions, people experience more negative emotions and do not flourish in these contexts.

The emergent theory reported here highlights that development-related perceptions of control for those in this research study are necessary so as to maintain a positive outlook on personal development in adulthood. For example, their perceptions of control of an adult status which is similar to that of adults in the general population appear as a central component in a syndrome of optimism, and satisfaction with choice situations for them. Furthermore, the emergent theory indicates that the variable nature of control perceptions can be constant or changing with regard to each choice situation. Nonetheless, the emergent theory demonstrates that their individual perceptions of control, whether consistent or changing, follow a differential pattern which is contingent on their past, present and future cognitive and emotional appraisals of each individual's personal experience of life course development. Moreover, the emergent theory demonstrates that increasing independence when initially linked with more positive perceptions of control over life choices may not follow through with concomitant pattern of satisfaction with life choices for some adults, but rather have an opposite effect. This opposite effect is reflected in the counterbalancing of control perceptions with which they respond emotionally and make adjustments and compromises, which feed back into their perceptions of control.

Wang and Saudino (2011) state that positively toned emotions can be brought about by an experience of stress as is apparent in the emergent theory. In this research study those tracking transparency when interpreting a choice situation have perceptions of engaging in self-control and are emotionally self-protecting while being satisfied with choices they make.

Interestingly, some of those who have bounded understanding when making interpretations are less certain or lack awareness regarding a choice situation, perceive greater external control, and their belief that others have a greater influence in directing their choices contributes to their framing control by greater external control. When this happens they tend to seek safety when responding to dense, uncertain, or fearful situations with submission or avoidance by self-preserving.

Selby et al (2013) state that negative emotions may cause a flood of racing negative emotional thoughts, which in turn increase levels of negative emotion in a vicious, repetitive cycle that results in an extremely aversive state. This cycle of rumination is inherent in the concept of emotional de-stabilizing in the emergent theory in this research. Furthermore, in attempting to demonstrate the link between negative emotions and behaviours which are difficult to control, Selby et al (2013) suggest that individuals engage in a process called “emotional cascade”, providing the example that individuals who self-injure may also have the tendency to ruminate on negative emotional thoughts and feelings which increase levels of negative emotion. The emergent theory goes further to explain how specific perceptions of control are continually being influenced by and influence specific emotional responses. With specific reference to emotional de-stabilizing similarities emergent in this research study are present in the literature. Those oppressed and powerless have lower perceptions of control with regard to choices, which contributes to their framing control by not being in control. The tendency for them to respond emotionally to the choice situation ranges from defensiveness and anger to desperation. This reflects the intensity of stress they are experiencing.

This theory explains how these adults are emotionally responding and adjusting to what they are being told to do within the realities of what they actually do. As their perceptions of control are informed by both subconscious and conscious ideas about their likely and actual power they interpret choice situations and determine perceptions of control. In the emergent theory framing control, emotional connecting and adjusting compliance are not only linked but also indicative of one another. Similar to the emergent theory, when adults engage in choices in which they frame control more positively, have higher levels of emotional wellbeing, and adjust easily to what they are being told to do within the boundaries of their actual doing, these adults are more likely to opt to return to these contexts and choice situations. Negative evaluations of perceived influence on choice outcomes and prospects, induces tendencies for them to minimize their engagement in choice situations.

Specifically, Henriques (2011) purports that emotions embedded in two broad domains of satisfying and aversive affective reactions form the foundational base of how individual response sets are organised; a positive emotional state is activated when there is minimal or no discrepancy between an individual's perceptions and goals. In the same way, a negative emotional state is activated when there is an increasing discrepancy between perceptions and goals, and where there is constant

interaction that feeds into complicated feedback loops (Henriques 2011). The theory proposes that perception of an actual state relative to a motivated state leads to an emotional state, whereby operant behaviour patterns are proactive and characterized by dynamic seek-and approach or avoid-and withdraw sequences. This merely endorses the strength of the current emergent theory which illustrates that when the adults are emotional connecting and adjusting compliance they are continually counterbalancing how they frame control. Furthermore, research has shown that positive emotions increase the tendency to engage in new and diversified activities (Quoidbach et al 2015). For instance, those experiencing positive emotions have been found to seek more variety relative to those in a neutral control condition, when choosing among different consumer products (Kahn and Isen 1993).

6.7.1 Emotions in intellectual disability literature

Traditionally, in the field of intellectual disability emotion was regarded as an integral component of various forms of psychopathology, such as, anxiety and mood disorders (Lindsay et al 1989), personality disorder (Reid and Ballinger 1987), addressing undesirable behaviours (McWilliams et al 2014; Hogue et al 2007), and often linked to those with severe and profound intellectual disability (Vos et al 2013). More recently the need to examine the emotional needs of individuals with intellectual disabilities has been recognised (Jahoda et al 2009) as it has been found that such individuals process different information than their carers when rating their emotional responses. Research showed their self-ratings of anger reflected their internal emotional state and mental health, whereas staff ratings were based on overt behaviours (Rose et al 2013).

There is increasing evidence that emotion regulation is becoming an integral component of support programs for people with intellectual disabilities as a competency (Hebblethwaite et al 2011; Samson et al 2012; Lui et al 2013; Rey et al 2013; Wood and Stenfort 2007) with a focus on mindfulness (Robertson 2011), and from an educational perspective (Brown et al 2013). Rey et al (2013) found evidence of the potential value of considering emotional competence in the improvement in the quality of life of these people and advise professionals to consider training programmes based on emotional competence as additional intervention strategies aimed at improving their well-being. Furthermore, Lui et al (2013) found that a well-adapted environment which provides clear instructions, controlled stimulation and appropriate feedback, support individuals to control emotions. However, as the control of emotions is dependent on the individual's own abilities, having acquired the techniques through the educational sessions, some may still have difficulty in actualizing the learnt techniques (Lui et al 2013). Samson et al (2012) found that individuals with Asperger's

Syndrome had greater difficulties identifying and describing their emotions, and in terms of emotional regulation used reappraisal less frequently and reported lower levels of reappraisal self-efficacy. Nonetheless, it has been found that the skill of emotion regulation can be enhanced and maintained over time (Wood and Stenfort 2007).

An individual's ability or willingness to make necessary adjustments is closely associated with the construct of control; for example, an individual's beliefs and perceptions of control are important for adjustment and well-being (Skinner 1996). By adjusting oneself to fit when responding to the personal psychological impact of objective conditions individuals use the strategy of secondary control rather than trying to alter them (Weisz et al 2010). As explained in aligning with the flow of control, from the outset adults are adjusting compliance.

Aligning with the flow of control explains how adults frame control and connect emotions is indicative of how they adjust in compliance. And such similarities are present in the literature. For example, prominent theories have linked perceptions of control in various forms to employee well-being, as well as to other variables (Spector et al 2002). For example, Bandura (1997, p.3) has defined perceived self-efficacy as "beliefs in one's capabilities to organize and execute the courses of action required to produce given attainments". Additionally, Frazier et al (2011) set out to gather initial evidence regarding the reliability and validity of scores on a new measure of perceived control over stressful events that distinguishes among past, present, and future control. Frazier et al (2011) found that perceived control over present aspects of a stressful event is associated with better adjustment and explains variance in adjustment beyond that explained by general control beliefs. And when studying cancer patients Suzanne et al (1993) found that those with greater perceptions of control were less depressed. Even when these patients had less control of their physical functioning and marital satisfaction, it was most important them to believe that they could control daily emotional reactions and physical symptoms if not the course of the disease. Patients who endorsed irrational beliefs had lower overall perceptions of control and the results indicated that even patients who were physically or psychosocially worse off were better adjusted if they had higher perceptions of control. Similarly adults, who frame control with greater positivity, are emotionally connecting through emotional self-protecting or emotional stabilizing and adjusting compliance through functional complying or model complying. And conversely aligning with the flow of control also accounts for situations, such as the presence of fear which does not enhance commitment, but rather feeds compliance (Holburn 1992; Maister 1997). Adults who frame control with greater negativity are emotional connecting through emotional self-preserving or emotional de-stabilizing and adjusting compliance through selective complying or dissentious complying.

6.8 Integrating literature on compliance

Glasser's choice theory (1998) purports that acting and thinking controlled by individuals followed by their feelings and physiology. For the adults in the emergent theory their compliance behaviours has more prominence than 'acting' and rather than leading an individual, these compliance behaviours both influence and are influenced by their thoughts of control, emotional responses, which occur in light of what they are being told and what they actually do, all of which feedback into how they frame control.

However in the extant literature compliance and non-compliance behaviours have proven to be complex in nature, despite a wealth of publications, to date, no single unified compliance theory can account for all aspects of compliance behaviour (Etienne 2011).

Some compliance theorists believe that compliance behaviours can be "automatic", the product of habits and routines (Lindenberg and Steg 2013), while others define compliance behaviour as behaviour which occurs as the result of an individual incapacity, incompetence, ignorance, or misunderstanding of regulatory prescriptions (Brehm and Hamilton 1996). Yet other compliance theorists contend that compliance behaviours can be "planned" and that compliance or noncompliance epitomizes the intentional pursuit of various goals, such as to maximize one's utility, fulfil a moral obligation, or dispose of one's fear of sanctions (Etienne 2011). The emergent theory adds to the clarification of the concept of compliance as it explains it in the context of the behavioural adjustments they make. Additionally this theory enhances an understanding of the concept of compliance as it outlines its relationships with how they are continually framing control and emotional connecting while simultaneously adjusting compliance, all of which act as a feedback mechanism to how they frame control.

In developing a compliance theory of goal framing approach, Etienne (2011) considers that compliance and non-compliance behaviours are conceptualized as goal-oriented action. The way they are adjusting compliance emerges as a category in this theory, and unlike Etienne's (2011) compliance theory of goal framing approach which consider whether automatic behaviours are reflexive habits, or routines, the emergent theory not only does so, but also analyses these behaviours in the context of the environments in which choices are made as they are continually making adjustments and comprises to what they are being told to do within the boundaries of their actual doing.

Similarities with the emergent theory are also found with affective and behavioural dimensions of Geary's (2005) motive to control theory which stems from his formulation that the foundational base of the mind is the motive to control resource flow, and the components of which are: (1) affective; (2) cognitive; (3) conscious-psychological; and (4) behavioural. There are similarities between these components and the concepts emerging in this theory but differences in the nature of their relationships. The similarities can be found in agreement with Geary's (2005) preposition that affective systems guide behavioural strategies and provide feedback to individuals regarding the effectiveness of their behavioural strategies, and thus facilitate them to mentally represent and manipulate information processed by their sensory and perceptual systems.

However, differences can be found in relationships in the sense that, as stated above Geary's (2005) motive to control theory purports that it is affective systems which both guide the behavioural strategies of the individual and also provide feedback to the individual regarding the effectiveness of the behavioural strategies facilitating individuals to make mental representations and manipulate information processed by sensory and perceptual systems, as well as inhibit behavioural impulses predicted to yield problematic outcomes. In the same way, Staat's (1996) theory advocates that nature has built into individuals (animals) emotional systems that make assessments as to whether the individuals are effectively moving toward or away from their goals and subsequently individuals modify behaviour accordingly. However, the emergent theory proposes that the mental representations informing how they frame control sets the direction of the aligning cycle which is counterbalanced by how they are emotional connecting and adjusting compliance, all of which continually feedback into framing control.

Similarities can be found between emergent concepts of framing control and adjusting compliance and LaCerra's (2003) Adaptive Representation Networks theory which proposes that a catalogue of memories link together internal states, external conditions, actions, and the subsequent value of the consequences, all of which together form a bank of information which individuals draw upon to make predictions about which behavioural investments will be most effective in the current situation. However LaCerra's theory does not take into consideration the power of emotions in counterbalancing the thoughts and behaviour of individuals; for example, fear does not enhance commitment, but rather it feeds compliance (Holburn 1992; Maister 1997).

Drawing on the above theories Henriques (2011) develops Behavioural Investment Theory which takes into consideration LaCerra's (2003) Adaptive Representation Networks theory. The manner in which the negative feedback loops actions is also congruent with Powers (1973) perceptual control theory. In both theories, input is referenced against some desired goal state and the discrepancy activates a behavioural response (Henriques 2011). Henriques (2011) Behavioural Investment Theory

adds credence to the hypothesis of LaCerra and Bingham (1998) which claims that actions have consequences for allocation of mental resources and shape the direction of future actions; a point with which Powers (1973) would undoubtedly agree (Henriques, 2011). Henriques (2011) Behavioural Investment Theory incorporates the notion that different environmental affordances will result in different levels of work effort, has some affinity to the concept of adult engagement in the emergent theory. The emergent theory of aligning with the flow of control has similarities with Behavioural Investment theory as Henriques (2011) views the control portion of the computational control principle as crucial, and in the section on the architecture of the human mind he offers a schematic of the human mental system as a control system. Aligning with the flow of control attributes its sub-core category framing control as the crux of how adults respond to their main issue of concern, that of having control in environments that are controlling of them.

6.8.1 Compliance and intellectual disability literature

Evidence of compliance in intellectual disability literature is reflective of the paradigm shifts in service provision. For example, during the 1990's, focus was placed on compliance training of people with intellectual disabilities so as to decrease non-compliance and maladaptive behaviours (Ellison 1997). Additionally individuals with intellectual disabilities undertook skills instructions programmes so as to increase their abilities for compliance with activities of living (Cameron et al 1992; Walters et al 2007). As the need to increase opportunities of people with intellectual disabilities to have more choice and control in their lives, commensurate education in instructional behaviour which could increase experiences of self-control were facilitated for these individuals (Grote 2003) and training individuals was undertaken so as to gain compliance with healthcare treatment regime (Cromartie 2014). Rather than focusing on the need to change the individual so as to ensure 'compliant' behaviour, the focus changed to assessing suggestibility of an individual's compliance behaviour, such as, in the context of prisoners with unidentified intellectual disabilities (Sondenaa et al 2010), rather than gaining 'compliance', from service-users, terms such as 'improving adherence' are now used to explore ways to promote health and well-being for and with individuals with intellectual disabilities (Perez-Cruzado and Cuesta-Vargas 2013).

6.9 Aligning with the flow of control: an intrinsic regimential choice response

When adults are continually being told what to do they frame control which is counter-balanced by emotional connecting and adjusting compliance within the boundaries of their actual doing which conceptualize the coping strategies which they enlist as they make choices in the context of services accessed and support available. The theory presented within this thesis highlights the dilemmas, in which they are operating as an adult, accessing services and being dependent on others for support, while experiencing differing levels of control in the context of making life choices.

This thesis characterises adults with intellectual disabilities as those who, based on their control beliefs make necessary adjustments and compromises, and who create a balance, which situates an equilibrium between what they are told to do and what they actually do. While they may determine that they have differing levels of control in the context of different choice situations, it is important to note that they are never either entirely person-driven or entirely other driven, but are constantly engaged in negotiation between the two.

From the emergent theory it is interesting to note that when being told what to do the adults are framing control, wherein when faced with a choice situation they make assumptions about the control they have with regard to the choice being made in the realities of what they are actually doing. In this research study they continually draw from frames of reference whilst simultaneously making interpretations with regard to the choice situation and position control so as to frame the control they have over what they are actually doing while being told what to do. In this way, they are using these frames of reference and making interpretations with which to position their assumptions of the control they have and their perceived levels of satisfaction and success with anticipated choice outcome.

Whatever the level of control they assume is available to them with regard to the choice situation, making interpretations and developing control beliefs enables them to psychologically control how they respond to the choice situation. When they exert control of their psychological responses to the choice situation they find that the choice situation is more psychologically manageable. This initial motivation, illustrated in the terminology of this thesis, is centralised as they frame control. For example, when positioning control they continually make comparisons between what they are told to do and the realities of their actual doing. Thus in accordance with emotional connecting and adjusting compliance the state of equilibrium is ultimately determined as they respond to what they are told to do. The complexity of human situations means that their choices are not always simple and straightforward. But generally when choices are made in the context of a group-managed service provision, some ultimately have limiting control over the final outcome of the choice made. Choices

that are facilitated outside of the remit of group-managed service provision engender greater opportunities for control.

This thesis has therefore added to Glasser's choice theory the concept of framing control as a means of conceptualizing adult thinking in the ways in which adults compare what they are being told to do with what they are actually doing and take direction from how they are frame the control they have, and while taking into consideration their emotions, are adjusting their actions to adapt to the choice situation. Both emotional connecting and adjusting compliance help them to alleviate dilemmas created by any incompatibilities identified by self or highlighted when being told. The power in emotional connecting is driven by their awareness of how far or near being told from the realities of their actual doing. The reconciliatory power of adjusting compliance ranges from affording those who are accepting seemingly inappropriate choice a promise of sustained or greater freedoms, even if the they feel that they are currently making very little progress towards their perceived outcome of having independence, or, by affording those who are no longer able to cope with the current situation, the opportunity to opt out of the choice situation, and putting the onus back on the requirements of what they are being told to be reviewed. By way of framing control they are able to gauge whether or not they are moving nearer to or away from the ideal outcome. Conversely, if emotional connecting and adjusting compliance leads to the acceptance of a particularly appropriate choice offer, for example, accepting a choice offer about which they feel comfortable and competent, framing control will be positively reinforced because their actual doing is closer to requirements of what they are being told to do and vice versa.

As the beliefs and values that govern their perceptions are grounded in historical and normative societal change, they are themselves subject to changes. Generally during adulthood, subjective beliefs, values and self-precepts of control over life choices become more differentiated and concrete (Brandtstadter 1989). This is presumably the case for individuals with intellectual disabilities as the developmental desire for independence, self-direction and having a sense of control also gain importance for those seeking to live of equality with others in society (Lill and Hartwell 2013). While functional diversity has emerged in this theory to account for variations in domains and levels of functioning, when combined with support and adult engagement, the concept of adult's actual doing also becomes apparent. A wide variation occurs for individual adults, but when being told what to do, they ultimately differentiate between which aspects of their life choices can be actively altered and self-directed and which aspects are externally directed. The argument developed in this chapter is that while perceptions of control over choices have an important and variable impact pertaining to making life choices, their emotional responses and subsequent behaviour positively or negatively influences how they counterbalance those perceptions of control. The theoretical concepts mentioned above, generate some general hypotheses of how their perceptions of control relate to other facets of their

cognitive appraisal of choice situations impacting on their emotional and behavioural responses. The next section explains how their differential perceptions of control are both informed by and inform their emotions and behaviours, in the context of discussing evidenced based literature relevant to emotional connecting and adjusting compliance.

6.10 Conclusion

While it is widely acknowledged that control is an important quality of life construct for people with intellectual disabilities, there is limiting evidence of either their perceptions or experiences of control. There is a scarcity of research on perceptual control theories as it pertains to these adults and research in the context of locus of control, while limited, exists in educational and criminal justice perspectives.

This thesis posits that the interactive nature of what adults are being told to do and their actual doing act as a necessary catalyst for how they are aligning with the flow of control. When their actual doing interacts with what they are being told to do, their past experiences and current interpretation of the choice situation, combined with their perceptions of control with regard to making choices, leads to framing control which may be circumstantial and subject to change.

This thesis also asserts that the interactive experiences of being told what to do and what adults actually do while interacting can simultaneously be constricting and/or facilitating in aligning with the flow of control. As both the human and organisational dimension of service delivery, along with the functional diversity of the individual adult, provide contexts for framing control, they decide what to do next based upon an assessment of the situational factors. The equilibrium of aligning with the flow of control is counterbalanced by how the adult is emotional connecting and adjusting compliance, where one is indicative of the other. Additionally, Tatlow-Golden et al (2014) contend that a further under-researched aspect of deinstitutionalisation is organisational culture; that is, the uncontested customs and practices that dictate roles, positions, behaviours and interactions within it.

Aligning with the flow of control as a unified theory of control has emerged from this grounded theory study. Incorporated in the theory is framing control the sub-core category when adults are being told what to do, how they emotionally connect and make adjustments in what they actually do. Furthermore, emotional connecting and adjusting compliance are counterbalancing factors in how they are aligning with the flow of control. Therefore further research exploring how they cope

emotionally with choice situations and how this impacts on adjustments made when combined are the feedback loop into how they frame control.

Regardless of the ideal or the operationalizing of ‘control’ for and with people with intellectual disabilities, ultimately it is their beliefs and perceptions of control which are crucial aspects of choice making. The emergent theory demonstrated control to be a main issue of concern for the adults as they make choices and they respond by aligning with the flow of control. They are aligning with the flow of by framing control, emotional connecting and adjusting compliance to what they are being told to do within the boundaries of their actual doing. Furthermore in explaining the latent pattern of behaviour of these adults, aligning offers further cohesive explanations on the construct of control, explaining how they frame the control they have in the context of making daily choices is influenced by and influences their emotions and behaviours. Aligning with the flow of control offers explanations of four different accounts of how they respond to what they are being told to do in the realities of their actual doing.

7 Summary and Conclusion

7.1 Introduction

The aim of this study was to develop a grounded theory that identified the main concern of adults with intellectual disabilities, and conceptualize how this concern was continually resolved. It was essentially an exploratory study which sought to explain “what is actually going on” when they make choices. Using a classic grounded theory approach, this research study presents their main concern as control in environments that are controlling of them, and developed the emergent grounded theory of aligning with the flow of control as the means through which this concern is resolved. The theory emerged from rigorous application of the classic grounded theory methodology in the substantive area of how they make choices.

This chapter summarizes the emergent theory of aligning with the flow of control. The credibility of this research study is evaluated according to the classic grounded theory criteria of fit, work, relevance and modifiability. The contributions of this theory (Appendix 11) are condensed reflecting on its theoretical, methodological and practical implications. Some possible recommendations for, policy, research, practice and education, limitations of the research study, opportunities for future developments and researcher reflections are considered.

7.2 Summary of emergent grounded theory

The grounded theory of aligning with the flow of control accounts for the continuous negotiation of adults’ main concern; that of control in environments that are controlling of them. This theory offers a conceptual delineation of the way they manage the daily tensions and harmonies which reside in the interactions of what they are being told to do and their actual doing. The theory of aligning with the flow of control proposes that they continually appraise choice situations, frame the control they have while responding emotionally as they adjust in order to navigate how their individual needs and aspirations fit with external requirements.

Aligning with the flow of control is not a fixed state, but is conceptualized as a dynamic oscillating equilibrium amidst interactions of their being told what to do with their actual doing. Adults exist.

neither fully at one extreme or the other, but are engaged in an iterative, ongoing, and responsive process. When they automatically meet the requirements of what they are being told to do their actual doing is amplified and a positive aligning cycle maintains the equilibrium. Conversely, when their actual doing is externally directed the fact that they are being told amplifies and a negative aligning cycle maintains the equilibrium.

The extent to which their actual doing deviates from or complies with what they are being told to do is influenced by the counterbalancing concepts of emotional connecting and adjusting compliance. Being told is amplified or de-amplified based on the interaction with their actual doing and vice versa. Ultimately, their actual doing, can only be stretched so far, as their functional diversity, support and engagement, determines both their scope and willingness to make adjustments and compromises so as to meet requirements of what they are being told to do. But in totality aligning with the flow of control is pre-regulated by framing control the sub-core category.

The nature and extent of aligning with the flow of control is shaped and directed by how they frame the control they have in choice situations, in which their fundamental beliefs of control pre-empt their responses, as they continually summarise the compatibility of what they are being told to do in light of the current realities of their actual doing. Framing control can effectively facilitate either the closing or the widening of the divergence between what they are being told to do and their actual doing, where they are either self-directed or externally directed in their approach to choices. Frames of reference solidifies their general beliefs regarding the scope of autonomy available to them in the interaction of what they are being told with their actual doing, pre-regulating the extent to which aligning with the flow of control will be required to comply with authoritative requirements. And it is by making interpretations and positioning the control they have in specific choice situations, that they appraise the interaction of what they are being told to do and what they do in light of anticipated outcomes in the context of their functional diversity and so determine the degree of the alteration, modification and adjustment required.

Thus whilst framing control primarily fulfils regulatory functions, the corrective and counteractive powers set the direction for positively or negatively aligning with the flow of control which is counterbalanced by emotional connecting and adjusting compliance, which iteratively feed back into how they frame control. Illuminating the importance of emotions and compliance behaviours as counterbalancing factors in adults aligning behaviours is crucial to understanding adult's choice behaviours.

This theory suggests that the notion of compliance behaviour offers a promising addition to choice research, not necessarily in trying to eliminate non-compliance, or in understanding the extent to which diversification occurs, but rather to explicate what works well for those within intellectual disability settings. The benefit of ascertaining how well they are adjusting compliance is not in

simply measuring the ability of each one in the context of each choice situation, but in knowing how each choice situation differs as a step towards being able to more accurately judge the effectiveness of support offered and how compatible what a person is being told to do is with what they are actually doing. Rather than evaluating compliance as an end in itself, this theory has concluded that it is more worthwhile to consider whether different levels of compliance lead to significant differences in choice satisfaction outcomes for the adults. Indeed, the purpose of evaluation within choice situations should not simply be about ascertaining outcomes, but about understanding how these outcomes have been brought about. This is particularly important for the effective piloting of new choice initiatives. By determining the extent and nature of aligning with the flow of control within a particular choice situation, it would be possible to explore which elements of the choice arrangement were appropriate for the adult group and learn from best practice, or to identify areas that require refinement or modification.

7.3 Classic grounded theory methodology

This study has supported the full and rigorous use of classic grounded theory procedures as a means of systematically generating an explanatory theory to explain the resolving of the main concern of adults in this research study. This theory has critically explored how grounded theory methodology has been utilised in research in a variety of ways. A discussion of the inherent similarities, compatibilities, differences, and incompatibilities between approaches labelled as grounded theory has been provided and the classic grounded theory methodology utilised in this research study has been classified. The inappropriate labelling of frameworks claiming to be grounded theory forcing preconceived ideas upon the data, rather than allowing the theory to emerge inductively have been challenged. Additionally, the emergent theory has produced a complex structure, integrated around an interactive family theoretical code that has challenged the widely recognised, yet incorrect assumption that the classic grounded theory researcher is always concerned with finding a process to explain the theory (Glaser 2005). Instead, this theory has demonstrated that essential to achieving a sophisticated integration of theoretical propositions, is a requirement for the classic grounded theory researcher to be sensitive to multiple theoretical codes. By offering a conceptual explanation of the development process through which the emergent grounded theory was abstracted from empirical data, this research study provides a further contribution to the methodological literature on classic grounded theory. Considerable methodological guidance on classic grounded theory methodology through the constant comparative method and the interchangeability of indicators is readily available (Glaser 1978, 1992, 1998, 2001, 2003, 2005). This research study contributes to the knowledge of classic grounded theory by the researchers' use of experiential reflection of the classic grounded

theory journey. Ultimately, this serves two purposes. By explaining in detail the challenges and opportunities encountered by the researcher on this journey, an important educational resource is provided for novice classic grounded theorists learning and applying the practicalities of using the methodology. Furthermore, this theory provides evidence of procedural credibility demonstrating the classic grounded theory methodology is not intuitively conjectured by the researcher but rather empirically grounded in the data. In describing the creative and iterative process of theory development, the researcher has acknowledged the opportunities and challenges with regard to the contested appropriateness of computer assisted data analysis software (NVivo 10) in classic grounded theory analysis. The researcher, while suggesting that NVivo 10 can be used to comprehensively store and manage data collected, and provide reports, found that, the NVivo 10 package does not initiate ideas for memo writing and use of and development of the constant comparative method, therefore stifling the preconscious processing of the researcher, which can also be stifled by absence of the nonlinear hands-on process of theoretically sorting memos. Using NVivo statistical package for: storage and management of the data, frequency word searches, and grouping of set questions of the data when combined with the constant handwriting of memos to stimulate ideas for theoretical sensitivity and relationships between concepts provides a coherent approach for the rigorous use of classic grounded theory.

Finally, this theory has highlighted some of the challenges of using the full complement of classic grounded theory procedures, particularly in relation to the interface between the inductive nature of classic grounded theory and the organisational context of modern healthcare research. The perception that data collection and analysis should start straight away is perhaps slightly unrealistic within the context of lengthy ethical approval procedures. Similarly, the amount and flexibility of theoretical sampling is not simply within the control of the individual researcher, but is influenced significantly by external organisational factors. This theory then perhaps demonstrates that it is sometimes necessary to reframe methodological ideals to fit research realities. Drawing on the theoretical ideas presented within this theory, it is also proposed that methodological ideals can be stretched only so far before they become a different methodology altogether. Both the experience of conducting this study and the theoretical output thus contribute to knowledge of classic grounded theory by highlighting the realities and practicalities of its practical application.

7.3.1 Evaluating the credibility of the emergent theory

The credibility of the emergent theory aligning with the flow of control will be explained in evaluating how this research study meets with the criteria for a classic grounded theory. By using classic grounded theory methodology the aim is to offer an explanation of theoretical propositions which account for how they resolve their main concern. The use of classic grounded theory methodology is not intended to provide verifiable results or interpretive findings, as the essence of the research study is conceptual suggestion rather than the verification of fact (Glaser 2003). It is in conceptual integration and generality of the generated theory that the credibility of a classic grounded theory study can be established. Glaser's (1978) criteria of fit, work, relevance and modifiability were outlined and explained within the methodology chapter of this theory. Against these criteria, this section evaluates the emergent grounded theory of aligning with the flow of control.

7.3.2 Fit

The criterion of "fit" refers essentially to the "validity" of the emergent grounded theory; that is, the extent to which the theory represents the behaviour under investigation (Glaser 1978). It has been demonstrated through the comparison and integration of extant literature that the main concern identified within this theory, namely, control in controlling environments, aptly captures the dilemma of many adults who access supports and live with choice outcomes amidst their perceptions of compatibilities and incompatibilities between what they are being told to do and their actual doing. It is a concern supported within choice research, in addition to theories of bureaucracy, control, self-determination and emotional regulation and compliance. The grounded theory presented in this theory also has been generated through the rigorous and systematic application of the full complement of classic grounded theory procedures. The constant grounding of concepts in the data, and their fitting and re-fitting to new data, has ensured that the final theoretical product remains sufficiently close to the data from which it was derived (Glaser 1998). Rigorous application of the constant comparative method means that codes and concepts have emerged directly from empirical data rather than being preconceived or conjectured. Every effort has been made to ensure that concept names have retained the essence of the data, whilst also raising the conceptual level of the final theoretical product. This gradual refinement of fit is demonstrated and provides a description of the data analysis process through which the theory of aligning with the flow of control was developed.

7.3.3 Work

The capacity of the emergent theory to explain, with much variation, the means through which participants resolve their main concern relates to the concept of 'work' (Glaser 1978). Use of open coding, memo writing, and the constant comparative method embedded in the empirical data collected from the substantive area, has allowed the emergence of the main concern and behaviours conceptualized in this theory. Additionally, the suitability of the theory to summarise and synthesise findings from other studies, has demonstrated the workability of the theory relation to issues of choice and control.

7.3.4 Relevance

The "grab" of the emergent theory refers to the importance of the core concern in the substantive area, which provides for the relevance of the theory (Glaser, 1978, 1998). When the emergent theory sufficiently captures a significant concern for the research participants, the theory is deemed to be of relevance. In this research study relevance has been optimised by ensuring the systematic and rigorous application of theoretical sampling and the use of the constant comparative method, which progressively refined the emerging theory. The researcher avoided forcing preconceptions on the data by delaying the review of the literature and instead engaging in continual memo writing, from the empirical data grounded in experiences and the core category emerged reflective of the data from which it was derived. Relevance refers to the core-category fitting, meaning it fits and works in the view of other researchers, participants and practitioners. Therefore the relevance of this theory, while initially supported by the rigour with which the data was analysed, can also be supported by further research with regard to the emergent categories and their relationships. The researcher presented and discussed the theory with a registered intellectual disability nurse working as a Clinical Nurse Manager in a different service. The nurse could identify the relevance of the theory in her area of practice and voiced that in light of the accountability of her role, and the inordinate amount of paper work to be completed to meet service and external requirements (e.g. HIQA), she had felt compelled to focus on justifications of risk assessments which had consequences for increasing or decreasing control in the person's life. The Clinical Nurse Manager acknowledged that less consideration was afforded to the emotional wellbeing of individuals in the context of how they framed control or on focusing on what they are actually doing that works well for them and makes sense to them. Following our discussion, the Clinical Nurse Manager aimed to centralize understanding of what such individuals are actually doing that works well for them and makes sense to them, how this is:

illuminated, and the opportunities they have for control in the daily interactions with staff and relevant others. Although developed within the context of choice situations, this theory has relevance with the integration of extant literature and has provided additional data that is suggestive of the conceptual generality of the theory of aligning with the flow of control. As the breadth of literature incorporated within this theory suggests, there are several different perspectives from which to understand the tensions between the ideals and realities of making choices. Furthermore, the theory of aligning with the flow of control inheres' potential relevance for other areas of intellectual disability service provision where adults are continually negotiating a balance between being self-directed or being other directed whilst accessing support and complying with what they are being told to do. This is suggestive also of the opportunity to develop a formal theory that more generally explains the complex process of control in environments that are controlling, which according to Glaser (1978), is indicative of a relevant core category with sufficient conceptual grab.

7.3.5 Modifiability

The ability of the grounded theory to be altered in response to comparison of new relevant data refers to the modifiability of the theory (Thulesius et al 2003). New ideas can increase the density and scope of the theory by adding further variation while not refuting the emergent theory. A classic grounded theory, once developed, while not intended to be proven, can be modified through further constant comparison (Glaser 2003). It is possible that the density of the theory would be increased by further theoretical sampling across a wider range of sites, for example, by sampling in choice situations where requirements for compliance are less rigidly imposed. As the integration of extant literature has demonstrated, this is a potentially common concern that will span several domains in which people in power positions deliver services to other people in less powerful positions, such as other areas of healthcare, welfare agencies, social work or education. Ultimately, however, sampling cannot go on forever and "must come to an end, usually based on human limits, with an appeal to future research to give directions for a subsequent grounded theory researcher" (Glaser 2001, p.183). The theory of aligning with the flow of control is thus presented as sufficiently demonstrating fit, relevance, and workability within the substantive area and remaining open to modification from further data. Its openness to future modification means that the theory will have lasting relevance and usefulness.

7.4 Contribution to policy, research and practice

Grounded theory can offer new insights into an old problem or can develop new theory in substantive areas where there has been little research (Glaser 1998). While the theory presented in this thesis has been derived from how adults make choices, offering insight into a relatively new substantive area, the conceptual nature of the theory has also permitted an extension into old problems, most notably in the fields of behavioural psychology, service provision, and service user-involvement. This theory has confirmed some existing knowledge claims, challenged others, and offered some new knowledge claims. Ultimately, the central focus of this theory's contributions to new knowledge of this theory is on the delicate balance between the requirements and realities of making choices. By explicating the interactive relationship between being told and actual doing, the theory offers insight into the antecedents and outcomes of the tensions between "what adults are told to do" and "what they actually do" in the context of making choices. Derived from empirically grounded indicators in the substantive area of choice, the ideas presented in this theory also have "grab" and relevance in other areas where those in similar situations access support. The key contributions to knowledge of this theory relate to choice behaviour, control, emotions, compliance, and classic grounded theory.

The theory of aligning with the flow of control wherein the interaction of being told and actual doing present a set of variables that determine adult experience of support, which highlight the influence of authority on determining their autonomy in how choices are arranged and delivered, and the extent to which their perspectives of that ideal outcomes are achieved. This theory contributes to policy, research and practice of choice for adults in the context of service delivery by presenting a new emergent grounded theory of aligning with the flow of control. The theory conceptualizes the means through which adults continually frame the control they have in choice situations, respond emotionally and adapt their compliance behaviour to what they are being told to do. In so doing, this theory makes a timely contribution to policy, research and practice.

7.4.1 Contribution to policy

This section focuses on the contribution of the theory to international, national and local policy.

From an international perspective, this theory supports approaches to remove legal and social barriers to citizenship and equalization of opportunities for these adults. These are particularly prominent given the imminent reform stipulated by the United Nations Convention for Persons with Disabilities (2006) which challenges the Irish Government to draw on best available evidence so as to make the

necessary reforms to enable these adults live lives equal to other citizens in society. Internationally there is growing evidence that choices must be targeted effectively, appropriately reinforced, and monitored meaningfully as supports are personalised and allied with greater opportunities for community inclusion improving the quality of people's lives (McConkey et al 2009). Globally capacity policy and legislative makers grapple with how best to support individuals whose capacity could be questioned. An example of what good support might be is offered in the form a ssistant decision-makers chosen by the person, and someone who the person trusts to assist them with making (ADMB 2013). This theory provides a contribution to how that element of 'trust' could be enhanced.

Nationally, the Irish Government has underpinned a new model of disability service pro vision with values of person-centredness, inclusion, community integration, participation, independence and choice (NDA 2010; Linehan et al 2014) indicating that future health-related support must be flexible and person centred (Future Health, DOH, 2012). This model is equipped with key characteristics of personalisation emphasizing self-determination and tailoring supports around the specific and individualised needs of the person (McConkey et al 2013). The Irish Government have committed to introducing new and innovative ways of funding services that support choice, person-centeredness, accountability and best value (HSE 2012), and the introduction of inspections to residential services for people with intellectual disabilities has been welcomed (HIQA 2013). It is particularly pertinent that outcome targets are informed by evidence of adult's actual doing rather than idealized conceptions. For example, the Comptroller and Auditor General financial audits (HSE 2005; DOH 2012), have suggested the ineffectiveness of current pathways, particularly in provider led areas, has resulted in inefficiencies in performance monitoring. And the concerns expressed by of some of the adults in this study regarding the compatibility of "what they want to do" with their money and "what they actually do" with their money is indicative of this discord.

Locally in the delivery of services there is an increased emphasis on 'choice' and 'control'. And varied methods of service evaluation have been enlisted, such as goal setting and reviewing, staff appraisals, service-user involvement and individualised outcome measures (Young and Chesson 2006). Within many evaluations to date, there has been an unstated, and perhaps unrecognised, assumption that choices are facilitated in a standardised fashion (Fryson and Cromby 2013). There is also a lack of evidence- based research on the potential impact of the differences between individual choice arrangements for those who have differing physical or mental health needs. Specifically there is a dearth of evidenced information available on the impact of the personalisation of services from self-reported experiences of people with intellectual disabilities (Sims et al 2014). While previous studies (e.g. Agran et al 2010) have acknowledged the lack of information on their actual choice making experiences, other studies have begun to evaluated their perspectives in the context of specific

choices (Martorell et al 2008; McCarthy 2010). This theory has been grounded in the realities of adults with intellectual disabilities and explains aligning with the flow of control as their latent pattern of behaviour when choices are made, thus making a significant contribution in offering a framework for service providers to consider when evaluating choice and developing service policy.

7.4.2 Contribution to research

This section illuminates choice behaviour of adults in the emergent theory, compares and contrasts choice and control theory with literature on emotions and compliance acknowledging the contribution of this theory to research.

Choice behaviour as understood in the context of this theory is a five-way interactive phenomenon, based not only upon the interaction between adult and environment, but also influenced by fundamental beliefs, emotional responses and compliance behaviour of the adult and vice versa.

Similar to Powers (2011) perceptual control theory, the grounded theory of aligning with the flow of control has proposed that while service providers and those in power positions establish rules about “how things are to be done”, individual adults act, based on their knowledge and priorities, to adapt, ignore or oppose what they are being told to do. Framing control, the sub-core category presented within this theory has supported Powers (1973, 2005, 2008, 2011) idea that action is determined by knowledge and contextuality. This theory reaffirms that actions are always situated within contexts that can either constrain or enable adults. Similarly, as supported by the cumulative nature of framing control, the more adults know and understand, the more confident and willing they are to enact rules within the service context unless opposed to their aspirations.

Critical comparison between this theory and Powers (1973, 2005, 2008, 2011) has disputed some of the fundamental aspects of perceptual control theory. This theory has conceptualized the interaction of between being told what to do and adult’s actual doing as the influencing factor which shapes perceptions, emotions, and behaviours. While the boundaries of what adults are being told to do may be adapted to suit their actual doing, a central premise of the theory of aligning with the flow of control is that the boundaries of being told and actual doing can be stretched only so far. The nature of the requirements for adult behaviour depends on an oscillating equilibrium between whether they are self-directed or externally directed and, although dynamic in nature, equilibrium can be maintained or changed contingent on whether or not they sustain how they meet the requirements of what they are being told to do. Maintaining equilibrium supports Powers (1973, 2007) conception of collective action as maintaining social structures, but for those adults who burst the boundaries of

what they are being told to do, breaching the equilibrium challenges the accounts of Powers theory. In contrast to Powers (1973, 2007), this theory has explained functional diversity to be inherent in adults, and when combined with, support and adult engagement, underpins their actual doing. Despite some initial similarities, this theory has therefore challenged Powers (1973, 2007), perception of structure and agency as two sides of the same coin by conceptualizing being told and actual doing to be both distinct and inter-dependent. Additionally, this theory illuminates the impact of emotions and compliance behaviour on how adults frame control.

Frames of reference denote the fundamental motivators in framing control and while influenced by opposing drivers of enacting practices and functional diversity these reference signals that though open to change, are fairly consistent and representative of the identity, power, and mind -sets of adults, and act to synthesise findings from existing qualitative research which has ring-fenced terms such as “humanisation”, “de-humanisation” “oppression”, “obedience”, “dependence”, “liberation”, “empowerment” and “independence” (Carlson 2010; Bond and Hurst 2009).

Along with drawing on frames of reference, adults in the emergent theory are interpreting choice situations. According to Lifshitz et al (2011), researching reasoning abilities in individuals with intellectual disabilities is particularly challenging because it is highly context-dependent and adults often exhibit varying individual difficulties and levels of expertise. Using a classic grounded theory approach, this theory has been able to offer a conceptual rendering of decision -making that offers a degree of conceptual generality into other areas, with the potential to have relevance for other adults outside the original substantive area. By focusing in particular upon the interaction between what adults are being told to do and their actual doing, this theory provides insight into the complexities of their decision-making within a modern health and social care context, where loyalties are often divided between the self, peers and powerful others. Interpreting is conceptualized in this theory as their knowledge and thinking in the delineation of non-sequential choice opportunities. Additionally, in support of Larkin et al (2013), interpreting does not represent a straightforward process but is also characterised by continual change and adaptation in response to presenting circumstances.

Basically, interpreting influences of how adults are positioning control, for example, when being told what to do is contradictory or ambiguous, ill-defined, or conflicting with their aspirations, it is understandable that they have less emotional stability and are more likely to engage in dissentious complying or deviate significantly in their implementation of these rules and directives. On the other hand, when the requirements of being told and support are significant to their aspirations, clearly defined and transparent it is understandable that they will have greater emotional stability and are more likely to engage in compliance behaviour.

This theory not only supports the non-sequential and situational nature of how adults interpret choice situations, but also conceptualizes the impact that context has in the decisions made. The theory of aligning with the flow of control therefore adds to existing conceptions of decision-making (Werner 2012), attesting to both the choice contexts and personal contexts. More over, through integration of relevant literature this theory has identified the potential for those in power positions to affect the personal situation of these adults, particularly where there are perceived tensions between what they are being told to do and how they perform within the boundaries of their actual doing. Providing a conceptual explanation which demonstrates the means through which adults manage conflicts between the ideals and realities of making choices, the theory presented here can potentially contribute to the education of service providers, support persons and people with intellectual disabilities.

The theory presented in this thesis has been compared to Glasser's (1998) choice theory, highlighting both similarities and differences. Similar to choice theory, the grounded theory of aligning with the flow of control has proposed that how adults are thinking, feeling and doing impacts greatly on their choice behaviour. However the emergent theory differed from Glasser's (1998) choice theory this theory does not see feelings, thinking, acting and physiology as presented the Total Behaviour Car metaphor as distinct components of wheels of a car, but rather of an interactive iterative cyclical arrangement where each interacts with and has influence on the other. In contrast to Glasser's choice theory, in the emergent theory framing control provides for a focus on what adults are thinking about and furthermore as explained in the emergent theory how adults frame control sets the direction of the aligning cycle which is crucial to understanding their choice behaviour.

Similar to Glasser's choice theory is the recognition that feelings are an inherent part of choice behaviour. But furthermore, for the adults in this research many of their feelings regarding choices and choice opportunities evoked strong emotions, and how they connected their emotions with how they framed control of choices impacted on their general well-being and how they adjusted to choice situations. This theory strongly supports literature which purports that emotions follow cognitive appraisals (Tenebaum et al 2008), that emotions influence behaviours (Tenebaum et al 2008), that positive beliefs of having control are strongly associated with positive emotions, and that positive emotions influence positive behaviour. Further, there is also strong support in this theory that negative beliefs of having control is strongly associated with negative emotions (Watkins and Nolen-Hoeksema 2014; Turner et al 2012) and that negative emotions influence maladaptive or negative behaviour (Hanin 2000). Pekrun's control-value theory (2000) particularly underscores the importance of control beliefs and personal values as the vehicle for linking individuals' unique cognition, emotions and motivations (Turner et al 2012).

The strength of this theory is also attested in Xue et al's (2013) findings that positive emotions can facilitate cognitive control processing, providing evidence of the feedback loop system. Additionally, Linehan's (1993) findings that beliefs about control of emotions were formed as a result of invalidating environments, leading people to believe that their emotions are out of control, that they ought to be controlled, and that they can be controlled easily is strongly supported in this emergent theory and explained by frames of reference, highlighting the importance of the adults' ideas about their identities, power and mind-sets. The emergent theory adds to the research which explicates relationships between specific control beliefs and specific emotions. Additionally the emergent theory illuminates the relationships between emotions and behaviours by in distinguishing between emotional connecting and adjusting compliance. However, despite a plethora of published studies on emotion regulation, relatively few have discussed its applicability to individuals with intellectual disabilities (McClure et al 2009). The contribution of this theory in explaining how emotions impact on adults choice behaviour highlight a need for more education of support persons with regard to how depressive rumination can lead to depression by enhancing negative mood-congruent thinking, impairing problem solving, and interfering with instrumental behaviour (Watkins and Nolen - Hoeksema 2014; Nolen-Hoeksema et al 2008).

Adjusting compliance, explained as the extent to which adults comply with what they are being told to do, has been highlighted within this theory as an important consideration in how they behave and also informs how they evaluate choice outcomes. Similar to Glasser's choice theory is the recognition that actions are an inherent part of choice behaviour. This theory goes further to explain that such actions from adults with intellectual disabilities are evident in their willingness and ability to comply with what they are being told to do in the boundaries of what they actually do. This theory has supported findings in the literature that services values, visions, and skills which aim to promote empowerment, independence and person-centredness for individuals with intellectual disabilities, are pre-loaded with an increasingly complex web of regulations, standards and legal requirements which facilitate health and safety systems, at the cost of embedded structures which rely on the compliance of the individuals which it is designed to serve (Gaventa 2008; Sondenaa et al 2010). Subsequently adults are continually adjusting their compliance behaviours to what they are being told to do when engaging with services accessed. The theory of aligning with the flow of control presents a new conceptual theory that explains how, as they shift between compliance and non-compliance with what they are being told to do, they experience variations in their perceptions of control while seeking not to breach the boundaries of what they are being told to do. The theory offers a conceptual perspective from which to begin to understand how and why they comply with or deviate from what they are being told to do. By offering insight into the nature of aligning with the flow of control, this theory suggests that, at one extreme those with high emotional stability demonstrate greater ability and enthusiasm in complying with what they are being told to do, while at the other extreme, while it may be desirable

and possible for those to defy those in the power situation, non-compliance occurs only when emotional stability is at its lowest.

When the requirements of being told and support are, contradictory or ambiguous, ill-defined or oppositional to adult aspirations, it is understandable that adults are likely to deviate significantly in their implementation of these rules and directives. In this case service structures can either inhibit or permit aligning with the flow of control, but it is the relative malleability of adults to adjust to the requirements of being told that is ultimately indicative of the level of compliance enlisted. This theory therefore supports existing literature by confirming that their inclusion in decision-making and clearly defined expectations and standards which are tailored to their individual needs is essential to optimising the potential for adjusting compliance (Hurtado et al 2014; Mulrooney 2014; Hanson 2008). Even when what they are being told to do is clearly defined however, this theory has also supported and added some other challenges to choice implementation. Adjusting compliance is dependent on their willingness and ability to engage in the choice situation. While supporting Mulrooney (2014), this theory suggests that fully informing them about the requirements and benefits of participation can optimise engagement in choice situations; it is further argued that their participation will also be affected by external influences that remain beyond the control of the support person. Undoubtedly, these external influences will impact upon their capability to engage in the choice situation as intended. Moreover, being told can itself provide a strategy for encouraging their engagement. As such, it can be concluded that there is not necessarily a link between compliance and effectiveness. They may deviate significantly from what they are being told to do, but when engagement is optimised, the potential for their actual doing can be increased.

In conceptualizing their experiences, and the variable nature and extent of how they frame control when being told what to do, this theory has challenged the broadened scope of labelling these adults with the term 'intellectual disability'. In early stages of data collection, codes relating to identity and status were significant, suggesting perhaps that even centuries on from the first creation of labels, such individuals are still struggling to attain an adult identity role. In order to ensure that their identities are more positively created, neo-liberal emphasis on choice needs to be tempered and a more nuanced and inclusive notion of personhood be adopted.

7.4.3 Contribution to practice

This section discusses similarities and differences in how enacting practices of those in power positions impact on how adult's frame control within the boundaries of what they are actually doing and acknowledges the contribution of this theory to practice.

Experiencing support while accessing a group-managed service while seeking to live life as an adult, presents both challenges and opportunities for those in this research study. From their self-reports there is evidence that enacting practices have the indirect capacity to humanise or dehumanise the individual's identity as a person and as an adult, and the authority to dictate power at all levels in the hierarchy, both of which contribute to influence the inherent mind-sets developed and how they are framing control. Along with enacting practices wherein rules are used to gain conformity from adults to fit with service expectations, they respond by making adjustments to their own goals to fit with these expectations. Perceptions of support can be satisfactory either when they fit to the service or the service fits to them. Indeed, aligning with the flow of control was often evident in relation to the use of outcome measures in this study, whenever they expressed difficulties or opportunities with "fitting in".

This supports the findings of Mahar et al (2014) who contended that measures of belonging may be the single most important outcome measure for quality of life and well-being. Moreover, the nature of frames of reference emphasised that, rather than maintaining ideal configuration of core components of what they are being told to do which is consistently focused on standards of normality, choice situations which would provide flexible service provision that is personalised to and illuminates the contributions of each individual's actual doing. This would ultimately focus on optimising positivity such as identifying as an adult human and with satisfaction in frames of reference.

While enacting practices and support influence frames of reference, they themselves contribute to their own ideas of power and control and perceived ability to perform in choice situations. This theory supports assertions in existing research (Arvidsson et al 2008) that while there is a link between the extent to which they are able and willing to engage in achieving choice outcomes, there is a dearth of published research in this area.

Given the importance of engagement, it is suggested that future research should explore the effectiveness of both discretionary and mandatory choice situations. By highlighting the requirement for engagement this theory also suggests that the future development of choice situations should focus on "getting the timing right". In order to fully actualise the vision of flexible and personalised choice arrangements, it is crucial to consider when, and what choice opportunities, are most appropriate as they journey through their adult lives, and whether there is better support to be accessed before rolling out the choice situation. By explaining the foundational principles in frames of reference, this theory has the potential to contribute to the effective targeting of choice arrangements while supporting tailored personalisation.

7.5 Recommendations

This section summarizes some possible recommendations for, policy, research, practice and education.

7.5.1 Policy

In the drive to empower adults with intellectual disabilities to lives equal to others in society crucial discussion forums of policy makers have hotly debated the rights of these individuals to opportunities for choice and control, capacity assessments and supported decision making. Understanding an individuals' choice behaviour is a crucial but currently absent component which needs to be integrated into policies at international, national and local levels. Furthermore, further research on developing an evidence base of what 'trust' is and how it can be actualised for the person whose capacity is at question is critical to the successful roll-out of assisted decision-making (ADMB 2013). Establishing such an evidence base is as significant as assessment of capacity and functional diversity. And assessment of functional diversity should include assessments of adult aspirations.

On-going evaluation is a widely recognised requirement for service structures comprising the views and experiences of key stakeholders, for instance, individuals with intellectual disabilities, their families and relevant support persons (Cocks and Boaden 2011). This theory suggests that the opportunities individual adults have to actually interact with service policies and supports, and the degree to which their actions are congruent with their own aspirations and the requirements for their behaviour, should be a pertinent concern when attempting to make comparative evaluations across support. For example, there should be more involvement of adults with intellectual disabilities in the employment of support staff.

Service policies need to ensure that evidence is available as to what an individual wants, how that information is communicated by the person and the given response ensuring that there is flexibility and creativity afforded in differing choice situations which are tailored to meet individual needs and aspirations. While policy may provide guidelines in a particular way, future research must consider the likelihood of variations in the actual operationalization of such policy and guidelines in practice. Failing this, the credibility of the evaluation is compromised, rendering it difficult to make meaningful conclusions about what has contributed to outcomes.

7.5.2 Research

Recommendations are made to provide opportunities for education and training in research for both people with intellectual disabilities and intellectual disability researchers with specific focus on enhancing research participation, advancements in technology and the protection of data in the current digital era. People with intellectual disabilities should be included as representatives on ethics committees, or be in paid positions so as to provide advice to intellectual disability researchers on accessible research literacy. Further research should be undertaken to explore the roles gatekeepers and support persons in facilitating intellectual disability research. And by establishing an evidence base of how dual or group consent could facilitate an informed consent process for adults with intellectual disabilities would enhance inclusive research.

This substantive grounded theory can contribute to the development of an initial organising framework for future development of appropriate supports within choice situations. It is important firstly to research the current choice behaviour of adults with intellectual disabilities in a variety of contexts and settings. Further theoretical sampling within other services facilitating independent living and individualised budgets could increase the scope and density of theory, increasing its generality and relevance. More research on what adults with intellectual disabilities deem as good support to make choices is required.

Framing control underpinned by concepts of frames of reference, interpreting and positioning control which can contribute to the development of service provision that is personalised and flexible by providing a means of understanding and directing adults' individual trajectory to experiencing a satisfactory sense of control. Further exploration of this concept and its related properties has the potential to develop an outcome measurement tool which may be as sensitive to choice-making as the actual decision-making skills required by individuals to make choices.

Furthermore, this theory provides for explanations that how adults frame control influences and is influenced by their emotions and compliance behaviours. And the more congruent their actual doing is with what they are being told the more positive they are in framing control and vice versa. Further research to explicate these categories and examine these interactions is necessary to as to provide optimal support to these individuals when choices are made. It is important to determine how such guidelines as Glasser's could facilitate the incorporation of choice theory and reality therapy in the lives of people with intellectual disabilities.

This theory provides opportunities for the development of a formal grounded theory explaining ways in which adults negotiate a balance between being person-driven and other-driven as they navigate their way through imposed power structures so as to arrive at the life they want to live.

7.5.3 Education

This theory concurs with the findings of Gates and Statham (2013) that there is an urgent need to turn attention to the review and strategic planning for education in the field of intellectual disability.

This theory challenges the current relentless focus of education for adults with intellectual disabilities as a means of ensuring increasing compliance with the requirements of behaviour (Tinney et al 2014). Instead the emergent theory firmly contends that their subjective judgement of whether support offered or implemented is tailored to their individual needs and aspirations is the most influential factor in determining satisfaction with choice outcomes. For example, in challenging the role of supervision in monitoring and ensuring compliance (Hithersay et al 2014), the emergent theory shows that while supervision can maximize compliance, both through direct intervention and as a structural presence, it can also compromise emotional stability. When feeling overwhelmed by the level of supervision, for instance adults not in control of space, time and opportunity for privacy, are oppositional to what they are being told to do. Therefore, it is important to make reasonable adjustments tailored to their individual needs and outcomes when providing support to these adults (Tuffrey-Wijne et al 2014). As already observed with regard to choice situations, without understanding the extent of their experience of the choice situation, it is difficult to make meaningful conclusions regarding the contribution of support made available to the adult. Support for adults to engage in choices should be primarily determined by their aspirations and the extent to which their individual needs and circumstances are taken into consideration. Therefore education and training to promote compliance behaviours cannot be presumed to be the only option to bridge the differences between what adults are being told to do and their actual doing. Functional diversity should not necessarily be based upon specific conditions or problems, but rather on the support required to enable their engagement in choice situations. Furthermore services should personalise their efforts to support these adults based on an analysis of the individual's particular way of dealing with power dynamics.

A core recommendation of the emergent theory is the promotion of education on choice behaviour for adults with intellectual disabilities and those who support them. Specifically there is a need for both parties to engage in relationship training. Undertaking such education and training is a crucial to building trustful relationships behaviour and its significance for the person with regard to making decisions.

7.5.4 Practice

Services need to provide clear expectations and account for how their philosophies are being operationalised. Service philosophies and mission statements should include goals on 'interpersonal relations and 'autonomy' as well as 'intellectual development' and 'basic skills. There needs to be accessible, transparent, confidential complaint procedures set up for adults who use the services.

This theory has also questioned assumptions of the need to assess adult reasoning in order to determine abilities to comply with what they are being told to do (Willner 2011). The emergent theory rather advocates that their interpretation of the control they have in the choice situation should be the initial focus of the interaction.

Offering insight into how policy and legislation impacts on support, publications subsequent to this theory have the potential to inform future development of policy and subsequent supportive interventions enabling these adults to make meaningful choices.

Support persons must be fully equipped to understand not only how adults frame control in the context of individual choice situations, but also their emotions and the adjustments they make in the realities of what they actually do. People with intellectual disabilities are challenged to live their lives within the boundaries of their functional diversity while continually being told what to do, but what can doubly compound or make life more bearable are the enacting practices of those in power positions. Support persons in intellectual disability practice must be equipped with knowledge, attitudes and practices that will ensure that support is tailored to functional diversity and that their own enacting practices are communicated in a respectful way.

Many adults in this research study reported experiences of supporting peers or being supported by peers. In light of developing positive identity frames which contribute to how adults are framing control, more research in this area is recommended for ways to acknowledge and promote the positive contributions of peer support facilitated by adults in practice settings.

7.6 Study limitations

Grounded theory offers conceptual power to the researcher, facilitating the abstraction of qualitative data into conceptual theory (Glaser 2003). However, a methodology is ultimately only as good as the researcher employing it. While significant effort was invested by the researcher to increase theoretical sensitivity through reading in other fields, it is important to acknowledge that, in the early stages, the breadth, depth and comprehension of multiple theoretical codes may have been limited. The theory of aligning with the flow of control conceptualizes one pattern of behaviour. As such, it is acknowledged that adults may also be engaged in other patterns of behaviour that warrant further, future exploration. For example, other studies determining choice situations and decision-making in different countries with different societal cultural norms did not emerge as relevant to the theory of aligning with the flow of control. This is not necessarily a limitation of the study, as these concepts did not appear to have significant fit and relevance with the data obtained in this study. Instead, this has highlighted an area for further exploration through theoretical sampling. It is important to reiterate that this theory does not intend to explain adults' entire being or doing. Rather, it presents a grounded theory that accounts for and explains the continual resolving of one main concern in a substantive area. Undoubtedly, further theoretical sampling or additional research exploring individual theoretical propositions would add to, refine and modify this theory. As it is presented at this time however, it is considered sufficient, demonstrating fit, work and relevance within the health and social care arena from which it is derived. The theory itself has the potential to be expanded or refined by adding or changing concepts through further theoretical sampling. Indeed, one of the greatest strengths of the methodology wherein the emergent theory is not presented as final but as a dynamic concept to be further explored and developed. Finally, while the theory presented in this theory demonstrates the potential for conceptual generality, it is important to acknowledge that this potential must be actualised through further theoretical sampling in broader areas. The theory undoubtedly has the potential to offer a generalised explanation of the ways in which these adults manage the inherent tensions and harmonies between the ideals and realities of making choices, but it is important to remember that it has been generated within one specific substantive area only and will thus require development of a formal theory before claiming full generalised applicability.

7.7 Further possible developments

Further possible developments subsequent to the development of this theory are to:

Continue having an input into education and training of those interested in being involved in intellectual disability research.

As a member of the Irish Research Network, the researcher aspires to ensuring that adults with intellectual disabilities are recognised and employed as being experts in offering advice to intellectual disability researchers and ethics committees on research projects which affects their lives.

Establish links with Irish William Glasser Institute with a view to undertaking further research on choice behaviour of adults with intellectual disabilities.

Promote the training and resources available from the Irish William Glasser Institute to education institutions, curriculum designs and services which support people with intellectual disabilities.

Promote the significance of choice behaviour and reality therapy in the promotion of mental health especially in schools, day-services and residential and all other services supporting people with intellectual disabilities.

7.8 Concluding reflections

Over the past three decades the researcher has witnessed changes in service provision and choice opportunities for adults with intellectual disabilities. Ironically as the final concluding reflections draw this thesis to a close, concurrently in Ireland religious orders which have predominately governed services for people with intellectual disability in Ireland are dwindling. The researcher feels privileged to have shared the lives of people who lived in residential services and of those religious orders who governed services. Philosophers propagandize that for each day these individuals lived in segregated settings they were wronged by the societies in which they lived, and while duly so, scant recognition has been given to the work of those religious orders that cared for those rejected. From the experiences of the researcher, services provided though limited in resources and funding were prosperous in love, recognition and acceptance of the individuality of those who accessed services and with little materialistic possessions homely atmospheres were created and maintained whereby, religious hierarchy held vigilance.

Despite the recent recession and fiscal constraints Ireland is a country which has flourished economically, socially and culturally. But the fast pace of community life currently has consequences for many people living in silos, with some being isolated and lonely. In the current epoch of rights and empowerment few things are more important than the successful re-integration of these individual's back into their communities. And even though the pace of such change has been slow, such endeavours have created positivity in the lives of this group of people but the researcher cautions the need for love and belongingness to be balanced with equity of rights and access to services. Communities are challenged to create arenas for these individuals to network and meet, enabling them to share their unique life experiences and draw support from each other.

The researcher has valued the time spent with the adults who participated in this research study. The richness of their reports of the daily realities of making choices which they brought to research interviews offered the researcher much to learn from. From a personal perspective the researcher was astounded with the enormity of how issues of control affected the daily realities of choice for these individuals. Through the use of reflexivity the researcher developed a greater awareness not only of her impact on research participants but also of their impact on her. And surprisingly for the researcher, at times, she found herself in awe of adult participants as they reported on their responses to issues of control in their lives. Confronting her changing perceptions of what doing intellectual disability research was about the researcher questioning her assumptions that she was the research expert and instead recognising the expertise relayed by the research participants and reporting accordingly.

Professionally the researcher was challenged to question her lecture content on issues of rights to 'more choice and control' 'actively listening' and 'actually hearing' what these people are saying. Ideal theoretical components enlisted across policy, guidelines and mission statements and problem based learning scenarios on how to best to afford choice opportunities to people with intellectual disabilities in light of current support had been prominent issues for lecture discussion. But indeed, from undertaking this research study, more challenging than changing the structures currently utilised to support these individuals is to change the mind-sets both of many of these individuals and those who support them. In Ireland the rollout of the Assisted Decision Making (Capacity) Bill (ADMB 2013) is going to be a crucial element of influencing such required changes in these mind-sets. From the learning gained from the individuals in this research study the researcher firmly believes that the successful implementation of this legislation, rather than being totally dependent on capacity or functional assessments is contingent on the necessity to train and educate individuals using the legislation to understand the importance of relationships, how to establish and maintain good relationships and how to avoid breakdown in relationships when choices are made. Such requirements in education and training centre on choice theory and reality therapy, as in

understanding relationships, the importance of quality worlds, commitment to the seven caring habits and the obliteration of the seven deadly sins a framework worthy of consideration is offered.

This research study provided the researcher with a forum to write about and discuss issues pertaining to people with intellectual disabilities. This research was driven by the researcher's passion for change and a need to have a vision of how things could be improved for this group of people and their support persons. Learning to do intellectual disability research is about engaging with oneself which is reiterated in some of the key learning moments available in reflections of the researcher in this research study. As the researcher came to embrace the ways that intellectual disability touched her and learned from the voices, perspectives and experiences of the research participants, this research study has helped to create new possibilities and visions for people with intellectual disabilities and those who support them. The researcher hopes that in sharing some of her visions, passions and actions for intellectual disability research that a creative and diverse research body of intellectual disability researchers willing to continually push the limits of making the personal political will be attracted.

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Appendices

Appendix 1: Notification of Ethical Approval from Faculty of Health Sciences Ethics Committee



THE UNIVERSITY OF DUBLIN
TRINITY COLLEGE

SCHOOL OF MEDICINE
FACULTY OF HEALTH SCIENCES

Professor Dermot Kelleher, MD, FRCPI, FRCP, F Med Sci
Head of School of Medicine
Vice Provost for Medical Affairs
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School Administrator

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Ms Eileen Carey,
Shower,
Newport,
Co. Tipperary

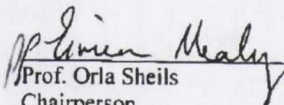
Thursday, 22 April 2010

Study: A Classical Glaserian Grounded Theory of the Processes of Consent in the Context of Life Choices as Experienced by Adults with Intellectual Disabilities Engaging in Day Services in the Midwest Region of Ireland

Dear Applicant (s),

Further to a meeting of the Faculty of Health Sciences Ethics Committee held in January 2010, we are pleased to inform you that the above project has been approved without further audit.

Yours sincerely


Prof. Orla Sheils
Chairperson
Faculty of Health Sciences Ethics Committee

Cc
Fintan Sheerin, Colin Griffiths,
School of Nursing & Midwifery,
24 D'Olier Street,
Trinity College,
Dublin 2

Appendix 2: Notification of Ethical Approval from Service Ethics Committee

To maintain anonymity the name of the service and the chairperson have been removed.

SERVICE
for Persons with Intellectual Disability
(Supported by HSE)

Central Management Office

Ms. Eileen Carey
Shower Cross
Newport
Co. Tipperary

26 May 2010

**Re: Your proposal to undertake a research project based on the
Service**

Dear Eileen,

The Research Approval's Subcommittee of the Ethics Committee has approved your proposal. You have satisfactorily responded to the queries raised.

I appreciate that you are conscious of the need for sensitivity and confidentiality but I would like to emphasise it and in addition the absolute requirement to ensure that service users or employees are not in any way identified in your course submissions.

I would also like to stress that any outcomes or evaluation results would remain the property of the [redacted] and any use that they might be put to outside the service, in terms of presentations, other than the assignment for which they are produced, would be dependant on approval being given by the Chief Executive Officer.

I acknowledge that some issues may arise from your research that can benefit the Service and in that regard I request that you keep in touch with me should any such issues arise at any time during the course of your research.

I wish you every success on your project.

Yours sincerely

CC:

XXXXX
XXXX

Date:

Dear XXXXXXXXXXXXX

My name is Eileen Carey. I am a PhD student in Trinity College Dublin. My supervisors are Dr. Fintan Sheerin and Mr. Colin Griffiths, School of Nursing and Midwifery, Trinity College Dublin. I have been granted ethical approval by both Trinity College and XXXX ethics committees to undertake a research study. I am requesting your permission to access XXXXXXXX day service and name of an associated gatekeeper.

The title of the study is: *A grounded theory of the processes of consent in the context of life choices as experienced by adults with intellectual disabilities engaging in day services in the Midwest region of Ireland.*

The Mental Capacity Act (2005) and the Scheme of the Mental Capacity Bill (2008) assumes that all citizens (including people with intellectual disabilities) have the capacity to make decisions unless proven otherwise. Such decision making encompasses the concept of consent, that being, individuals have opportunities to access choices, and make decisions. However, there is a dearth in the literature from an Irish perspective in relation to how people with intellectual disabilities experience choice. Using a classical Glaserian grounded theory approach this research study proposes to develop a conceptual and theoretical framework of how adults with intellectual disabilities make choices. Through developing a theory explaining how adults with intellectual disabilities make choices, it is believed that current opportunities and challenges identified by the adults themselves will help to inform policy, society, education and practice.

Ten adults from the community based day service of your organisation will initially be invited to participate in the study. In grounded theory theoretical sampling is used by researchers, therefore the researcher may seek access to further potential participants to add to the fullness of the understanding of the emergent concepts. Data collection will involve semi-structured interviews. Ethical principles will be upheld throughout the study. Anonymity and confidentiality of participants will be taken into consideration when storing information relating to the study. Participation in the study is voluntarily. Adults will be informed that they are not obliged to participate in the study and also that they may withdraw at any time with no affect to their services or legal rights.

A report of the findings of the study will be made available to the participants and to the service providers in accessible formats.

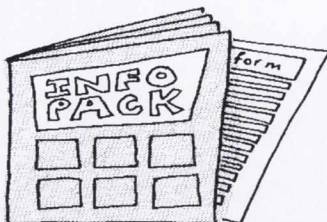
If you have any further queries, I would be pleased to discuss this study with you

Hoping to hear from you shortly,

Kind regards

Eileen Carey
Contact: xxxxxx

Invitation to information session



Project: What happens when adults with intellectual disabilities agree and disagree to life choices?

Background:

Adults have the right to make life choices. What is really important is to explore what happens when adults agree and disagree to life choices.

About the study

My name is Eileen Carey. I am a PhD student at Trinity College Dublin. I am interested in your experiences of how you agree and disagree to life choices. By exploring what happens when you agree and disagree to life choices, I will be able to identify what works well for you and what does not work well for you.

**You can say YES to be in this study
or
you can say NO if you do not want to be in the
study.**

**If you say YES and want to be in this study please
come to the
Information Session**

ON: _____
IN: _____
AT: _____

**Appendix 5A About the Study
(Option 1)**

Project: What happens when adults with intellectual disabilities agree and disagree to life choices?

Background:

Adults have the right to make life choices. What is really important is to explore what happens when adults agree and disagree to life choices.

About the study

My name is Eileen Carey. I am a PhD student at Trinity College Dublin. I am interested in your experiences of how you agree and disagree to life choices. By exploring what happens when you agree and disagree to life choices, I will be able to identify what works well for you and what does not work well for you.

What happens if I agree to be in the study?

Meeting with Eileen

I will meet with Eileen in a private place
I can talk to Eileen about what happens when I agree and disagree to things in my life.

These things can be about:

My Rights

My Work

My Friends

My Leisure

My House

My Choice

My Health

MY Money

Access

Or anything else that happens to me that I agree or disagree with

Eileen will meet me where I want to meet and at a time that suits me

The meeting will last about an hour

I can have a break or stop the meeting if I want to

Meetings will be recorded

Eileen will keep a record of what I say

My name will not be on the record

Eileen's supervisors will listen to what I say but will not know my name

I will meet with Eileen to listen to my recording

I can make changes to my recording if I want to

Eileen may come back to meet with me next year

My Information

My information will be locked in Eileen's office where only Eileen can get it

What I tell Eileen will be locked in her office in a file without my name on it

The information may be published but people will not know my name

Being in the study:

Taking part in this study gives me a chance to say what I want

Telling Eileen things about myself may make me feel happy or sad

I know that if I tell Eileen about nasty things that happened to me Eileen will have to tell the XXXXXXXX

I know that I can say NO at any time and stop taking part in the study.

What happens if I want to stop being in the study

I do not have to take part in this study

If I take part in the study, I know that I can stop being in the study at any time with no affect to my services or legal rights

I can tell XXXX or Eileen if I want to stop being in the study

What happens now

Eileen will be available at (time) (Place) each day for one week to answer any questions I have before I agree or disagree to be in the study.

I will receive a report of the study in a format I understand.

Thanks

Eileen

Phone me: 202422 (0863824001)

About the Study (Option 2)



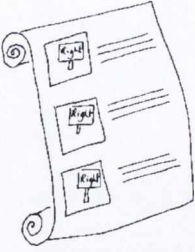
Project: What happens when adults with intellectual disabilities agree and disagree to life choices?

Background:

Adults with Intellectual Disabilities have the right to make life choices. What is really important is to explore what happens when adults agree and disagree to life choices.

About the study

My name is Eileen Carey. I am a PhD student at Trinity College Dublin. I am interested in your experiences of what happens when you agree and disagree to life choices. By exploring what happens, I will be able to identify what works well for you and what does not work well for you.



Permission has been given for this study
by the _____ Research Ethics
Committee
Information which I will give Eileen will
only be used for this study
This information may be published

YES



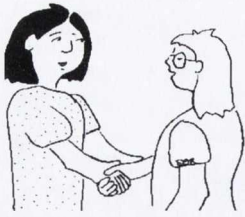
To be included in the study I need
to:

✓ Want to take part in the study

NO



I cannot be in the study if I:
× Do not wish to take part in the
study

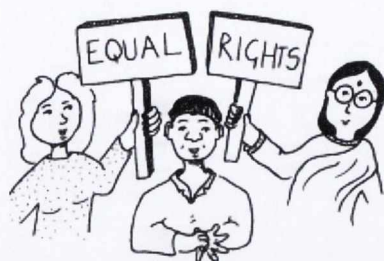


**Eileen will meet with me
I will talk to Eileen about what
happens when I agree and disagree
to things in my life.**



**Eileen wants to listen to my ideas
about what happens when I agree
and disagree to life choices.**

These ideas can be about my:



Rights



Work



Friends



Leisure



Housing



Choices



Health

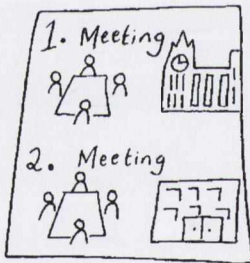


Money

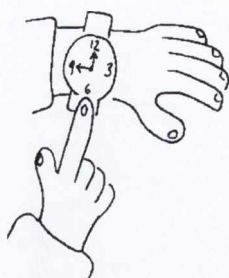




Access



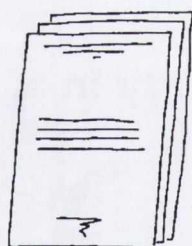
**Eileen can meet with me at a private
place of my choice**



at a time that suits me



I can stop the meeting if I want to



**Meetings will be recorded
Eileen will keep a record of what I
say
My name will not be on the record
Eileen's supervisors will listen to
what I say but not know my name
I can meet with Eileen to listen to my
recording
I can change something if I want**



**What I tell Eileen will be locked in a press in her office
The file will not have my name on it
The form that I sign my name on will be locked in another press
Eileen will have the key to this press.
My information will be kept on a computer. Only Eileen will have the password for the computer**



I will receive a report of the study in a format I can understand



Taking part in this study gives me a chance to say what I want



**Telling Eileen things about myself
may make me feel happy or sad**



**If I tell Eileen about nasty things
that happened to me I know that
she has to report this to the
Administrator/Manager XXXX**



**I can say NO at any time if I do not
wish to be in the study. This will
not affect my services or legal
rights**



**If I wish to have more information
I can ask _____**



Questions??

**Eileen will be available at (time)
(Place) each day for one week to
answer any questions before I
consent or refuse to be in the study.**

Phone Eileen: XXXXX

**Thank you
Eileen**

Informed Consent Form (Option 1)

Project: What happens when adults with intellectual disabilities agree and disagree to life choices?

Background:

Adults with Intellectual Disabilities have the right to make life choices. What is really important is to explore what happens when adults agree and disagree to life choices.

About the study

My name is Eileen Carey. I am a PhD student at Trinity College Dublin. I am interested in your experiences of what happens when you agree and disagree to life choices. By exploring what happens, I will be able to identify what works well for you and what does not work well for you.

Please tick YES if you agree and No if you do not agree

I will have a meeting with Eileen at a time and place that will suit me	Yes	No
I can take a break when I want		
I can stop the meeting if I wish to do so		
Eileen will meet with me so that I can read/hear what I said at our meeting	Yes	No
I can make changes if I want		
Eileen may come back to have another meeting with me		

Informed Consent:

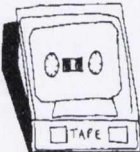
I have read and have had read to me the information about the study	Yes	No
I have discussed the information with Eileen Carey	Yes	No
My questions have been answered	Yes	No
I want to be in the study	Yes	No
I know that I can stop being in the study at any time	Yes	No

Participant
Signature_____Date:_____

Address: _____Tel:_____

If the participant is unable to provide a signature, informed consent will be obtained in a format most suitable to the participant. A written record of the consent interview will be kept by the researcher.

Participant to tick Informed Consent Format which he/she wants:

		Tick
Paper copy ✓ for Yes × for NO		
Recording ☐ for Yes × for NO		
Other		

Support persons Declaration: I have had explained to me the purpose and procedures and possible consequences associated with this study. I believe this participant understands this study and is freely giving consent to participate

Supporters
Signature _____ **Date:** _____

Researchers Declaration:
I have explained the purpose, procedures and possible consequences associated with this study to this person. I have answered any questions. I feel this participant understands this study and is freely giving consent to participate.

Signature of
Researcher _____ **Date:** _____

Informed Consent Form (Option 2)



Project: What happens when adults with intellectual disabilities agree and disagree to life choices?

Background:

Adults with Intellectual Disabilities have the right to make life choices. What is really important is to explore what happens when adults agree and disagree to life choices.

About the study

My name is Eileen Carey. I am a PhD student at Trinity College Dublin. I am interested in your experiences of what happens when you agree and disagree to life choices. By exploring what happens, I will be able to identify what works well for you and what does not work well for you.



I have read/have had read to me the information on this study



I have discussed the information with _____ and Eileen

I am satisfied that my questions have been answered.

I know that other people may read what I say

These people will not know my name



I know that I can stop being in this study at any time.

This will not affect my services or legal rights



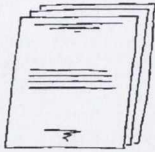
YES I want to be in this study

Participant
Signature _____ Date: _____

Address: _____ Tel: _____

If the participant is unable to provide a signature, informed consent will be obtained in a format most suitable to the participant. A written record of the consent interview will be kept by the researcher.

Participant to tick Informed Consent Format which he/she wants:

		Tick
Paper copy ✓ for Yes x for NO		
Recording ✓ for Yes x for NO		
Other		

Support persons Declaration: I have had explained to me the purpose and procedures and possible consequences associated with this study. I believe this participant understands this study and is freely giving consent to participate

Supporters
Signature_____ **Date:**_____

Researchers Declaration: I have explained the purpose, procedures and possible consequences associated with this study to this person. I have answered any questions. I feel this participant understands this study and is freely giving consent to participate.

Signature of
Researcher_____ **Date:**_____

Project: A classical Glaserian grounded theory of the processes of consent as experienced by adults with intellectual disabilities engaging in day services in the Midwest region of Ireland.

Background:

Adults with intellectual disabilities have the right to make life choices. What is really important is to explore what happens when these adults agree and disagree to life choices.

Making the interview accessible:

- 1. In keeping with Guidelines for Researchers when Interviewing People with intellectual disabilities (NDA, 2005) the researcher will identify herself, strive to establish a good rapport with the interviewee and use incidental conversation to start the interview.
- 2. Best communication practices will be adopted by using websites such as www.easyinfo.org.uk and www.bris.ac.uk/Depts/NorahFry/Plainfacts; www.changepeople.co.uk/ . These websites focus on how to make information more accessible for people with Intellectual Disabilities e.g. using the words (agrees and disagrees rather than consent and refuses to consent).
- 3. By using images which the person uses in the context of his/her life choices
- 4. By discussing photos deemed important by the participant in the context of their life experiences

In keeping with a Grounded Theory approach the interview topic guide is kept general and open. Grounded theory interviews rely on the emergent data to stimulate and generate discussion on the topic as relevant and important to participant

Ice breaking questions:

- How is you day going?
- Tell me about yourself?

Questions	
What are your dreams/goals?	How do you tell people what you want to do?
What are you doing to make those goals happen?	What happened when you.....?
What is helping you to achieve those goals?	What information did you get in relation to?
Is there something that you are not doing that you would like to do?	What format was the information in?
Tell me about it?	How was the information presented?
What happens when you do not want to do something that you are asked to do?	What did you understand about the information as it relates to...? () life choice?
	How did you agree or disagree to..... () life choice?
	What is your previous experience in relation to () life choice?
	How did you agree or disagree to..... () life choice?
	Tell me about your Individual Programme Planning meeting?

Finishing questions:

- What would you do if you won the lottery?

Follow-up

Thank you – I will return with the recording of the interview so that you can clarify what you have said and add anything else you wish to add.

Biographical details

Code:

1. Demographic data:

2. Gender: M F

3. Age: 18-23yrs 24-30yrs 31-37yrs
38-44yrs 45-51yrs 52-58yrs 59-65yrs

4. Duration of time in current service: 0-2yrs 2-4yrs 4-6yrs
6-8yrs 8-10yrs over 10yrs

5. Separate employment in conjunction with service:
.5 day 1day 2 days 3days 4 days

6. Plan of Care

Individual Programme Plan	
Training Plan	
Lifestyle Plan	
Person Centred Plan	
Health Action Plan	
Other	

7. Paid work:
Contract work: Other income:

8. Disability Allowance:

9. Group membership:
Rights Group: Advocacy Group: Other:

10. Committee member:
In the day centre: In a residential centre: In the community:

Name of Committee:

access achievements **adjusting agency** another authority autonomy awareness
belong best burden care carrying **change**
choices communication conforming connections content
control coping current declining **depending**
devaluation differing directives discussion environment **exclusion**
expected experiences express failure family **fear** feelings filtered finding
fit general **getting** greater health independence
information ingrained instructional interest intrusion knowing **lacking**
learning levels life limited live made maintaining **making** managed match
meeting mobility **needs** new non obedience obey occurs opportunities
options orders organisation **others** parents perceived **personal**
positions power privacy provision receiving requested **results**
routine rules **seeking** self sense silencing social stress
support telling thing time told **Wanting**
within

What is the main issue of concern? Word frequency query

The following presents extracts from the NVivo 10 which facilitate explanation of the theory: Shaping compliant autonomy through controlling hierarchies

Nodes

Name	Sources	Referenc	Created On	Created B	M
Shaping compliant autonomy through controlling hiera	0	0	28/01/2013 14:2	EC	
Choice Fittings	150	150	15/03/2013 10:	EC	20/
Compliant Autonomy	0	0	19/03/2013 12:	EC	20/
Choice Shapers	0	0	13/03/2013 13:	EC	20/
Choice Manipulators	0	0	20/03/2013 11:	EC	20/
Choice Regulators	0	0	20/03/2013 11:	EC	20/
Agency Informally Controlled	14	14	20/03/2013 12:	EC	20/
Arranged choices	74	77	20/03/2013 11:	EC	15/
Agency Formally Controlled	18	18	20/03/2013 12:	EC	20/
Agency Informally Controlled	0	0	20/03/2013 12:	EC	20/
Agentcontrolled	0	0	20/03/2013 11:	EC	18/
Choice Denial	68	68	20/03/2013 12:	EC	20/
Pearranged	58	58	20/03/2013 12:	EC	20/
Selective Choices	1	1	20/03/2013 12:	EC	20/
Choice Enablers	0	0	20/03/2013 12:	EC	20/
Choice Stagers	10	10	13/03/2013 13:	EC	20/
Choice Deterrents	0	0	20/03/2013 14:	EC	20/
Choice Enhancers	0	0	15/03/2013 15:	EC	20/
Choice Fixtures	0	0	20/03/2013 13:	EC	20/
Choice Situators	0	0	20/03/2013 13:	EC	20/
Mindset Fitting	0	0	20/03/2013 13:	EC	20/
Mindsets	0	0	20/03/2013 13:	EC	14/
Choice Impeders	0	0	15/03/2013 15:	EC	20/
Choice Motivators	0	0	13/03/2013 13:	EC	13/

Automating Regulation

Nodes

Name	Sources	References	Created On	Created By	Modified O
Automating regulation	0	0	28/01/2013 14:23	EC	25/03/2013
Choice Automaters	151	151	15/03/2013 10:40	EC	26/03/2013
Complying	0	0	21/03/2013 18:35	EC	25/03/2013
Control	4	4	21/03/2013 10:14	EC	03/12/2014
Choice Regulators	0	0	13/03/2013 13:31	EC	25/03/2013
Formal Regulation	85	87	21/03/2013 09:14	EC	21/03/2013
Informal Regulation	14	14	21/03/2013 09:14	EC	21/03/2013
Choice Situators	10	10	13/03/2013 13:30	EC	21/03/2013
Choice Deterrents	34	34	20/03/2013 14:14	EC	20/03/2013
Beliefs in Lackin	37	37	21/03/2013 13:10	EC	21/03/2013
Delayed thinking	1	1	21/03/2013 13:10	EC	13/03/2013
Emotional Stress	0	0	21/03/2013 13:10	EC	21/03/2013
Limited thinking	8	8	21/03/2013 13:10	EC	11/03/2013
Negative Thinkin	0	0	21/03/2013 13:10	EC	13/03/2013
Rigid Thinking	5	5	21/03/2013 13:10	EC	07/03/2013
Choice Motivators	0	0	13/03/2013 13:30	EC	13/03/2013
Choice Enhancer	0	0	21/03/2013 11:36	EC	21/03/2013
Emotional Wellb	0	0	21/03/2013 10:54	EC	21/03/2013
Choice Orientators	0	0	20/03/2013 13:54	EC	21/03/2013
Choice Significa	127	128	21/03/2013 18:33	EC	21/03/2013
Status	0	0	21/03/2013 18:33	EC	21/03/2013

Fitting Systems by Automating Controlled Choices
Nodes

Name	Sources	References	Created On
Fitting Systems by Automating Controlled Choices	0	0	28/01/2013 14:23
Choice Automating	0	0	06/04/2013 13:03
Actual Automating	0	0	19/04/2013 17:30
Fractional Automating	0	0	19/04/2013 17:30
Nominal Automating	1	1	19/04/2013 17:30
Primal Automating	0	0	22/04/2013 13:59
Choice Regulators-Regulatory system	0	0	13/03/2013 13:31
Filters	8	8	06/04/2013 15:29
Choice Filtering	85	87	10/04/2013 09:55
Control Filtering	0	0	10/04/2013 10:01
Directive Filtering	115	115	08/04/2013 16:23
Information Filtering	0	0	24/04/2013 10:35
Supervision Filtering	36	36	24/04/2013 11:43
Mindset Fitters	0	0	10/04/2013 11:22
Operators	14	14	21/03/2013 09:14
Strippers	0	0	23/04/2013 11:55
Timers	50	50	19/04/2013 17:18
Choice Situaturs-Organismic System	0	0	13/03/2013 13:30
Being	164	169	24/04/2013 13:55
Cognitive Status	3	3	24/04/2013 13:55
Functioning Status	0	0	24/04/2013 13:55
Material Status	0	0	24/04/2013 13:55
Physical Status	10	10	24/04/2013 13:55
Psychological Status	4	4	24/04/2013 13:55
Social Status	0	0	24/04/2013 13:55
Fitting	10	11	24/04/2013 13:57
Current Fitting	0	0	24/04/2013 14:53
Difficulties Fitting	48	49	24/04/2013 14:01
Mode of Fitting	0	0	25/04/2013 09:48
Sense of Fitting	89	96	24/04/2013 13:58
Seeking	129	131	24/04/2013 13:55

The above presents an extracts of initial efforts of open coding and concept development. The next extract is from a submitted draft of the emerging theory *Fitting Systems by Automating Regulation*:

Extract from Submission to Dr. Judith Holton on 17.06.13

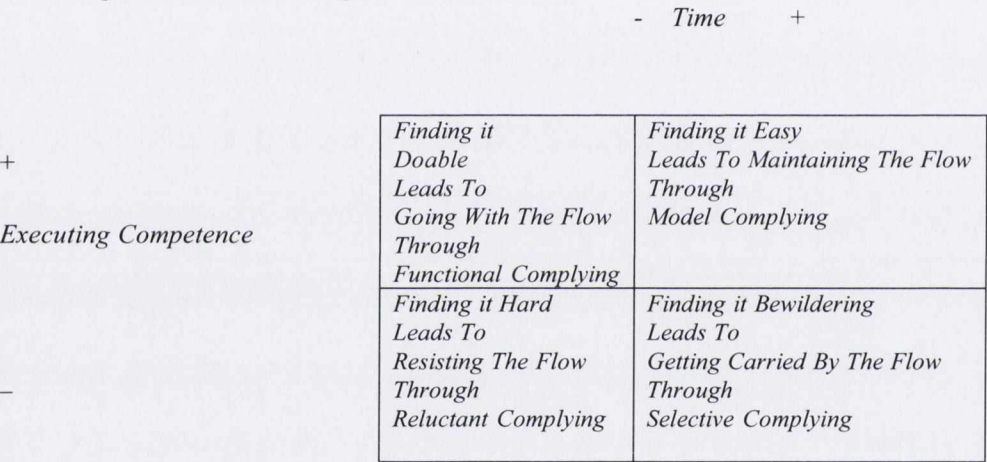
Having regulation in their lives emerges as a main concern for the research participants. Regulation is the actions undertaken by those in power positions which control how the agents make choices. Those in power positions can be peers, family, service providers and relevant external agencies, but the main focus for the agents is the regulation, which accompanies the service provision. The agents engage in fitting the organismic system (self) to the regulatory system (regulation). The regulatory system incorporates *Specifications* (*Valuing, Screening*), and *Mechanics* (*Mindset Fitting, Autonomy Filtering, Identity*

Decorating and Motion Setting). In fitting systems the agents engage in *Automating Regulation*. There are different ways in which the agents engage in *Automating Regulation*. *Automating* is explained as *Primal Automating*, *Nominal Automating*, *Fractional Automating* and *Actual Automating*. This chapter firstly describes *Regulation* and then explains how the agents engage in *Automating Regulation*

Automating
Automating is explained as *Primal Automating*, *Nominal Automating*, *Fractional Automating*, *Optimal Automating* and *Actual Automating*. *Primal Automating* is explained through the concepts of *Functioning Competence* of the agent. The state of *Primal Automating* is both influenced by and drives subsequent *Automating* responses of the agent as the agent interacts with the regulatory system with regard to the choice to be made.

Functioning Competence is explained as: *Cognitive Competence*, *Emotional Competence* *Physical Competence*, *Pacing Competence*, *Physical Competence* and *Social Competence*.

Functioning Competence is a property of *Automating*. *Functioning Competence* impacts on the *Executing Competence* of the agent with regard to the choice to be made. Figure 1 demonstrates how a high or low degree of *Executing Competence* affects levels of *Compliance* and across time, gives different patterns of *Automating*.



Extracts taken from email correspondence from Judith 28.06.13
 The feedback from Judith which shaped the direction of the theory:
 “.... you have certainly moved from the descriptive to the conceptual but it is perhaps a bit too abstract and dense for the reader who is being introduced to your theory.
 - I really don't get 'automating regulation' - again feels very mechanistic - what is automated?
 Is 'aligning' a better word?

I wonder if you aren't trying to do too much? Whether all of the concepts highlighted in your draft are needed to explain the main concern and how it is processed by the participants. There are many concepts (in italics) without any elaboration/explanation. If you attempt to explain all of these you will be really bogged down and the density of your theory will be too much. Also, it seems you are trying to present the theory from both the 'agents' perspective and the service providers perspective. This may be part of the confusion that I am feeling in trying to work my way through the theory - they have different main concerns and therefore different latent patterns to explain how the main concerns

are resolved. Perhaps you need to pick one - agents or service providers - or separate the theories into two chapters - one chapter devoted to explaining the latent pattern for each group?

You have done some phenomenal work in conceptualizing some very challenging data. It is now just the importance of bringing the theory(ies) to life with parsimony and by lightening up the level of abstraction."

On reading the feedback, I immediately recognised that 'aligning' was a concept that could have workability within the emerging theory but I needed to go back to the data and my memos. What was a relief was that I was writing two theories which had been adding to my confusion. Based on the principle that I had set out to focus on writing a theory explaining the latent pattern of behaviour as presented by the adult participants who had volunteered to be in this research study, I decided to focus on the main concern, as identified by the research participants, and to explain the latent pattern of behaviour used by this group to resolve the main issue of concern. I revisited the data and memos accordingly. The next stage of theory development which emerges as Aligning with the flow of control can be seen in another extract from the theory *aligning with the flow of control* which was submitted for advice to Dr. Judith Holton:

Aligning with the flow of control

It is becoming evident that adults respond to the issue of having control in controlling environments by aligning with the flow of control. This theory provides an explanation of the latent pattern of behaviour of aligning with the flow of control which adults with intellectual disabilities engage in as they respond to how they experience the choices in their lives. There are differences in the way that adults respond when aligning with the flow of control. Adults can engage in *embracing the flow of control, going with the flow of control, getting carried by the flow of control* and *resisting the flow of control*. The following presents a synopsis of *getting carried by the flow of control*.

Getting Carried By the Flow

When an agent has beliefs of greater external control, (*not being able to control, selective controlling, selective supervision*), the agent experiences selective choices and a dependent mind-set exists. The dependent mind-set of the individual impacts on how the individual responds to the flow of control. An agent who has beliefs of greater external control engages in *getting carried by the flow*.

Getting carried by the flow when a dependent mind-set engages in *selective complying*
Dense regulation exists when the agent either finds it difficult to fully understand or follow through the expectations associated with the regulation. *Discerning dense regulation* has properties of *discriminatory knowing* and *selective thinking, selective complying and emotional preserving*. *Discriminatory knowing* has properties of *false knowing partial knowing expectation obscurity*. *Selective thinking* has properties of *insufficient thinking*. *Emotional preserving* has properties of *acquiescence, fear avoidance apologising*. *Selective complying* has properties of *indebted complying partial complying and submissive complying*

Based on a draft of work submitted from which the above is an extract the following is an email correspondence from Judith Holton 25.09.13

"....Overall I like what you have done here – your theoretical coding clearly explains the different responses that individuals adopt to align with the flow of control. I love the concept of flow of control! And 'aligning' clearly explains the varied responses.

As you continue to write your thesis chapters, remember to balance the abstract concepts – of which there are many in your theory – with concrete illustrations that nest your theory in the substantive area – important especially for practitioners to see the relevance of your theory in its practical application to their work."

At this stage of the writing the theory I initially went to write the theory as a typology but experienced further difficulties and confusion. I found that the theory in its totality was not accounted for within the typology. I returned to Barney's books on theoretical coding seeking to an appropriate theoretical code. At this stage I grappled with incorporating the use of a binary opposite theoretical code for

Service User Realities and Directive Regulation, with a typology to write the theory while. I wrote the theory at a conceptual level with footnotes indicating the relevant field note and memos. As well as support from my supervisors having the opportunity to have further contact with Dr. Judith Holton facilitated the explanation of the emergent theory.

Extract of theory sent to Judith on 12.05.14 on Aligning with the flow of control

Aligning with the flow of control is the core category of the theory and conceptualizes the means through which Directive Regulation is either deconstructed or reinstated while service users are seeking to have control over factors influencing the choice being made while Connecting Emotional Stability and Adjusting Compliance within the boundaries of Service User Realities. Directive Regulation and Service User Realities are conceptualized as binary opposites. While Directive Regulation conceptualizes what is expected of service users, Service User Realities determine what service users can actually do in the daily realities of making choices. Directive Regulation defines the boundaries stipulating the expected behaviour of service users, conveyed by those in power positions to those in subservient positions and categorized by concepts (External Directives, Support Ethic, and Agency Directives). And Service User Realities define the boundaries of the actual service user behaviour conceptualized as Regulated Choices, Service User Engagement and Actual Performance. A sub-core category of Framing the Flow of Control conceptualizes service users continual interpretation of Directive Regulation and has consequences for the direction of Aligning with the flow of control, so instigating consistent or changing states of equilibrium between Directive Regulation and Service User Realities.

Extract of email correspondence from Judith Holton 15.05.14

"- your paragraphs are very long. Try breaking them up into shorter sections. - several of your concepts are labelled with very managerialist terms (e.g. service user realities, directive regulation, regulated choices, etc.) and this is a bit unexpected when your area of research is so a human-centred. Are these terms commonly used in your field? Or, are there more humanistic labels that would tie your theory more closely to your substantive area? Remember, the goal is to develop a substantive theory and others in your field should be able to relate readily to it. If you use concepts that are too formal/abstract, it will miss this important substantive grounding (i.e., they won't get it)."

Email correspondence from Dr. Tom Andrews 07.07.14

".....It seems as if you have two competing TCs which will confuse you and the reader. One will predominate. It might be that the typology you refer to fits better within the sub-core category of "framing control". There may well be a typology or range, ranging from resisting the flow to embracing it. Think carefully about how the categories relate to each other. You might need to change them around as suggested above. This is not at all unusual in GT. How does idea of resisting the flow of control fit with the core category if they are concerned with aligning? The binary opposite of being told what to do is not being told what to do"

With regard to the above feedback I was challenged to return to theoretical coding and to focus on writing the theory in a more simplistic way which would be understood by people in the substantive area. The following is an extract from NVivo on *aligning with the flow of control*:

Nodes

Name	Sources	References	Created On
Aligning The Flow of Control	0	0	28/01/2013 14:23
Adjusting Compliance	0	0	04/09/2014 15:49
Dissentious Complying	547	1247	04/09/2014 15:51
Functional Complying	333	829	04/09/2014 15:55
Model Complying	0	0	04/09/2014 15:55
Selective Complying	135	187	10/12/2014 12:06
Being Told What To Do	834	2131	07/06/2013 09:16
Communication Directives	0	0	28/11/2013 14:20
External Influences	0	0	19/11/2013 10:04
Rules	119	198	10/12/2014 17:16
Connecting Emotional Stability	0	0	04/09/2014 16:21
Emotional De-Stabilizing	531	1205	04/09/2014 16:21
Emotional Preserving	527	1369	10/12/2014 11:25
Emotional Protecting	226	319	10/12/2014 11:46
Emotional Stabilizing	154	511	10/12/2014 12:11
Framing the Flow of Control	0	0	04/09/2014 15:45
Formulating Frames of Reference	0	0	04/09/2014 15:46
Interpreting The Choice Situation	0	0	04/09/2014 15:46
Positioning Beliefs of Control	0	0	04/09/2014 15:46
What Adults Actually Do	0	0	04/09/2014 15:41
Adult Engagement	0	0	04/09/2014 15:45
Functional Diversity	0	0	04/09/2014 15:44
Domains of Functioning	258	721	10/12/2014 13:39
Aesthetic Acceptance	0	0	10/12/2014 14:44
Cognitive Intellectualising	0	0	11/12/2014 09:43
Materialistic Wellbeing	54	64	10/12/2014 14:41
Movement Synchronization	0	0	11/12/2014 09:40
Physical Wellbeing	5	5	10/12/2014 14:39
Psychological Wellbeing	4	4	10/12/2014 14:40
Social Relating	0	0	10/12/2014 14:42
What Adults Are Able To Do	0	0	10/12/2014 11:48
What Adults Want To Do	0	0	10/12/2014 11:48
Support Experience	48	48	04/09/2014 15:42
Arranged Choices	0	0	10/12/2014 14:02
Consultation	0	0	12/12/2014 12:16
Getting Facilitative Support	0	0	12/12/2014 10:51
Lacking Facilitative Support	0	0	10/12/2014 14:02
Monitoring	0	0	12/12/2014 10:49
Resources	0	0	12/12/2014 12:30

The above presents a final version of the NVivo program on the emergent theory of aligning with the flow of control. The following section presents an example of an emergent concept.

Wanting was an initial open code identified and from the early stages of theory development it was clear that adults were clearly able to articulate examples of what they wanted to do. When undertaking the constant comparative method it became obvious that there were similarities and differences in adult experience of *wanting* and so the concept of *what adults want to do* emerged. For example, *wanting out* and *wanting independence* has greater significance for some adults than it has for others. In writing further memos explanations of *what adults want to do* emerged as strongly related to physical, psychological, material, social, movement, cognitive domains as these were the most common issues arising from the adults explanations. These domains were initially grouped as *status*, *state of being* and then *functioning competence* and later grouped under the concept *domains of functioning*. Adults presented with a diverse variety of functioning with regard to each of the *domains of functioning*. This diversity was captured in the concept of *what adults are able to do* explained through adults reported experiences of *finding it hard*, *finding it difficult*, *finding it doable* and *finding it easy*. When *what adults are able to do* is congruent with *what adults want to do* a positive synergy is created for *functional diversity* and visa versa when *what adults are able to do* is not congruent with *what adults want to do* the synergy for *functional diversity* is lessened. Writing further memos on *what adults want to do* and *what adults are able to do* while adding to the boundaries of the concept of *functional diversity*, when combined with *adult engagement* and *support experience* facilitated the emergence of the concept of *what adults actually do*.

Appendix 10: Memos and field notes relevant to mind-sets

Memo 356 Mindsets

Pragmatic mind-sets occur for those who experience a sense of *pragmatism*. *Pragmatic mind-sets* occur when they have liberating *freedom to choose*, and what they are *actual doing* is compatible with what they are *being told*. *Pragmatic mind-sets* occur when they have greater *freedom to choose* and sufficient *functional diversity* and having *support* has consequences for those *finding it doable* to comply with what they are *being told*. Those who have *pragmatic mind-sets* are more likely to be *tracking transparency*. *Pragmatic mind-sets* occur when *support* is adequately meeting their *aspirations* and *functional diversity*. Those who experience more *pragmatic mind-sets* experience greater *mind-set harmony*, are gaining trust and are more likely to engage with *support*.

An example of a pragmatic mind-set:

Pragmatic mind-sets
FNID26.01.12.P6.1.24.12:00 practical reasoning
P6 wants to get married in time. She currently has a boyfriend whom she meets on a regular basis. She goes on some day trips to meet some of his family. She knows her boyfriend for two years and says that down the line when would get married. She does not wish to get engaged this year saying that it's a bit too soon to get engaged. She envisages that they will get engaged in the future.

Independent mind-sets occur when they experience a sense of *independence*. *Independent mind-sets* occur when they have full *freedom to choose*, as what they are *actual doing* is compatible with what they are *being told*. *Independent mind-sets* occur when they have full *freedom to choose* and *functional diversity* which leads to them *finding it easy* to comply with what they are *being told*. Those who have *independent mind-sets* are more likely to be *targeting set practices*. *Independent mind-sets* occur when *support* is adequately meeting their *aspirations* and *functional diversity*. Those who experience more *independent mind-sets* experience greater *mind-set harmony* when their *aspirations* are congruent with what they are *being told* and they are *trusting* of those in power positions and are more likely to engage with *support*. An example of *independent mind-set*:

Independent mind-set
FNID06.02.12.P6.1.60.69:60 independence
P6 articulates her rules for planning holidays. Both herself and her husband have travelled to England to see his sister. She articulates places in Ireland where herself and her husband have been on holidays and states that "we sit down andsit down.....see what finances you have and then where you want to go.....you can't book anything if you can't afford it" "Dublin not a place for holidays, its more a place for concerts.... Galway or Killarney is for holidays" There is no agency involvement in planning the choice of where to go on holiday

Dependent mind-sets occur when they experience a sense of *dependence*. *Dependent mind-sets* can occur when they have selective *freedom to choose*, and their *actual doing* is often challenged to meet the expectations of *being told*. Those who have *dependent mind-sets* are more likely to have *bounded understanding*. Those who experience more *dependent mind-sets* can experience greater levels of mixed mind-set harmony. The more dependent they are on others for support, the more they either fit with *being told* or the more expectations of *being told* fits with their *aspirations* and *functional diversity* which has consequences for more mind-set harmony. As when they perceive that *support* is meeting their needs, they experience more mind-set harmony. They experience *mixed mind-set harmony* when there is a disjoint between their *functional diversity* and *aspirations* and what those in power positions assume are the needs and aspirations of the individual. Mixed mind-set harmony is more likely to occur as those *seeking trust* will move more frequently from states of trust to states of mistrust as their perceived needs and aspirations are either met or not met. Those who experience mind-set harmony are more trustful of those who support or assist them in meeting their needs and achieving their aspirations. These adults are comfortable with the *support* offered.

An example of dependent mind-set

FNID27.01.12.P11.1.17.27:00 dependence

P11 depends on her mum to make her hair appointment. She knows when her hair is getting long and thinks about when she asks her mum to make an appointment "I will ask my mum to book an appointment for next Thursday". She is familiar with the routine that her mum organises for her hairdresser to cut her hair.

FNID23.01.12.P1.1.6.6:26

P1 is not managing her own medication-she is given medications by the houseparent. When asked if she would like to manage her own medication she procrastinates providing an immediate yes or no but rather discusses the implications if somebody happened to take the medication in error. She talks a lot about the possibility of somebody taking the medication and she appears scared that this would happen to her and her medication if she were to manage it herself. She is of the understanding that the health board has implemented such policies which subsequently have rules which have to be abided by. She has learned to abide by the rules even if she does not agree with them.

Oppressed mind-sets occur when they experience a sense of oppression. Oppressed mind-sets can occur when they are lacking in freedom to choose, and their actual doing is incompatible with expectations of being told. Conversely, oppressed mind-sets can occur when they have greater freedom to choose but when expectations of being told are higher than their functional diversity and in the absence of support they are consequently finding it hard to comply with being told. Those who experience more oppressed mind-sets experience greater mind-set disharmony and are distrusting of those in power positions and are least likely to engage with support. They experience mind-set disharmony when their aspirations are competing with or in opposition to being told. Those who have oppressed mind-sets are more likely to be detecting powerlessness when interpreting choices. An example of an oppressed mind-set:

FNID30.01.12.P9.1.24.23:16 Oppression

P9 feels that she has been put into community residential services against her will. She blames the social worker for putting her into community residential services. She feels that the social worker twisted and turned the story so that instead of being a part time community residential service user, she now finds that she is a full time community residential service user. This is what she does not want. She feels that the social worker went to the community residential services manager and told him that this is what she wanted, when this is what she did not want. She considers going to the community residential services manager "to get out of this fucking dump" but she does not know how to access the manager. She currently complies with the rules and regulations, saying "it's not good for me". She gets extremely upset when discussing how the choice has been made to place her against her will in full time community residential care setting and P9 threatens to kill herself; to throw herself out of the window

Appendix 11: Summary of the contribution of the theory aligning with the flow of control

	Confirmed knowledge claims	Challenged existing knowledge claims	Added new knowledge
Policy and legislation	This theory supports approaches the prominent United Nations Convention for Persons with Disabilities (2006) and the Irish Government (NDA, 2010; DOH, 2012) which enable these adults live lives equal to other citizens in society.	This theory has challenged the extended scope of labelling adults with the term ‘intellectual disability’.	The way in which adults interact with service policies and supports, and the degree to which what they do matches with their own aspirations and what they are told to do should be considered a pertinent concern when attempting to make comparative evaluations across support.
Education and training	This theory supports that education and training influences the way in which they engage in choice situations. (Holly and Sharp 2012)	This theory has proposed that the maximization of control for adults cannot be categorised wholly by education and training.	Education and training should not be presumed to be the sole mechanism for bridging the divide between what adults are being told to do and what they actually do.
	This thesis supports assertions (Arvidsson et al, 2008) that while there is a link between the extent to which they are able and willing to engage in achieving choice outcomes, there is a lack of published research in this area.		By highlighting engagement this thesis also asserts that the future development of choice situations should focus on “getting the timing right”. In order to fully actualise the vision of flexible and personalised choice arrangements, it is crucial to consider when and what choice opportunities are most appropriate as these adults journey through their lives, and whether there is more appropriate support to be accessed.
Interpreting and decision making	This theory supports Larkin et al (2013), in its claims that interpreting does not represent a straightforward process but is rather characterised by continuous change and adaptation in response to presenting circumstances.		Decision making as understood in the context of this theory is a five-way interactive phenomena, based not only upon the interaction between adult and environment, but also influenced by fundamental beliefs, emotional responses and compliance behaviour.
	This thesis supports Pashko’s (2014) observation that “response shift” is an inherent element in the dual information processing system of the adult, and should be equally valued from a perceptual viewpoint as from a conceptual one to represent the subjective understandings of the individual.		This theory adds greater clarification to Pashko’s (2014) theory of dual information processing systems by offering a conceptual understanding of the means through which these adults make interpretations of choice situations, based on their knowledge and thoughts, determining what to focus on and how with those in power positions, and continually store these thoughts as ideas to be drawn up (similar to rational-cognitive system). Furthermore, this thesis gives greater weight to the extent of how interpreting influences emotions.
Powers (1973, 2007, 2011) perceptual control	Like perceptual control theory, this theory has proposed that while service structures establish rules about “how things should be done”, individual adults act based	This theory has challenged some fundamental aspects of perceptual control theory. This thesis has conceptualized the	

theory,	on their knowledge and priorities, in order to adapt, ignore, or oppose the requirements for expected behaviour.	interaction of adults being told what to do and their actual doing, along with how they frame control, emotionally connect and adjust as the influencing factors which shape behaviours.	
	The sub-core category of framing control presented within this thesis has supported Powers (1973, 2007, 2011) idea that action is determined by knowledge and contextuality. This thesis reaffirms that actions are always situated within a context which can either constrain or enable adults. As supported by the cumulative nature of framing control, it is also clear that the more they know and understand, the more confident and willing they are to enact rules within the service context unless opposed to their aspirations.		
	This theory supports Powers (1973, 2007) conception of collective action maintaining social structures. As the nature of what they are told to do depends on an oscillating equilibrium between whether they are self-directed or externally directed and, although dynamic in nature, equilibrium is maintained.	This theory has challenged the accounts of Powers PCT when providing explanations for others who transgress the boundaries of what they are being told to do breaching the equilibrium	
		In contrast to Powers (1973, 2007), this thesis avers that functional diversity is inherent within adults, and when combined with support and adult engagement underpins their actual doing. This theory has therefore challenged Powers perception of structure and agency as two sides of the same coin by conceptualizing being told and actual doing to be distinct and interdependent and as a result, challenging the extent to which they are always able to act freely	This theory illuminates the impact that emotions and compliance behaviour has on perception of control.
Glasser's Choice Theory (1998)	This theory has similarities with the categories of framing control, emotional connecting and adjusting with fundamentals of Glasser's choice theory of thinking, feelings and actions.	Conversely similar to Glasser's choice theory the emergent theory illuminates and explicates that for the adults in this research study their thinking focused on	The emergent theory identifies that an individual thoughts of control are fundamental to how they make choices but while Glasser acknowledges thinking, feelings and actions and physiology as four

	And the identified component of physiology in Glasser’s theory is similar to the notion of equilibrium in the emergent theory.	their beliefs and perceptions of the control they had in choice situations, their emotions outshot their feelings and their actions were relentlessly reflected in their compliance behaviours as they interacted with what they were being told to do. And furthermore inherent in those interactions the emergent theory accounts for differences in individual’s psychological homeostasis.	distinct but inseparable components of choice behaviour, the emergent theory not only purports that how an individual thinks, emotionally connects and adjusts have influence on each other but are also driven by interactions between what adults are being told to do and what they are actually doing. In Glasser’s choice theory individuals are driven by the genetic needs of belonging and love freedom and fun, in the emergent theory adults primarily draw on a bank of ideas they form on their identities, abilities and mind-sets while interpreting choice situations and making determinations regarding the level of control they have. The essence of the emergent theory highlights the significance of when being told what to do adults frame control, connect emotionally and make adjustments and be it positive or negative create maintains or changes an equilibrium in the realities of what they actually do.
Emotions	This theory strongly supports claims that emotions follow cognitive appraisals, influence behaviours (Tenebaum et al, 2008); positive beliefs of having control are strongly associated with positive emotions and positive emotions influence positive behaviour; that negative beliefs of having control are strongly associated with negative emotions (Watkins and Nolen-Hoeksema, 2014); that negative emotions influence maladaptive or negative behaviour (Hanin, 2000). Pekrun’s control-value theory (2000) particularly underscores the importance of control beliefs and personal values as the vehicle for linking individuals’ unique cognition, emotions and motivations		The emergent theory adds to extant research explicating the relationships between specific control beliefs and specific emotions. Additionally the emergent theory illuminates the relationships between emotions and behaviours in distinguishing between emotional connecting and adjusting compliance. This theory highlights the importance of the adults’ ideas about their identities, power and mind-sets.
	The strength of this theory is attested in Xue et al (2013) findings that positive emotions can facilitate cognitive control processing, providing evidence of the feedback loop system. And Linehan’s (1993) findings that beliefs about control of emotions are partially formed as a result of invalidating environments.		

Compliance	This thesis has supported findings that services values, visions and skills which aim to promote empowerment, independence and person-centredness are imbued with an increasingly complex web of regulations, standards and legal requirements. These are facilitative for systems which seek to protect health and safety, but come at the cost of embedded structures which rely on the compliance of the individuals which it wishes to serve (Gaventa, 2008; Sondenaa et al 2010).		
	This theory supports existing literature by confirming that the inclusion of these adults in decision-making, and clearly defined expectations and standards which are tailored to their individual needs, are essential to optimising the potential for adjusting compliance (Hurtado et al 2014; Mulrooney, 2014; Hanson, 2008).	In support of Mulrooney (2014), this thesis suggests that fully informing adults about the requirements and benefits of participation can optimise engagement in choice situations. It is also argued that their participation will be affected by external influences which remain out-with the control of the support person.	This theory presents a new conceptual theory that explains how, as they shift between compliance and non-compliance with what they are being told to do, these adults experience variations in their perceptions of control while seeking not to breach expectations. The theory offers a conceptual perspective from which to begin to understand how and why they comply with or deviate from expectations of behaviour. This theory suggests that, at one extreme, those with high emotional stability demonstrate greater ability and enthusiasm in complying with expectations, while at the other extreme, while it may be desirable and possible for those to defy those in the power situation, non-compliance occurs only when emotional stability is at its lowest.
		This theory has challenged the assumptions of the need to assess reasoning in order to determine abilities to comply with expectations of behaviour (Willner, 2011). This thesis challenges the pressing need to educate adults as means of increasing compliance (Tinney et al, 2014)	This theory strongly advocates that the adults' interpretation of the choice situation should be the initial focus of the interaction, and their subjective judgement in determining whether support offered or implemented is tailored to their individual needs and aspirations.
		In challenging the role of supervision in ensuring compliance (Hithersay et al, 2014), the emergent theory asserts that while supervision can maximise compliance, it can also compromise emotional stability.	This theory suggests that the notion of compliance behaviour explicates what works well. Rather than evaluating compliance as an end in itself, it is more worthwhile to consider whether different levels of compliance lead to significant differences in choice satisfaction outcomes.

