Total tooth loss and oral health service use among older people with Intellectual Disabilities in Ireland

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

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Declaration

I hereby declare that the work contained in this thesis has not been submitted as an exercise for a degree at this or at any other University. The work described in this thesis, except where duly acknowledged, is my own. I hereby agree that the Library of Trinity College Dublin may lend or copy this thesis upon request. All mistakes and/or omissions are borne by the author.

Signed_________________________

Caoimhín Mac Giolla Phádraig

Date: ____________________
Summary

Background and rationale  As the population with Intellectual Disabilities (ID) age, the challenges to their successful ageing are unclear. It is important to understand how this population age: how their health changes into later life and how they and society, can respond to ensure successful ageing for all, while minimizing disparities. Total tooth loss is an accumulative disabling condition that reflects the burden of oral disease and the effectiveness of disease management over the life course, which increases in older age and seems to be more common among adults with ID than the general population. Research into the oral health of people with ID, has often explored both oral health and service use together, often with an emphasis on behaviour support, to allow appropriate health monitoring, service planning and policy. Given current oral health policy development in Ireland, research of this type is timely.

Aim  The aim of this study was to explore total tooth loss and oral health service use among older adults with intellectual disabilities in Ireland. To achieve this aim, two objectives were met by answering seven questions. The objectives of this study were to understand the prevalence, sequelae and impact of edentulism and to understand the frequency of dental attendance and use of behavioural supports among older adults with intellectual disabilities in Ireland.

Methods  This multi-methods study adopts quantitative, mixed methods and qualitative methodologies, conducted within the context of a larger longitudinal study on ageing and ID. The Intellectual Disability Supplement to The Irish Longitudinal study on Ageing (IDS-TILDA) is a unique longitudinal cohort study designed to explore features of ageing among older adults with ID. This study is comparable with The Irish Longitudinal Study on Ageing (TILDA). IDS-TILDA includes a nationally representative sample of adults with ID over 40 years of age who completed pre-interview questionnaires and interviews over two waves (concluding 2011 and 2014) of data collection.

Six dentists, who treat people with ID regularly, were also interviewed to explain some of the quantitative findings from IDS-TILDA in a sequential-explanatory mixed-methods design and to explore their experiences of behaviour support used in providing this care, in a small qualitative descriptive study.
Results  A total of 753 people participated in Wave 1 and 708 in Wave 2. Relating to Objective 1, the reported prevalence of edentulism was 34% among adults with ID over fifty years of age in Ireland. This compared to 14.9% of the general population. Once edentulous, two thirds of adults with ID did not wear dentures. This compared to between 5% and 9% of edentulous adults without ID. Nine out of ten participants without teeth did not wear dentures because they did not want them. Only 8 out of 117 people without dentures reportedly wanted them. Reliance on carers to respond on participants’ behalf was associated with not having dentures. Compared to people who have teeth, the odds of reporting difficulty eating was twice as high (OR=2.01, 95%CI=1.02-4.03) among edentulous participants without teeth or dentures and one fifth as high among edentulous participants who reportedly had dentures (OR =0.21, 95%CI=0.06-0.64), controlling for likely covariates. Edentulism is therefore a risk factor for difficulty eating among adults with ID, only if not treated with complete removable dentures. In fact, complete denture wear predicts a reduction in difficulty eating, relative to those who have teeth. Relating to Objective 2, the majority of older adults with ID in Ireland attended dental services regularly. This included 86.5% of the total sample, ranging from 95% of dentate and 60.5% of edentulous participants. This compared to literature based comparisons of 44% of dentate and 2.3% of edentulous adults over 65 years in Ireland. Most older adults who did not attend dental services, did so because they saw no need. This, in turn, was seen to be associated with the absence of both pain and teeth. Most older adults with ID reported the use of non-pharmacological support to receive dental care: 1% reported use of inhalation sedation; 2% Intravenous (IV) sedation; 8% general anaesthesia (GA) and 14% oral sedation for dental care. Expert dentists, who partook in the qualitative phase of this study, felt that these figures represented the unavailability of sedation and GA and inappropriate treatment. Compared to those who were not, participants reporting challenging behaviour (OR=2.3, 95%CI=1.43-3.20), significant difficulty speaking (OR=3.5, 95%CI=2.19-5.57) and obvious oral problems (OR=2.53, 95% (1.56-4.10) had greater odds of reporting treatment with GA or sedation rather than non-pharmacological supports. Experts applied behaviour support strategies, that they mostly learned ad hoc, to reduce reliance on, or increase the effectiveness of, pharmacological supports. Support strategies were selected through both rationalist and intuitive processes and were applied by the dentist iteratively assessing, applying, reassessing and adapting this approach. In this way the process formed through co-regulatory communication between dentist and patient.
Discussion  This study set out to study two seemingly distantly related phenomena: oral disease burden and oral health service use among adults with ID. This thesis considers edentulism as a barometer of both the experience of and the outcomes from oral disease. For adults with ID, this study demonstrates that oral health service use is high but outcomes are poor. This has a negative functional impact. This study suggests that GA and IV sedation are inaccessible, possibly making treatment inappropriate.

Conclusion  The oral health outcomes for people with ID are poor despite regular use of dental care. People with ID should be prioritised for appropriate services, through equitable policy. This thesis makes recommendations for practice, policy and research to ensure healthy ageing with appropriate support for all people in Ireland.
Dedication

To those who help others.

Ar son mo mháthair, Bernadette bean Mhic Giolla Phàdraig, a throid ‘s a ghoid ar son m’oideachas agus oideachas a clann. In ainneoin gach deacracht lean tú ort. Seachas do spriod ceanndána, ní bhéinn anseo inniú. Omós móir duit.

Ar son Ray Mac Mánais, príomhoide Gaelscoil Míde, a thug cothú d’ógáనach bog agus a chuir grá an oideas ina chróí. Tá an méad sin buíochas agam duit as ucht an chuaram a thug tú domsa, dom’ chlann agus an deis a thug tú d’uile páiste an gceantar.

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To June, my mentor, whose selfless work I have tried to mirror and whose influence has shaped my life. On behalf of the innumerable Irish families, whose lives have and will have been influenced by you, directly and indirectly, but who will never know the debt owed to you: thank you.

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Publications, awards and presentations

Peer reviewed Publications


Non-peer reviewed publications


Oral presentations


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<table>
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<th>Definition</th>
</tr>
</thead>
<tbody>
<tr>
<td>ASA score</td>
<td>The American Society of Anesthesiologists (ASA) Physical Status classification. A system to classify patients’ suitability for anaesthesia. Ranging from 1 (normal healthy patient) to 6 (a declared brain-dead patient whose organs are being removed for donor purposes).</td>
</tr>
<tr>
<td>Caries also, dental caries</td>
<td>Dental caries is the scientific term for tooth decay. Commonly referred to as tooth decay and referred to here as simply caries.</td>
</tr>
<tr>
<td>CPITN</td>
<td>A screening index of periodontal treatment needs developed by the WHO and used in epidemiological populations and, in a modified form, for screening and monitoring of individuals.</td>
</tr>
<tr>
<td>CRD</td>
<td>Complete Removable dentures: also referred to as complete dentures, full dentures or simply dentures. In this thesis the term denture refers to CRDs unless otherwise specified.</td>
</tr>
<tr>
<td>DD</td>
<td>Developmental disabilities</td>
</tr>
<tr>
<td>DMFT</td>
<td>Decayed, Missing and Filled Teeth: an irreversible index of caries experience. This measures the total number of teeth, which have experienced caries (D+M+F), and its treatment.</td>
</tr>
<tr>
<td>Edentulism</td>
<td>Edentulism describes the state of having no natural permanent teeth. This means that all 28 natural permanent teeth (excluding wisdom teeth) are missing.</td>
</tr>
<tr>
<td>Edentulous</td>
<td>Edentulous describes a person who has no natural permanent teeth.</td>
</tr>
<tr>
<td>HSE</td>
<td>Health Service Executive</td>
</tr>
<tr>
<td>ID</td>
<td>Intellectual Disability, referred to as learning disability in UK</td>
</tr>
<tr>
<td>IDD</td>
<td>Intellectual and Developmental Disabilities</td>
</tr>
<tr>
<td>Implant-retained prosthesis</td>
<td>Prosthetic dental appliance held in the mouth by an implanted titanium screw that has integrated into the bone. This prosthesis may be removable, like a denture, or fixed, like a bridge.</td>
</tr>
<tr>
<td>NIDD</td>
<td>National Intellectual Disability Database</td>
</tr>
<tr>
<td>Partial edentulism</td>
<td>Loss of at least one, but not all teeth. Can also refer to an upper or lower jaw with no teeth against an opposing jaw with teeth.</td>
</tr>
<tr>
<td>PDS</td>
<td>Public Dental Service</td>
</tr>
<tr>
<td>Periodontal</td>
<td>Of the periodontium, the supporting tissues surrounding the gum including gingiva, periodontal ligament and alveolar bone</td>
</tr>
<tr>
<td>Periodontitis</td>
<td>Inflammatory, plaque mediated disease of the gum and periodontal tissues. Often referred to as gum disease.</td>
</tr>
<tr>
<td>Root surface instrumentation</td>
<td>The manual treatment of infected root surfaces and adjacent tissues by dental professionals.</td>
</tr>
<tr>
<td>RPD</td>
<td>Removable Partial Dentures: also referred to as partial denture or simply denture, making the distinction between CRDs and RPDs difficult at times. In this thesis the term denture refers to CRDs unless specified.</td>
</tr>
</tbody>
</table>
Chapter 1 Introduction
1.1 Introduction

This chapter contextualises the current study by setting the scene for the investigation of oral health status and oral health service use among people with intellectual disabilities (ID). The chapter introduces the concept, definition and demographics of intellectual disability and the issues that population ageing brings to people with ID before setting the scene, briefly, regarding policy. The IDS-TILDA study is then briefly introduced. Some concepts, in outline, of oral health follow before oral health services for adults with ID in Ireland are explained and the current stage of oral health policy development is summarised.

1.2 Intellectual disability

1.2.1 Definition

Intellectual disability (ID) describes a state of being whereby a person’s ability to adapt to their environment is impaired, reflecting a limitation in intellectual function that arises during development. Limitations of practical, conceptual and social skills affect a person with ID’s potential for participation in all that life has to offer. The American Association of Intellectual and Developmental Disabilities offers the following definition: “Intellectual disability is a disability characterised by significant limitations in both intellectual functioning and in adaptive behaviour, which covers many everyday social and practical skills. This disability originates before the age of 18.” (Schalock et al., 2010). ID is often classified according to IQ scores as mild (55-70), moderate (40-55), severe (25-40) and profound (below 25). However, a spectrum of ability and support need belies the simplicity of this classification, which is best used to conceptualise ID, for example, for the study of ID, rather than describe an individual’s place in their world.

In Ireland, operationally, the World Health Organisation definition of Intellectual Disability is often adopted for purposes of diagnosis, which is defined as a “condition of arrested or incomplete development of the mind, which is especially characterized by impairment of skills manifested during the developmental period, skills which contribute to the overall level of intelligence, i.e. cognitive, language, motor, and social abilities” (WHO, ICD-10).
1.2.2 Demographics of ID

It is this WHO definition that is applied by those who report to the National Intellectual Disability Database (NIDD), a unique dataset that records trends in demographics; current service use and future service need for people with ID in Ireland. Registration is compulsory for all people with ID identified as using or needing specialised services in Ireland. The database is used for purpose of service planning. It is updated continuously and reported annually. According to the NIDD there are over 28,100 people with ID in Ireland, suggesting an Irish prevalence, if that is the right term, of ID at 6.13 per 1,000 population or 0.6% (Doyle and Carew, 2016). This is naturally thought to underestimate the actual prevalence of ID, especially among those with mild ID, because most people on the register use social, educational or medical supports that those with mild ID may not need. In comparison, the worldwide prevalence of ID is estimated to be at least 1% or 10 people in 1,000 population (Maulik et al., 2011, The Pomona Project, 2002-2004).

In 2015, more people with ID in Ireland were male (59% v 41%) than female. Virtually all used day services and almost 90% availed of one or more multidisciplinary support services such as ID-related medical, ID-related nursing, Dietician, Occupational therapy, Physiotherapy, Psychiatry, Psychology, Social work and Speech and language therapy services (Doyle and Carew, 2016). Three in every ten people with ID on the NIDD were in receipt of full time residential care (Doyle and Carew, 2016) increasing to 80% by the time they reached 55 years of age (Kelly and O'Donoghue, 2014).

At a time when people with moderate or severe ID could expect to reach their late 60s and 50s, respectively (Bittles et al., 2002), the average age at death for adults with ID in turn-of-the-century Ireland was just 46 years (Lavin et al., 2006). The reasons for this are unclear. It is known, however that older adults with ID in Ireland experience higher rates of age-related comorbid conditions (71%) than adults with ID from other countries (Evenhuis et al., 2001, McCarron et al., 2013). In addition, almost 45% have comorbid sensory or physical disability (Kelly and O'Donoghue, 2014).
1.2.3 ID and Population Ageing

Over time, people with ID are ageing as a population. Since 1974, the proportion of people with moderate, severe or profound ID, who are over 35 years of age has steadily increased from 28.5% to 48.7% and the number over 55 years of age has almost tripled in this period (Doyle and Carew, 2016). This trend is likely to continue, in line with trends within the general population (See Figure 1.1) of whom 12% were over 65 years of age in 2011. With population ageing, whereby older individuals become a proportionally larger share of the total population, this is set to triple within 30 years (United Nations, 2001). This intergenerational shift is occurring within a political, social and economic environment that is struggling to respond (United Nations, 2001). Challenges include the increasing competition for resources in longer retirement and changes in health and social service usage, against a declining dependency ratio to support these changes. These challenges are compounded for people with ID because as they age, the span of care they require from their parents extends into their old age, when their parents’ caregiving capacity decreases (Heller and Factor, 2008). Elderly parents become less able to care for their adult children with ID and smaller family size means that there are fewer siblings to support them. This change in the support ratio leads to critical pressure on housing, social and healthcare for which the Irish Government must provide as part of its obligations as a signatory to the Convention on the Rights of Persons with Disabilities (United Nations, 2006a).

Figure 1.1 Population pyramid for Ireland 1950 – 2050

Reproduced under Creative Commons licence (United Nations, 2001).

1.2.4 Policy context

In the face of these demographic realities and accepting responsibilities arising from Healthy Ireland, 2013 (Ireland, 2013), the Disability Act, 2005 (Department
of Justice Equality and Law Reform, 2005) and the UN Convention on the Rights of Persons with Disabilities (United Nations, 2006b), policy makers have shared plans to meet their obligations to safeguard and empower people with ID.

In 2011, the Irish Government outlined a 7-year plan to move away from congregated-, towards independent-living or small cohabitation in the community, for adults with ID ((HSE), 2011). This has the potential to change the way in which 9,500 people with ID, in around 1,200 residential services, live within their communities. This plan suggested that supports would be accessed outside of the traditional institutional delivery model. The standard of care in these residential services will heavily influence the lives of the many older adults who use them. Therefore, HIQA (Health Information and Quality Authority) has produced 92 standards for residential care of both people with disabilities and older persons to ensure effective services, standards of care and health and well-being, (Health Information & Quality Authority (HIQA), 2013, Health Information & Quality Authority (HIQA), 2009a).

Other emerging disability policy is rapidly changing how services ought to be accessed, funded and delivered for people with ID. Together, policies promote independent, community based provision of services that are based on need, preference and choice. For example New Directions ((HSE), 2012), suggests that older adults with ID should be supported to access mainstream services, within their choices, preferences and needs. Meanwhile the Congregated settings report ((HSE), 2011) suggested that supports will be accessed outside of the traditional institutional delivery model and Value for Money (Department Of Health, 2012) suggests that resources are allocated based on individual need, rather than through the direct funding of the service provider. This obviously has implications for how dental care is funded for such persons. Together, demographic shift and changes to how people with ID are supported to live in their communities will shape future service delivery.

1.3 Research into ageing for people with and without ID

Longitudinal research into ageing among the general population and those with ID is underway in Ireland. Studying the general population, The Irish Longitudinal Study on Ageing (TILDA), is a nationally representative, prospective cohort study on
ageing in Ireland. TILDA’s aim is to make Ireland the best place in the world to grow old. TILDA focuses on the economic circumstances, health and well being of those over 50 years of age, living independently in Ireland. To date this study has seen three waves of data collection. Wave one included a stratified clustered sample of 8,178 individuals, 6,995 of whom completed an interview at Wave 2 (Nolan et al., 2014). This study excluded people who were in supported living and those who lacked capacity to consent. It could be argued that such populations are exactly those who have most to gain from appropriate policy to ensure successful ageing. As such, a need and opportunity arose for the establishment of an ID supplement to TILDA.

To complement TILDA, The Intellectual Disability Supplement to The Irish Longitudinal Study on Ageing (IDS-TILDA) commenced in 2008. IDS-TILDA is a unique longitudinal cohort study designed to explore ageing among older adults with ID: their ageing profile, physical and behavioural health, health services needs, psychological health, social networks, living situations and community participation. This study is undertaken in recognition that there is a lack of longitudinal and incidence studies addressing health issues of elderly people with intellectual disability (Haveman, 2009) and that mainstream policy, and the evidence collected to inform and evaluate such policies, does not take into account the specific needs of older adults with ID. Longitudinal prospective research also offers many benefits including the ability to measure multiple exposures, determinants and outcomes, making it possible to infer relationships between variables over time and monitor the impact of policy response between waves. These studies are important because the data held therein act as multiple baselines against which to assess the impact of policy and measure disparities between those with ID and the general population. So far, two waves of data collection have been reported: Wave one concluding in 2011 and Wave 2 in 2014 (McCarron et al., 2011, McCarron et al., 2014). A third wave of data collection recently concluded in March 2017. It is within the context of this larger study that this PhD was undertaken.
1.4 Oral health

1.4.1 The importance of oral health for people with ID

Oral health offers the ability to speak, smile, smell, taste, touch, chew, swallow and convey a range of emotions through facial expressions with confidence and without pain, discomfort and disease of the craniofacial complex (Glick et al.). Oral health is intimately related to general health. In fact it is impossible to be healthy without a healthy mouth (U.S. Department of Health and Human Services, 2000). It is understood that oral health and general health share a bidirectional relationship. This means that oral health influences general health, and vice versa. Examples include the effect of periodontal disease management on glucose control in diabetes and the impact of glycemic control on severity of periodontitis, and the relationship between periodontal disease and ischaemic heart disease (Kinane and Bouchar, 2008). Particularly for people with disabilities, poor oral hygiene can lead to respiratory disease, a leading cause of mortality (Scannapieco and Rethman, 2003). Further, common risk factors often belie the link between oral and general diseases.

The health profile of people with ID is unique because they often present with conditions that have a specific impact on oral health (Evenhuis et al., 2001, Haveman, 2009). These include obesity and mobility impairment, which may impact on the dental management of those with ID; gastro-esophageal reflux disorder, known to cause dental tissue surface loss; and pneumonia and heart disease, both known for their links with periodontal disease and oral bacteria (Anders and Davis, 2010, Kinane and Bouchard, 2008, Scannapieco and Rethman, 2003).

So, we can see that people with ID are considered to be at increased risk from and of oral disease. They also suffer increased risk of oral disease and from its treatment. In Ireland, for many years, research has revealed that oral health for people with ID is poorer than that of the general public. As well, the oral health services available to them result in poorer outcomes, including more untreated gum disease and decay, and poorer treatment outcomes such as extractions rather than fillings, with a lack of functional replacement of lost teeth (Crowley et al., 2005, Costello,
Over the life course, the impact of oral disease has the potential to accumulate through successive tooth loss, leading to progressive oral disability. For people with ID, this cumulative impairment could prevent them from ageing independently, healthily and successfully. Equally, it might not: we simply do not know the oral status, impact of oral health over the lifespan and oral health services use of the population with ID.

1.4.2 Oral health services for people with ID in Ireland.

Dentistry is delivered across three publicly supported schemes in Ireland: the Dental Treatment Services Scheme (DTSS), the Dental Treatment Benefit Scheme (DTBS) and the Public Dental Service (PDS). Private care is also generally available but hospital based dentistry is restricted to centres in Dublin and Cork. To give the reader a sense of scale to these schemes: the DTSS is provided to 1.9 million medical cardholders who undergo means-tested eligibility for free medical services. In 2009, under the DTSS, 1,400 general dental practitioners carried out 1,584,068 treatments at a cost of 63 million euro (PA Consulting Group, 2010).

Since changes in April 2010, under emergency government legislation, this has become, essentially, a limited emergency care scheme (Primary Care Reimbursement Service, 27th April 2010) except for certain patient groups, for whom pre-approval is required, as per the HSE Circular No. 023/10 (Primary Care Reimbursement Service, 14th October 2010). While most people with ID are eligible for this service, anecdotally, it appears that only some adults with ID access this service, although there are no data to support this. Where data are available, most people with ID access care from the PDS, at least for those adults living in residential care (Mac Giolla Phadraig et al., 2015b, Crowley et al., 2005). Data on other services used by this population are lacking.

The PDS is, therefore, probably the main source of oral healthcare for people with ID, especially those who experience significant disability. It is run by the Health Service Executive and operates mainly within the framework of the Dental Health Action Plan (Department of Health, 1994). Of the 111,800 public servants employed in the Health sector, there were 806 whole-time equivalents employed in
the PDS in 2010. Of these, 325 were dentists or orthodontists (PA Consulting Group, 2010). It is, therefore, a far smaller workforce than in the DTSS. The PDS mainly provides care for children less than 16 years of age and people with special care needs. Generally, children are assessed two or three times during childhood and basic dental treatment is provided. Children with disabilities or medical indication may be seen more frequently. While risk based service provision has been recommended (Irish Oral Health Services Guideline Initiative, 2008, Irish Oral Health Services Guideline Initiative, 2009, Irish Oral Health Services Guideline Initiative, 2010, Irish Oral Health Services Guideline Initiative, 2012), implementation of these guidelines and the uptake of any service is unclear. There are no life-stage-specific services for people with ID, such as pre-school or older age services. People with ID may be selected for treatment through day services, residential services or schools, though this varies from clinic to clinic.

The PDS operates with significant local operational independence (PA Consulting Group, 2010), so it is impossible to describe the structure of care for adults with ID accurately, but in principle, there is a National Lead in Special Care Dentistry who coordinates care nationally. This position is vacant. Senior Dental Surgeons (Special Needs) quasi-independently coordinate care in nine Community Healthcare Organisations, formerly 16 Integrated Service Areas, formerly 32 Local Health Offices. This set up tends to change frequently. These services operate in parallel to other, disconnected health and social care services (such as the Primary Care Teams and Health Promotion teams with whom they often share premises but do not formally integrate).

For people with ID, many issues of access arise from within these structures and processes (Crowley et al., 2005, Smith et al., 2010, Taylor-Dillon et al., 2003, D'Eath et al., 2005). The Public Dental Service (PDS), which is tasked with providing the bulk of oral healthcare to people with disabilities in Ireland, is fragmented, providing care in an ad hoc manner. This degree of operational discretion has important limitations. The proportion of Public Dental Service output, delivered to patients considered as having “Special Needs” varies from just 2% of overall output to 20%, depending on area (PA Consulting Group, 2010). This means that services to children and adults with ID vary between neighbouring
schools or centres, which may fall geographically into distinct operating areas. Some people may even live in one area where day services are the units of clustering services, but attend day services in another, where residential services act as units of clustering services. A lack of resources for dental services (Crowley et al., 2005) and a lack of appropriately designed service models (Elliot et al., 2005) further impact the appropriateness of dental services. Limited access to adjuncts such as general anaesthesia (Irish Society of Disability and Oral Health, 2012) leads to increased waiting times, cost and treatment need (McGeown et al., 2012, Holland et al., 1997) while alternatives, such as appropriately trained dentists offering sedation services, are limited (Smith et al., 2010, Quinn et al., 2006). Oral health services are not designed to meet the needs or expectations of people with ID. They are therefore inappropriate (Mac Giolla Phadraig et al., 2015a). It seems that complex barriers to oral care exist in Ireland, in addition to, rather than resulting from, the person’s disability.

1.4.3 Oral Health Policy

Ireland is a signatory to the UN Convention on the Rights of Persons with Disabilities (United Nations, 2006b) since 30th March 2007. Its ratification, at the time of writing, was imminent. According to the UN Convention on the Rights of Persons with Disabilities (Article 25), there should not be any discrimination on the basis of disability (United Nations, 2006b). Thus, health services that are required by a person with a disability should be provided as early as possible and should be local to their community. The Disability Act, 2005 outlines the states’ responsibility in this regard (Department of Justice Equality and Law Reform, 2005). The growing population of people with disabilities and the growing recognition of their rights to equitable health, mean that there is increasing pressure to provide equitable, quality health care to all.

Health Policy in Ireland has long recognised these principles. Most recently, Healthy Ireland (Ireland, 2013), the National framework for health and well-being in Ireland, outlines four goals for the attainment of health for the Irish public. These aim to increase the proportion of people who are healthy at all stages of life and reduce health inequalities. Further back, in the same year that the policy document Shaping a Healthier Future (1994) promoted “equity, quality & accountability”, the Dental Health Action Plan, which underpins current oral
health services, proposed a service that would “provide comprehensive services to disabled and institutionalised” (Department of Health, 1994). It is evident now that this policy failed to deliver on this goal. The need for improved models of oral healthcare delivery persists (Mac Giolla Phadraig et al., 2014c, Elliot et al., 2005, PA Consulting Group, 2010).

To accommodate the needs and expectations of older adults with ID into the future, there is now a need to both catch up and look forward. Not only is there now a need to address the issues that have challenged services for decades, but also future-proof services to accommodate the changing demographics described in Section 1.2. This group are perhaps most readily able to benefit from evidence-based policy in this field. However, it is unclear how salient older adults with ID are to those who legislate and plan for dental services in Ireland. While a National Oral Health Policy is, in 2017, being developed, with the intent to prioritise care for older adults (Department of Health, 2015), the challenge for researchers and advocates is to deliver the information needed to help policy-makers make evidence-based decisions, at the point that these decisions are made, which will lead to successful ageing for adults with ID.

1.5 Conclusion

The regulatory framework within health and social services in Ireland is ostensibly supportive of the needs of adults with ID. However, the challenge of improving oral health service delivery for adults with ID is immense. The impetus for research informed service development has never been greater, especially given the changing demographics of this population. Therefore there is an onus on researchers to produce knowledge that will inform evidence-based models of care for older adults with ID in Ireland.
Chapter 2 Literature Review
2.1 Introduction

There is a need for good quality research into the oral health of people with ID (Haveman, 2009). In Ireland, the National Disability Authority recognises that such research can act as a vehicle with which to drive oral health service development for people with ID (Elliot et al., 2005). To date, much of the available evidence focuses on childhood and adulthood, with little evidence specific to older age (British Society for Disability and Oral Health/Faculty of Dental Surgery of Royal College of Surgeons of England, 2012, American Academy of Pediatric Dentistry, 2015). Guidance on oral care for people with ID highlights a specific need for research in older adulthood. One of two research priorities in the UK, identified for adults of all ages with ID was: “Assessment of the oral health status and use of services by older people with learning disabilities.” (British Society for Disability and Oral Health/Faculty of Dental Surgery of Royal College of Surgeons of England, 2012).

Research into the oral health of people with ID, more so than epidemiological practices among the general population, has often explored oral health and treatment need, alongside dental service and supports used or needed in order to receive dental care. Correspondingly, as will be seen below, many ID specific epidemiological studies record both elements together. So, although oral health status and service use are distinct topics, they are inherently linked, as will be seen by the approach taken in this thesis.

2.1.1 Aim of chapter

The purpose of this chapter is twofold: firstly, to review the evidence regarding edentulism and secondly, to review the literature regarding oral health service use among adults with intellectual disabilities.

2.1.2 Structure of Chapter

This literature review consists of multiple sub-reviews, adopting the most suitable method for the questions explored. Narrative review methods are applied in most sections. Sections 2.2 – 2.4 report a review of the literature regarding edentulism among adults with ID: its causes, prevalence and outcomes. As part of this, a sub-review explores the prevalence of edentulism among adults with ID (see Section
2.2) by adopting a narrative review informed by systematic review principles. Section 2.5 is large and contains three separate sub-reviews (See Figure 2.1) including sub-reviews of the frequency of oral health service use and the reported need for and use of pharmacological behaviour supports. Section 2.5.3 reports a systematic review exploring the non-pharmacological supports reported or recommended in the literature for use with adults with ID. A Prisma Statement for this section is available in Appendix 1. An overall summary of the literature is then reported before the aims, objectives and research questions in this study are listed.

Figure 2.1 A map of the sub-reviews in this literature review

*a Narrative review informed by systematic review principles; b Systematic Review
2.2 The prevalence of edentulism and ID: a narrative review informed by systematic review principles

This section firstly introduces edentulism as a concept and highlights the need for research among adults with ID. After a brief summary of the causes of edentulism, the methods applied in this section are summarised before reporting the prevalence of edentulism among adults with ID as found in the literature. Following this, the implications of edentulism and complete denture wear are discussed, based largely on the literature among the general adult population because there is little written specific to adults with ID. Conclusions are then given before exploring dental service use in a separate section.

2.2.1 Introduction

Edentulism is defined as complete tooth loss. This means that all 28 natural permanent teeth (excluding wisdom teeth) are missing. It has been termed the “dental equivalent to mortality” (Weintraub and Burt, 1985) and is considered the final marker of oral disease burden (Cunha-Cruz et al., 2007). As such, it acts as both a marker of oral disease as well as its poor management (U.S. Department of Health and Health Education and Welfare, 1960). This makes it a useful focus when monitoring oral health of populations throughout the world (Hobdell et al., 2003). In Ireland, for example, policy makers had set a target of reducing the proportion of adults over 65 years of age who are edentulous to less than 42% of the population by the year 2000 (Department of Health, 1994). In fact, Ireland used this target to shape services and in 2000/2002 the proportion over 65 years of age who are edentulous was 41%. This represented a drop from 72% self-reporting edentulism in 1979 (Whelton et al., 2007).

Internationally, rates of edentulism are heading in the right direction: the proportion of adults with total tooth loss is reducing (Beltran-Aguilar et al., 2005, Polzer et al., 2010, Kassebaum et al., 2014). After a dramatic decline decade-on-decade, the prevalence of edentulism among the adult population internationally sits somewhere between 2% and 8%, in recent studies (Beltran-Aguilar et al., 2005, Medina-Solis et al., 2008, Slade et al., 2014, Kassebaum et al., 2014), but somewhat higher in lower income countries (Kassebaum et al., 2014, Tyrovолос et al., 2016). These prevalence data are known to vary significantly across sociodemographic
circumstance, such as education, occupation, smoking status, gender, race, health, level of dependency, background and place of living, with increasing age being a very strong predictor of complete tooth loss (Kelly et al., 2000, Österberg et al., 1995, Müller et al., 2007). Incidence of tooth loss increases dramatically in the seventh decade (Kassebaum et al., 2014) and as seen in Chapter 1, this population is set to boom. So, despite the decline in the edentulous proportion, the demographic reality of population aging ensures that edentulism, and its precursor partial edentulism, will be prevalent for years to come.

Similar to the general population, there is value in identifying the rate of edentulism among the population with ID as a measure of oral disease burden and the appropriateness, or not, of dental disease management over time. Such data would allow appropriate planning, policy and monitoring within this population. In addition, such data would allow a measure of comparison between the general population and those with ID, who are often excluded from epidemiological research. This would highlight health disparity if such a phenomenon exists. Therefore, in this section we review the available literature to identify the proportion of people with ID who are edentulous. However, before exploring the results of this literature review, it is salient to consider, briefly, the causes of edentulism among people with ID.

2.2.1.1 Background: Causes of total tooth loss in intellectual disability

Edentulism represents a cumulative end-point of successive tooth loss. So, to understand edentulism, one must first consider tooth loss. The literature is unambiguous that tooth loss is more common in adults with ID than the general population (Cumella et al., 2000, Donnell et al., 2002, Gabre et al., 1999, Shaw et al., 1990, Tiller et al., 2001). This is true across all reporting standards: Between 33% and 63% of people with ID have at least one missing tooth (Shapira et al., 1998, Lopez del Valle et al., 2007, Fernandez Rojas et al., 2016) and the mean number of teeth missing (either in total or as the Missing component of DMFT index[Total of the Decayed, Missing and Filled Teeth], which under-reports tooth loss because it considers caries-related tooth loss only) lies between 3 and 28 missing teeth for adults with ID (Lindemann et al., 2001, Morgan et al., 2012, Pregliasco et al., 2001, Tiller et al., 2001, Seirawan et al., 2008).
The number of missing teeth has been found to accrue with age. Tooth loss may be minimal among healthy adults with ID in their early twenties (Fernandez Rojas et al., 2016). Turner, found that older athletes, those over 35 years of age, were more likely to have missing teeth than their younger peers (Turner et al., 2008). Likewise, Petrovic et al., in a contemporary study, found more missing teeth in older people with ID attending specialist clinics (Petrovic et al., 2016). An Italian study, in 2001, demonstrated a stark relationship between tooth loss and age. In this study, most untreated caries was found in middle age, while the mean number of missing teeth (MT) rose from 6.6 in early adulthood to 23-28 in those over 55 years of age (Pregliasco et al., 2001). In Ireland, similar trends were noted by Crowley et al. who found a sharp increase in tooth loss with age among institutionalised adults with ID; particularly over 55 years of age (Crowley et al., 2005).

Tooth loss is influenced by psychosocial, economic, environmental and political circumstance (Watt, 2007). However, this element is outside of the scope of this discussion. In this study we focus on caries and periodontal disease because, together, they account for almost 95% of tooth loss among adults with ID (Gabre et al., 2002, Gabre et al., 2001, Gabre, 2000, Gabre and Gahnberg, 1994). Both are highly prevalent, chronic conditions associated with dental plaque, which tend to have cumulative impact on oral health, potentially leading to successive tooth loss if not managed appropriately. Therefore, tooth loss represents a complex interplay of an individual’s history of dental disease and its treatment by dental services over the life course (Kassebaum et al., 2014). Gabre and colleagues undertook longitudinal analyses among adults with ID in a range of residential settings, to explore reasons for tooth loss. They found that dental caries and particularly periodontitis accounted for 37.3% and 57.4% of tooth loss, respectively (Gabre et al., 2001).

The prevalence of dental caries in populations with ID is considered similar or sometimes slightly lower than that in the general population (Anders and Davis, 2010). However, its sequelae are different within these groups. For adults with ID, dental caries is often untreated. Research shows that between 21% and 82% of adults with ID were found to have untreated caries (Petrovic et al., 2016, Oliveira
et al., 2013, Morgan et al., 2012, Fernandez et al., 2012, Oredugba and Perlman, 2010, Reid et al., 2003, Cumella et al., 2000, Shapira et al., 1998, Seirawan et al., 2008) and when treated, this was often by extraction rather than filling (Petrovic et al., 2016, Oliveira et al., 2013, Costello, 1990). Adults with ID, living in the community, demonstrate a tendency for higher levels of untreated caries and less treatment by extraction than those in institutions (Kendall, 1991, Gabre, 2000, Tiller et al., 2001), meaning that they are probably not receiving treatment of caries as often as their institutionalised counterparts.

People with ID are also found to have a greater prevalence of periodontal disease than the general population, ranging from 44% to 59% of samples reporting periodontal disease; while the prevalence of gingivitis (inflammation of the gum and associated tissues) can be as high as 95% (Fernandez Rojas et al., 2016, Morgan et al., 2012, Schulte et al., 2011, Oredugba and Perlman, 2010, Cumella et al., 2000, Naidu et al., 2001). The severity of this disease is also worse among adults with ID. In Ireland, 6.3% of 35-44-year-olds had deep pocketing around teeth (CPITN index score of P2), compared to 45% in people with intellectual disability aged 35-54, who had moderate/severe periodontal disease (Whelton et al., 2007, Crowley et al., 2005). While different indices were used to record these data, suggesting caution in comparison, the difference is stark. In Australia, for example, periodontitis was five times more prevalent among adults with developmental disabilities (Scott et al., 1998). Institutionalised persons and those with more profound ID are found to have higher levels of periodontal disease or gingival inflammation (Petrovic et al., 2016, Cumella et al., 2000, Kendall, 1992).

This introduction demonstrates that edentulism represents the final outcome of cumulative tooth loss, due predominantly to periodontal disease and caries, where effective prevention and/or treatment have not been achieved and that the underlying diseases and poor treatment decisions, that promote edentulism, are prevalent among adults with ID.
2.2.2 Methods

2.2.2.1 Search strategy and eligibility

To review the literature reporting the prevalence of edentulism among adults with ID, a systematic search strategy was developed. The following search string was entered into PubMed (last updated 01/01/2017): (((intellectual OR learning OR developmental) AND (disabilit* OR retardation OR retarded OR impairment)))) AND ((("replaced teeth" OR denture OR "dental prosthesis" OR "dental prostheses" OR RPD OR FPD)) OR ((tooth OR teeth OR "tooth loss" OR "tooth number" OR "number of teeth" OR "dental disease" OR "dental status"))). This led to the retrieval of 1089 titles and abstracts for screening (by only one author). Articles from the author’s bibliographic database were also reviewed (See Figure 2.2). Inclusion criteria included: 1. Study specifically focuses (solely or partly) on adults with ID or developmental disabilities; 2. Prevalence of edentulism reported, 3. Sample >50 persons.

Figure 2.2 Search and selection strategy (adopting Prisma Framework)
2.2.2.2 **Quality assessment and synthesis**

All included studies were critically appraised, although a formal tool to assess risk of bias was not applied in this review due to the high risk of bias expected in the included studies. Rather, to answer the research question and because of heterogeneity between studies, included studies were synthesised according to sample characteristics. That is whether the sample was drawn from Special Smiles, institutional or population or clinic-based patient cohorts. Accepting the heterogeneity within the literature, an estimate of the prevalence of edentulism among people with ID, who have been involved in research, was calculated by dividing the estimated sum of edentulous participants by the sum of included participants.

2.2.3 **Results of literature search**

2.2.3.1 **Design of studies**

Nineteen articles, based on eighteen studies met the inclusion criteria. Fourteen were identified from PubMed and five from other sources (Gray, 2005, Naidu et al., 2001, Crowley et al., 2005, Davies et al., 2008, Hall et al., 2011). All were cross-sectional surveys except Morgan’s, which was a retrospective analysis (Morgan et al., 2012) and one mixed methods study, which was largely cross-sectional (Hall et al., 2011). Sample sizes ranged from 50 to 9,620. Four of the studies were from the USA, nine from UK, two from the island of Ireland and three from the rest of the world. These studies are summarised in Table 2.1 While quality assessment was not undertaken, critical appraisal of the literature is presented below, according to the population that the samples represent.

2.2.3.2 **Description and appraisal of studies**

**Special Olympics Special Smiles (SOSS) populations**

Four studies sampled from the Special Olympics Special Smiles (SOSS) project. These represented large, international samples (mean n=3,715) in four of the eight most recent studies included. As Table 2.1 shows, recent research on oral/dental disease prevalence has focused on Special Olympics athletes (sum of n=14,862). This research serves an important role in delivering region-specific knowledge of oral health, collected with standardised instruments, to support the case for improved access to oral healthcare for people with ID. It is especially important
due to the lack of reliable population-based datasets. As a whole, these studies found very low rates of edentulism. An important point to consider is that, in general, Special Olympics athletes are young, well supported and high functioning (Fernandez Rojas et al., 2016, Reid et al., 2003). Therefore, whilst these studies add valuable data regarding the younger, higher-functioning section of this population, they offer limited generalisability to those who have more extensive, active dental disease and who are in need of more targeted support. While the methodology is strong, there are additional difficulties that arise in calibrating data collectors, as well as difficult field conditions, which may affect internal validity and reliability (Fernandez et al., 2012). Therefore, even though these recent studies show lower levels of edentulism, these differences may be accounted for by the fact that recent research has focused on a functional subgroup of people with ID and to a lesser degree, by methodological variation, rather than there necessarily being a lower prevalence of edentulism in adults with ID, as a whole.
<table>
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<tr>
<th>Study</th>
<th>Aim</th>
<th>Sample and setting</th>
<th>n</th>
<th>Data collection</th>
<th>Proportion edentulous</th>
<th>Population</th>
<th>Findings and comment</th>
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<tr>
<td>Morgan et al. 2012, USA</td>
<td>Assess oral health and treatment specially designed services in Massachusetts, USA.</td>
<td>n = 4,732 adults over 20 years of age with IDD using specially designed services in Massachusetts, USA.</td>
<td>4732</td>
<td>Retrospective review of electronic dental records through a state-supported system of dental clinics.</td>
<td>0.109</td>
<td>Dental clinic</td>
<td>Morgan found that 10.9% of sample was edentulous. Edentulous participants (mean age 64yrs) were older than dentate participants (mean age 47yrs). The major limitation is the reliance on service data but strengths include training of data collectors and large sample.</td>
</tr>
<tr>
<td>Gray, 2004, NI</td>
<td>Assess oral health and service need</td>
<td>n = 269 (214 allowed complete examination); age from 13-65+ years of age in Northern Ireland.</td>
<td>269</td>
<td>Clinical exam in day service or school by single assessor.</td>
<td>0.12</td>
<td>Institution</td>
<td>Gray found that 12% were edentulous. This increased with age. Only one person under 35 years of age was edentulous. This population was young.</td>
</tr>
<tr>
<td>Crowley et al., 2005, Ireland</td>
<td>Assess oral health and service need</td>
<td>n=219 adults with ID living in residential care in Ireland.</td>
<td>219</td>
<td>Assessment in residential care homes by single trainer and calibrated in WHO standardised methods, similar to national survey.</td>
<td>0.3</td>
<td>Institution</td>
<td>Crowley reported edentulism in 14% of 35-54 year olds and 61% of 55+ year olds had total loss of teeth. Sample from residential settings only, may bias findings when extrapolating to general population with ID.</td>
</tr>
<tr>
<td>Study</td>
<td>Assessed oral health and service need</td>
<td>Sample</td>
<td>Standardised clinical indices</td>
<td>Institution</td>
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<tr>
<td>Pregliasc et al., 2001, Italy</td>
<td>Assess oral health and service need in a long term care facility near Milan with an average age of 61.3 years.</td>
<td>219 residents</td>
<td>DMFT and CPITN were scored based on agreement between two raters.</td>
<td>0.215 Institution</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Lindemann et al., 2001, USA</td>
<td>Assess oral health and service need within an ID service. Mean age of 35 years. Convenience sample from a population of N= 2,434 in California.</td>
<td>325 adults</td>
<td>DMFT and subjective measures collected by a single dentist.</td>
<td>0.09 Institution</td>
<td></td>
<td></td>
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</tr>
<tr>
<td>Hinchliffe et al., 1998, UK</td>
<td>Assess oral health and treatment need among adults aged 16-55+ attending adult training centres in Hull, with 165 control from local workplace.</td>
<td>324 adults</td>
<td>DMFT and objective measures collected by a single, calibrated dentist.</td>
<td>0.22 Institution</td>
<td></td>
<td></td>
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</tr>
<tr>
<td>Whyman et al., 1995, NZ</td>
<td>Assess oral health and treatment need in residential care. About three quarters had ID. (The rest had a diagnosis of psychiatric disorder).</td>
<td>207 people</td>
<td>Examiner assessed treatment need in institutional setting.</td>
<td>0.5 Institution</td>
<td></td>
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</tbody>
</table>

Pregliasco reported that the percentage of residents who were edentulous was 21.5% (47 subjects), of whom 28 subjects (59.6%) were without dentures. Sample was random within defined population. Interrater reliability statistics were not reported.

Lindemann reported that 9% of this population was edentulous. Similar rate of edentulism to NHANES III sample. Convenience sampling is a limitation, although the authors demonstrated that sample demographics closely matched those of the population. Data collector training unclear.

Hinchliffe reported 22% of their sample edentulous. Far higher than control; 31% of those without teeth had no dentures; denture wear associated with degree of disability.

Whyman reported that 50% of the population was edentulous and one-quarter of the edentulous wore a denture or were considered capable of wearing a denture. More edentulism than among the general population.
Assess oral health and treatment need n=350 participants with ID ex. 481 invited from day services representing a range of levels of disability all living in the community or with family. Mean age of 33.9
Standardised clinical indices such as DMFT, Silness and Loe and Todd and Walker 0.10 Institution
Kendall reported that 10% were edentulous. Of those edentulous, 57% did not possess dentures and 11% were wearing inappropriate dentures. Therefore 68% needed full dentures. The sample size was fairly large although the local, convenience sample limited generalizability.

Shaw and Shaw, 1990, UK
Assess oral health and treatment need n= 382 people with ID living in the community and attending day centres. Mean age of 30.9
Standardised clinical indices such as DMFT and CPITN 0.136 Institution
Shaw found that 13.6% of sample were edentulous. Local convenience sample with large sample size.

Morton, 1977, UK
Assess oral health and service need n=90 long-stay adult females with ID within a single community.
Brief assessment under difficult ward conditions, followed by detailed dental examination 0.43 Institution
Morton reported a high prevalence of edentulism: 43% of this sample were edentulous. Limitations: The sample included females only, who tend to have higher rates of edentulism. This may artificially increase the level of edentulism. The convenience sample and small sample size limit generalizability.

Hall et al., 2011, UK
Assess oral health and service use n=628 adults with ID, representing 31.4% response rate. Mean age was 628 Postal questionnaire 0.064 Register
Hall reported that 6.4% of their sample reportedly had no teeth (93.6% of participants had one or more natural teeth). Of those participants with no natural teeth, 10% were edentulous. Of those edentulous, 57% did not possess dentures and 11% were wearing inappropriate dentures. Therefore 68% needed full dentures. The sample size was fairly large although the local, convenience sample limited generalizability.
40.2 years and ranged from 18 to 87 years. Random sample of 2000 people on the Sheffield learning disabilities database.

<table>
<thead>
<tr>
<th>Study</th>
<th>Sample Size</th>
<th>Methods</th>
<th>Results</th>
</tr>
</thead>
<tbody>
<tr>
<td>Davies et al, 2008, UK</td>
<td>n=440</td>
<td>To pilot data collection methods</td>
<td>Davies reported 22% edentulousness in the 353 participants who allowed complete examination. Non-random sampling and volunteer-based participation limits generalisability.</td>
</tr>
<tr>
<td>Naidu et al, 2001, UK</td>
<td>n=217</td>
<td>Assess oral health and treatment need</td>
<td>Naidu reported that 4.1% of participants were edentulous. Single examiner trained by calibrated trainer over one day. Even with this low number – by middle age the prevalence of edentulism was higher than the general population. Response rate not reported. This population were not using day services and adults living in registered residential homes or group homes were excluded. This study adopted a convenience sample, which limits generalisability.</td>
</tr>
<tr>
<td>Cumella et al., 2001, UK</td>
<td>n=50</td>
<td>Assess unmet needs and identify how</td>
<td>Cumella reported that 22% of subjects were edentate. 30% less than 20 teeth; 48% having 21 or more teeth; More missing teeth in sample than in general</td>
</tr>
</tbody>
</table>
oral care can be improved. Exhaustive sampling. RR = 50 ex 86 eligible participants. Participants were not in contact with the Community Dental Services.

<table>
<thead>
<tr>
<th>Study</th>
<th>Description</th>
<th>Population Size</th>
<th>Methodology</th>
<th>Findings</th>
</tr>
</thead>
<tbody>
<tr>
<td>Fernandez Rojas et al., 2016</td>
<td>Describe oral health status of athletes in SOSS from Poland, Romania and Slovenia with an average age of 23-28 years of age.</td>
<td>n=3,545</td>
<td>Standardised SOSS collection and analysis. Fernandez reported that 0.4% – 0.7% of the sample had total tooth loss. Strengths of study include the large sample size across multiple countries and standardised data collection and analysis. The main limitation is the lack of generalizability to the general ID population.</td>
<td></td>
</tr>
<tr>
<td>Fernandez et al., 2012</td>
<td>Describe oral health status of athletes in SOSS over 4 years in New York. Age ranged from 6 year olds to over 60.</td>
<td>n=664</td>
<td>Standardised SOSS collection and analysis. Fernandez reported that 2% of sample was edentulous. The strengths and weaknesses are shared with other SOSS studies.</td>
<td></td>
</tr>
<tr>
<td>Turner et al., 2008</td>
<td>Describe oral health status of athletes at 7th UK Special Olympics in 2005.</td>
<td>n=1033, representing 44% of SO athletes</td>
<td>Standardised SOSS collection and analysis. Turner reported edentulism in less than 1% of under 35 year olds and 15% in the over 35s. In total, 2% of sample was edentulous. Caution recommended when considering age-banded data due to low numbers of older participants in SOSS. The strengths and weaknesses are shared with other SOSS studies.</td>
<td></td>
</tr>
</tbody>
</table>
Reid et al., 2003, describe oral health status of athletes in SOSS n=9,620 Special Olympians from USA, China, Lebanon, Poland, South Africa, and Turkey. SOSS standardised SOSS collection and analysis. Reid reported that 0.1%-3.7% of populations were edentulous. The strengths and weaknesses are shared with other SOSS studies.

All studies adopted Cross-sectional survey design except Morgan (2012) adopting a retrospective design and Hall (2011), a mixed methods study; c Percentage calculated where a range of percentages were given based on subgroups, the median of the reported proportions was selected as a working estimate.
**Institution based populations**

Nine studies sampled participants from institutions, either day or residential. These tended to be older studies. As Table 2.1 shows, nine (Kendall, 1992, Shaw et al., 1990, Hinchliffe et al., 1988, Cumella et al., 2000, Crowley et al., 2005, Gray, 2005, Lindemann et al., 2001, Morton, Pregliasco et al., 2001) of the oldest twelve, and none of the most recent six studies, were institution-based. These studies were mainly undertaken in the UK and Ireland, involving fewer people than most SOSS studies, with between 90 and 400 participants (sum n=2,385; unweighted mean n= 265). These studies tended to show a higher prevalence of edentulism than other types of samples, ranging anywhere between 10% and 50% of the samples studied. While some researchers undertook random sampling within the institutions reviewed, most used convenience sampling (Table 1). Institution-based studies have limited generalisability outside of the services where they were undertaken. These studies aimed to identify treatment needs and inform service delivery locally and, as such, were not designed to be extrapolated to the larger population. Therefore, these studies offer a partial view only, of the condition of interest here.

**Register based populations**

There were four community-based studies sampled from local disability registers (Cumella et al., 2000, Davies et al., 2008, Hall et al., 2011, Naidu et al., 2001). These studies included between 50-628 participants (mean n=334). These were all reported in the UK. Exhaustive sampling, of a specific subset of eligible people i.e. those not in touch with day services, was undertaken in two studies (Cumella et al., 2000, Naidu et al., 2001). One study adopted random sampling (Hall et al., 2011) but it should be noted that postal questionnaires were used in this study for data collection. Response rates, where reported or calculable, were between 31% and 58%. The results of these studies could be extrapolated to the population on the specific register.

**Dental clinic populations**

Applying service level data, Morgan adopted a review of dental service data in a retrospective study of dental patients with ID. A team of trained data collectors
collected the information over a year. This study found that 10.9% of the sample, which had a mean age of 47 years, was edentulous (Morgan et al., 2012). This overall percentage was higher than the 7.6% of the American population without teeth in 1999-2002 (Beltran-Aguilar et al., 2005) but within the broader range reported in the literature (Emami et al., 2013).

2.2.3.3 Synthesis

**Prevalence of edentulism**

Of the 23,314 participants included in the 18 reviewed studies, approximately 1,384 were edentulous, meaning that approximately 5.9% of people with ID, who took part in the research reviewed here, had no teeth. However, the prevalence across the studies included ranged from 0 to 50%. To understand this range, let us consider the literature according to sample type: On average (unweighted mean), 1.6% of participants in reported Special Olympics Special Smiles (SOSS) samples were edentulous (Fernandez Rojas et al., 2016, Fernandez et al., 2012, Reid et al., 2003, Turner et al., 2008), compared to 23.5% of institutional samples (Kendall, 1992, Shaw et al., 1990, Hinchliffe et al., 1988, Cumella et al., 2000, Crowley et al., 2005, Gray, 2005, Lindemann et al., 2001, Morton, Pregliasco et al., 2001) and 13.6% of local database samples (Cumella et al., 2000, Davies et al., 2008, Hall et al., 2011, Naidu et al., 2001). By comparison, 10.9% of Morgan’s patient-cohort sample was edentulous, a group who by definition attended the dentist.

**Age-banded prevalence**

The preceding summary focuses on edentulism across total samples of varying age ranges. However, edentulism is so strongly related to age that is necessary to explore the data by age-ranges. Because age banding is not standardised in the literature, Figure 2.3 illustrates the prevalence of edentulism across studies with varying age-bands, where such data were reported. Corresponding rates from
Figure 2.3 Age banded prevalence of edentulism among adults with ID.

Legend: This figure presents age-banded edentulism percentages for studies of people with ID. Because of a lack of standardization of age bands, they are displayed by their reported age bands above corresponding data from the general population, where available. **General populations are in bold.** Where no lower age range is defined, the sample is given a lower age limit of 18, where no upper age range is defined, the sample is given an upper age limit of 100. Percentages are rounded to nearest whole figure.
comparable general populations are presented below and in bold, where available. As a point of reference, data from IDS-TILDA and TILDA are also presented, acknowledging that these data come from analyses presented in Chapter 4. By age-bandung, it is clear that edentulism is often seen even in younger groups (Cumella et al., 2000, Morgan et al., 2012) and accumulates in older groups, where between a half and two thirds of older people with ID had no teeth (Crowley et al., 2005, Morgan et al., 2012, Pregliasco et al., 2001). These older groups can include people as young as 55 years of age. Readers should note that some older groups may have included small numbers, which limits the external validity of the data, in one study at least (Turner et al., 2008).

2.2.4 Discussion

2.2.4.1 Main results

There are no nationally representative prevalence data for rates of edentulism for adults with ID. The obvious problem with identifying this from the literature reviewed, is the lack of nationally representative samples with ID, either as part of national dental epidemiological studies or included in ID-specific research. By synthesizing the results of included studies, the overall proportion of adults with ID, without any teeth, who have taken part in published research, was estimated at less than 6%. This is similar to that of the general population (Marcus et al., 1996). However, when edentulism was reported by age, a clear disparity becomes evident by comparison with the general population (see Figure 2.3). People with ID had a high prevalence of edentulism as they aged, particularly in comparison to the general population. This disparity started with early total tooth loss and continued throughout life, in samples from across the world. A lack of age-standardization probably explains this discrepancy – meaning that ID samples are probably, on average, younger, than those from the general population. While we can say that edentulism is declining for adults in general, we do not know if this is the case for adults with ID.

2.2.4.2 Limitations of literature reviewed.

There were many methodological issues in the literature reviewed that impede confident synthesis. Firstly, there was huge variation in the populations studied
with respect to differences in inclusion/exclusion criteria (e.g. SOSS athletes versus institutionalised adults), and sampling techniques. The literature has focused on four different types of samples. While sample generation is consistent across SOSS studies, this is not so in institution and population sampling studies. It is known that people with ID are extremely heterogeneous regarding their oral health (Kendall, 1992) meaning that rates of edentulism will likely vary, depending on which subsamples of the ID population are studied. This literature review confirms this. Studies also had small sample sizes and differences in the procedure, measurement and how setting of data collection was reported (See Table 2.1). Chronologic and geographic disparity limit comparison between such samples (Emami et al., 2013, Müller et al., 2007). This is because oral health is changing rapidly over time among populations in general, and that these populations reflect variation in background rates of edentulism in their community or country.

The reporting of response rates, exclusion criteria, sampling strategies and sample descriptors limited the ability to generate valid prevalence of edentulism. Often an overall sample prevalence was not generated. Crowley, for example reported age-banded but not population level prevalence. Reid, reported a range (0.1%-3.7%) of subsamples by country (Reid et al., 2003). This meant that the author made estimates of prevalence at times.

2.2.4.3 Limitations of review process
This is a narrative review that adopts a systematic approach. It is not a systematic review: the process described falls short of accepted systematic review criteria (Higgins and Green, 2008). A systematic review of this literature would have led to a much smaller review, based on more robust data. Even if we applied the criteria used by Muller et al. in their literature review of total tooth loss in the general population, none of the studies in Table 2.1 would have been included (Müller et al., 2007). With these limitations in mind, this section demonstrates that it is impossible to reliably determine levels of edentulism among the population of adults with ID from the existing literature. It is only possible to generate an estimate.

Study selection was biased in this study. It is likely that a much larger literature, reporting prevalence of edentulism among adults with ID exists, for two reasons.
Firstly, the search strategy applied was limited to a single database, screened by one researcher. This was due to limited capacity to undertake larger searches within the frame of the current research programme. There are likely to be other articles, particularly in the grey literature: in theses, service evaluations and oral health needs assessments that would add to these data. Secondly, often edentulism was not the aim or topic of the research where it is reported. It is simply one of a large list of variables reported. This makes it difficult to identify edentulism measurement from title and abstract screening, meaning that whole article review was often warranted. The number of full text readings was not recorded in this review, although, if systematic review methods had been adopted, this would have been necessary. This study merely adopted elements of SR methods within a narrative review, as this method allowed for a systematic approach that would allow identification and inclusion of the most relevant articles that answer this background research question, whereas a systematic review could not have done so.

2.2.4.4 Conclusions

It is apparent that, historically at least, edentulism was prevalent among adults associated with residential and day services. Most recent research shows low levels of edentulism based on younger, independent individuals, who are unlikely to present with edentulism at this young age. Their future oral health profile is unclear. When compared to the general population, levels of edentulism were higher amongst adults with ID. Total tooth loss occurred at younger ages and continued to be more prevalent in older age, where edentulism was very common among the adults with ID studied. Difficulties in comparing across studies, both within the population with ID and by comparison with the general public, are due to variation between the physical conditions required for clinical examination, demographic and clinical variables, study population size and inclusion criteria (Morgan et al., 2012). No nationally representative data exist because the aim of most data collection to date was not for this purpose. The absence of such data is limiting: it inhibits monitoring of oral disease burden at population level; it prevents the establishment and assessment of comprehensive oral health goals for this population; it also limits the ability to plan and monitor oral health service outcomes nationally for this population over time. Comparison with the general population is also impossible, meaning that health inequality may go unnoticed.
2.3 Impact of total tooth loss and denture wear on people with intellectual disabilities

With a high prevalence of edentulism identified, this section considers what this means for people with ID and explores the rehabilitation of this condition by using the most commonly applied treatment: complete removable dentures (CRDs).

2.3.1 Impact of total tooth loss

The completely edentulous person meets the World Health Organisation’s criteria for being physically disabled (Felton, 2015). Of the 16.5 million years lived with disability (YLDs), for which oral disease was accountable worldwide in 2013, edentulism accounted for one third of this burden (Vos et al.). A particular feature of edentulism is that it is non-reversible - its burden lasts for the duration of a person’s life. The functional impact of edentulism extends to nutrition, health and quality of life.

Firstly, among the general population, edentulism affects chewing efficiency, but more importantly it limits food choice, selection and preparation, especially of fruit and vegetables, which are rich in Vitamin C and fibre (Walls and Steele, 2004). Edentulism is also associated with malnutrition and, ironically, obesity (Felton, 2015, Sheiham et al., 2002). Diet and nutrition (along with inflammation and infection) are seen as important biological vectors for the relationship between tooth loss and mortality (Polzer et al., 2010). It is difficult to transfer these findings to people with ID, who face vastly different issues regarding difficulty eating and nutrition than do the general population – for example, malnutrition, a major concern among frail elderly, is a rarity among older adults with ID in Ireland (McCarron et al., 2014) and for whom feeding difficulties are far more complex than seen among the general population (Gravestock, 2003).

Secondly, edentulism is associated with general health. Dental diseases share common risk factors with other chronic, non-communicable diseases (Tyrovolas et al., 2016). A number of reviews, again among the general population have found that edentulism may increase the risk of cardiovascular disease, some cancers, diabetes, asthma, sleep apnoea, physical inactivity, chronic inflammatory changes to the upper gastro-intestinal tract, cognitive impairment, dementia and even death.
(Walls et al., 2000, Felton, 2015, Polzer et al., 2010, Emami et al., 2013). Despite the significance of many of the conditions listed above for the welfare of the ageing population with ID (Haveman, 2009, McCarron et al., 2013), there has been, to date, no research specifically exploring the functional or health impact of edentulism and denture wear among adults with ID.

Thirdly, edentulism directly modifies normal orofacial physiology through alteration of the soft and hard tooth supporting tissues and orofacial musculature, leading to changes in facial height and appearance (Allen and McMillan, 2003, Bhoyar et al., 2012). The result is an aged facial appearance.

Lastly, researchers have also found that edentulism has a psychosocially disabling impact on those who have no teeth, among the population without ID at least. Edentulism is associated with depression (Kassebaum et al., 2014) and edentulous people may avoid participation in social activities (Rodrigues et al., 2012). Unique because of its focus on people with ID, Alves and colleagues found that an unmet need for prostheses was associated with worse quality of life among 119 adults with ID (Alves et al., 2016). Fiske and colleagues demonstrated, in a qualitative study, that denture wearers have low self-confidence, altered self-image and behaviour in socializing and forming close relationships (Fiske et al., 1998). Others found that the psychosocial impact may be offset somewhat, by wearing dentures (Jones et al., 2003), however it seems that implant-retained prostheses, rather than complete removable dentures, may best promote quality of life, amongst the general population at least (Awad et al., 2000). It seems that people with ID may experience less self-consciousness due to poor oral health (Hall et al., 2011), although some authors would disagree (Stiefel, 2002). We simply do not know the psychosocial impact of edentulism and its treatment among this group. While not the focus of the current study, research into oral health related quality of life among people with ID has been limited to impact assessment of dental treatment under anaesthesia (Chang et al., 2014, McGeown and Nunn, 2015). It could be argued that this should be refocused to expand our understanding of the relationship between edentulism, denture wear and oral health related quality of life among people with ID.
2.3.2 Impact of complete denture wear

The immediate effect of denture wear is the replacement of lost hard and soft tissues with prosthetic material, customised to enable function. While this improves oro-facial function it does not fully restore it. In western society, most edentulous older people have dentures. Those who do not wear their dentures are more likely to have nutritional problems than those who do. Do Nascimento et al. reported, in a study of their edentulous patient cohort, that those who do not wear dentures were at an increased risk of being both obese (OR = 2.88, CI=1.14-13.64) and underweight (OR=3.94, CI=1.12-7.40) (Luísa Helena do Nascimento et al., 2013). Saarela and colleagues reported that complete edentulism without denture wear was predictive of malnutrition among their institutionalised sample of 1,475 older adults in residential care (Saarela et al., 2014). Perhaps the explanation for these associations relate to the fact that unremediated edentulism is linked to increased difficulty in eating hard foods, increased mashed food consumption and decreased eating pleasure (Lamy et al., 1999), as well as poorer micronutrient intake (Han and Kim, 2016).

Given these differences, it is probably not surprising that when Polzer and colleagues reviewed the literature on mortality and edentulism, focusing on the remediating impact of denture wear, they found evidence, albeit of moderate to weak strength, that the use of prostheses was associated with reduced risk of death (Polzer et al., 2010). However, denture wear also brings risks. These include an increased risk of stomatitis, candidiasis and oral ulceration, which may offer a port of entry to pathogens and compromise the health of older adults (MacEntee et al., 1993, MacEntee et al., 1998). Denture plaque also has the potential for respiratory pathogenesis, though this is putative (Emami et al., 2013).

Recent research on the prosthetic management of edentulism among adults with ID is limited to a handful of case series reporting implant-supported prostheses (Romero-Perez et al., 2014, Oczakir et al., 2005, Lopez-Jimenez et al., 2003, Griess et al., 1998, Feijoo et al., 2012, Ekfeldt et al., 2013, Durham et al., 2006). With the exception of a handful of articles agreeing that denture wear is low among edentulous adults with ID, complete denture wear tends to have been overlooked by the research community.
2.3.3 Conclusion on the impact of total tooth loss and denture wear in intellectual disability

Complete denture wear is uncommon among adults with ID who lose some or all of their teeth (Hall et al., 2011, Pregliasco et al., 2001, Kendall, 1991). The impact of tooth loss and its management is therefore important for this group. However, the impact of edentulism and denture wear for them is unclear. While we can extrapolate from the research above that edentulism is likely to have a negative impact on older people with ID, and that denture wear may ameliorate this to some degree, the risk from edentulism and the benefit of denture wear are simply unknown.

2.4 Conclusion regarding edentulism and ID

Based on the findings presented and discussed in Section 2.2, there are no nationally representative edentulism data among adults with ID. This limits policy, practice and research in this field. The absence of such data is stultifying: the monitoring of the oral disease burden of this population is impeded; it is impossible to establish and assess comprehensive oral health goals for this population; the development of initiatives to promote health is impeded and the ability to plan and monitor oral health services for this population over time is limited. Comparison with the general population is also impossible, meaning that health inequality goes unnoticed.

2.5 Dental service use for adults with ID

This large section opens with a brief, narrative review of the frequency of dental service use by adults with ID, before reviewing the frequency with which pharmacological supports are provided or needed by adults with ID to receive dental care. The literature on the non-pharmacological supports provided to people with ID, when accessing services, is systematically reviewed later in this section.
2.5.1 Frequency of oral health service use among adults with ID.

2.5.1.1 Background

Adults with ID are said to be the largest underserved population globally, experiencing inequities in health access and outcomes (Lollar and Andresen, 2011). Yet, reported healthcare utilization rates for this population can surpass those of the general population. Dental services are among the most commonly accessed type of support service used by people with ID, far higher than that of the general population (McCarron et al., 2014). It is important to understand the nature of this dental service use by adults with ID: how often services are used, and to understand whether services are appropriate. This information will inform service planning and allow better understanding of the process and outcomes of care. Therefore, this section reviews the frequency of dental service use by adults with ID in the literature.

2.5.1.2 Results and discussion

The literature reviewed in Table 2.2 demonstrates that a consistent proportion of people with ID report a recent visit to the dentist. Between 65% and 77% of people in selected studies visited the dentist within the last year, or at least, reported that they had (See Figure 2.4). This is high relative to the general population: between 2000-2002, 44% of Irish adults, over 65 years of age, reportedly attended the dentist within the last two years (Whelton et al., 2007), whereas in the UK, 59% of adults claimed to be regular attenders in 2009 (Hill et al., 2013). The major limitation of these data is the high reliance on self-report, which often over-represents the frequency of dental attendance (Nuttall and Davies, 1991, Eddie, 1984). This means that actual utilisation may be lower.
<table>
<thead>
<tr>
<th>Study</th>
<th>Design</th>
<th>Aim</th>
<th>Sample and setting</th>
<th>Data collection</th>
<th>Findings and comment</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pradhan, et al., 2009</td>
<td>Cross-sectional</td>
<td>To describe usual pattern of dental attendance, requirement for sedation or general anaesthesia and dental services received</td>
<td>n= 485 adults with physical or intellectual disabilities aged 18–44 years using disability services in Australia. Calculated response rate 485/1448 registered service users.</td>
<td>Postal questionnaires to carers.</td>
<td>Pradhan reported that 73% of adults in the institutions studied attended the dentist at least annually. Risk of systemic difference between those who responded and those who did not.</td>
</tr>
<tr>
<td>Brister, et al, 2008</td>
<td>Patient cohort</td>
<td>Evaluate the dental utilization of Medicaid-enrolled adults in Iowa residential care facilities</td>
<td>n=1,423 Medicaid-enrolled adults in Iowa residential care facilities.</td>
<td>Review of service data for retrospective cohort.</td>
<td>Data based only on the 74% who attended dental services within a year. This compares to 29% of those with public coverage, including Medicaid. Brister found that utilisation declined with age.</td>
</tr>
<tr>
<td>Davies, 2008</td>
<td>Cross-sectional</td>
<td>To design data collection methods.</td>
<td>n=440 adults with ID drawn from local database, convenience sample.</td>
<td>Clinical examination in day centres, community care and family homes.</td>
<td>Davies reported 74% of this sample reported attendance in the previous year.</td>
</tr>
<tr>
<td>Seirawan, et al., 2008</td>
<td>Cross-sectional</td>
<td>To survey the oral health among persons with developmental disabilities (PDD), and to evaluate the impact of the routine</td>
<td>n=102 adults with ID at a regional centre in an underprivileged area of California; age range 18 - 85 yrs. Random selection using</td>
<td>Clinical examination by a single research team across settings. Survey questionnaire data collected using</td>
<td>Seirawan reported that 64.7% of participants had attended dental services in the last year. This varied across residential setting. This study applied random sampling methods but response rates varied across settings. Robust processes of data collection, using modified instruments for data</td>
</tr>
<tr>
<td>Researcher</td>
<td>Study Type</td>
<td>Objective</td>
<td>Sample Size</td>
<td>Data Collection</td>
<td>Findings</td>
</tr>
<tr>
<td>------------</td>
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<td>-------------</td>
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<td>----------</td>
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<tr>
<td>Hall et al., 2008</td>
<td>Cross-sectional survey</td>
<td>The aim of the quantitative strand was to investigate the oral health and dental service use of adults with learning disabilities in Sheffield.</td>
<td>n=628, RR=31.4% response rate. Random sample of 2,000 people on the Sheffield learning disabilities register. Mean age 40.2 years, range 18 to 87 years</td>
<td>Postal questionnaire</td>
<td>Overall 86.0% of participants reported attending the dentist within the past two years, 4.0% attended between two and five years ago, 7.5% more than five years ago and 1.9% reported never attending. Compared to health service figures that suggest only 61.8% had done so. Responses were completed by the individual only in 27.7% of cases, introducing risk of misattribution bias when responses were completed by someone else.</td>
</tr>
<tr>
<td>Stanfield et al., 2003</td>
<td>Cross-sectional survey &amp; retrospective chart review</td>
<td>To investigate changes in the oral healthcare of adults with ID after transfer from long-stay hospital care to community-based care.</td>
<td>n=106 adults with ID, who were in transition from hospital to community care from 1995–1998.</td>
<td>Self-reported attendance from survey post-deinstitutionalisation; chart review to confirm attendance pre-deinstitutionalisation.</td>
<td>Stanfield found that 77% of their sample saw the dentist within a year. Higher rates of attendance and operative care (especially for scaling) were seen in institutional residential set-up. Strengths: High response rate (68%) and access to clinical notes. Weakness: Very few people responded to the element on poor attendance.</td>
</tr>
<tr>
<td>Cumella et al., 2013</td>
<td>Cross-sectional survey</td>
<td>Assess unmet needs and identify how oral care can be provided to adults with ID.</td>
<td>n=60 (50 plus 10 who gave interview data but refused)</td>
<td>Self-reported attendance from survey</td>
<td>Cumella found that 66% claimed to have visited a dentist during the last 12 months, while the remainder gave more...</td>
</tr>
</tbody>
</table>
2001, UK

survey be improved. clinical examination) adults with ID living in the community. Age ranged from 25 and 44 years of age.

Scott et al., 1998, Aus Cross sectional survey To describe the prevalence of oral health problems in adults with DD in Sydney. n=101, a subsample of 202 people with developmental disabilities living in a range of settings in Sydney aged from 21 to 53 years, with a mean of 33yrs.

Oral health assessment

Scott found that 65% of sample attended dentist in last 12 months, more than the age-standardised general public (65% v 50%; OR=1.9; CI=1.3-2.8)
The literature suggests that utilisation of dental services differs by age ID and residential setting. Firstly, the rate of attendance decreases (Brister et al., 2008). The level of ID also impacts on type of service use. In an older study of 350 community dwelling adults with ID across three providers, Kendall found that 74% of people with mild ID attended dental services, while up to 70% of those with a more severe ID, attended the community dental service (Kendall, 1992, Kendall, 1991). Residential setting impacted on how often people attended the dentist. People in residential units are more likely to attend the dentist than their counterparts living independently in the community (Seirawan et al., 2008). This seems to be a social rather than a personal phenomenon. Stanfield, in an insightful case study of a populations’ move from congregated to community care, highlighted inadvertent difficulties that the move into dispersed community living these were cited as reduced frequency of oral examination and preventive care, reported unwillingness of dentists to care for people with ID due to behaviour issues, financial disincentives, and “(supposed) inadequate equipment” (Stanfield et al., 2003). Annual dental review dropped from 100% to 77% in this group as they transitioned into the community (Stanfield et al., 2003).
In conclusion, people with ID are consistently found to be disproportionately high users of dental services, especially when living in supported residential settings. The frequency and type of service use varies depending on level of ID, age and residential setting. Consideration of the demographics of this population is therefore important when planning services and researching the frequency of dental service use.

2.5.2 The need for and use of pharmacological supports

2.5.2.1 Background

Dental treatment is often invasive, which may test patients’ coping capacity. For example, simple root surface instrumentation for the prevention and treatment of periodontal disease, commonly known as a scale and polish, can involve at least two instruments and four hands, delivering sensations of cold, pain and vibration, while the person experiences a restricted capacity to breath and swallow freely. For those with periodontal disease this can be required on a three-monthly basis, for life.

For people with ID, cognitive, physical and behavioural issues may make it difficult to accept such aversive dental stimuli (Morgan et al., 2012). Historically, dentists were often thought to lack the training, time, incentive and perhaps inclination to treat adults with disabilities. They reported that it can be hard to “manage” or support people with disabilities during dental visits (Smith et al., 2010, Casamassimo et al., 2004). Such difficulty in providing care is due to three reasons. Firstly, as stated above, dental care can be difficult to receive (Peltier, 2009, Lyons, 2009). Secondly, people with ID can present with communication, physical, medical, access or behavioural issues (Lyons, 2009), which mean that they are less able to tolerate such stimuli, especially for prolonged or invasive interventions. Lastly, there is a large need for dental treatment among people with ID. In Ireland, for example, periodontal disease is seven times more prevalent among populations with ID than in general and dental caries is often untreated (Whelton et al., 2007, Crowley et al., 2005). Therefore, there is likely to be a high need for both invasive intervention and consequently “behaviour support” to make the receipt of care by populations with ID in Ireland, acceptable. These supports, which can be considered broadly as pharmacological
and non-pharmacological, are routinely applied to facilitate care: pharmacological supports such as general anaesthesia (GA) and conscious sedation are used successfully to provide care to people with ID (McKelvey et al., 2014, Ananthanarayan et al., 1998, Boyle et al., 2000, Ransford et al., 2010). Access to GA and sedation is limited (British Society for Disability and Oral Health/Faculty of Dental Surgery of Royal College of Surgeons of England, 2012, Irish Society of Disability and Oral Health, 2012, Quinn et al., 2006). This is not surprising because the provision of such supports is expensive, with long waiting lists and often undertaken in specialised facilities by multidisciplinary, highly skilled teams. It is important to get an accurate view of how often these resources are used and needed, in order to understand demand and delivery, and to plan for the future. This section considers the relevant literature, in order to establish if there is consensus on how often such supports are needed and used. This has been accomplished by adopting a narrative review of selected articles.

2.5.2.2 Results

Based on the articles listed in Table 2.3 the need for behaviour support is reported in three ways: by a participant’s level of cooperation, scored across a range of indices; by dentists’ guess-estimates as to the need for support for a range of imagined procedures; and by reporting the participants’ previous use of general anaesthesia.
<p>| Table 2.3 Frequency of support use / need for supports / distribution of cooperation |
|----------------------------------------|-------------------|-----------------|-------------------|------------------------|
| <strong>Design</strong>                             | <strong>Aim</strong>           | <strong>Sample</strong>      | <strong>Data collection</strong> | <strong>Measurement</strong>       | <strong>Findings</strong> | <strong>Comment</strong> |
| Morgan et al., 2012, USA               | Retrospective study | To record levels of cooperation and use of behavioural supports, as part of larger set of aims. | n=4,732 adults with IDD using services. | Review of electronic dental records through a state-supported system of dental clinics. | Cooperation: &quot;Cooperation Level Scale&quot; Scored on a seven-point scale (developed by TDF dental clinicians to guide the evaluation of a patient’s ability to accept dental evaluation and treatment procedures during dental clinic visits, on which “0” indicates the least cooperative and “6” the most cooperative. | Morgan reported that 40% required some form of behavioural assistance to receive dental treatment and one-third were able to receive dental treatment without these modalities; 91.3% cooperation level of 3 or higher; 75.9% cooperation levels 4, 5 and 6. Nearly one-quarter had only a limited ability to accept any dental intervention without the application of advanced behaviour management techniques. Reporting unclear and validation not reported. |
| Pregliasco et al., 2001, Italy         | Cross-sectional survey | To estimate levels of cooperation as part of larger set of aims | n=219 residents in long term care with mean age of 61.3 years. | Subjective global cooperation score in among residents to inform service development | Cooperation: Level of Cooperation scored with three categories: good/fair/poor | Pregliasco reported that the degree of cooperation was good for 59.8% and fair for 36.1% and poor for 4.1%. Scores not qualified and validation not reported. |
| Meurs et al., 2010, NL                 | Post-test only experimental design | To investigate the effect of patient information, delivered to the dentist on level of cooperation during a first dental visit. | n=57 dental patients with ID with mean age 24.3 years (range: 4 to 69), randomly allocated from waiting list. | Behaviour scale scored by two calibrated dental student observers, demonstrating acceptable inter-rater reliability. | Cooperation: Behaviour rating scale (van Grunsven); previously published index with five categories: Untreatable(0); Noncooperative(1); Hesitant(2); Passive(3); Cooperative(4) | Meurs reported that 58% of sample were either resistant, uncooperative or untreatable, while 42% were passive or cooperative. A higher level of intellectual functioning is significantly associated with better cooperation. Validation not reported. |
| Crowley et al., 2005, Ire             | Cross-sectional survey. | To estimate levels of cooperation as part of larger set of aims | n=219 adults with ID living in residential care in Ireland. | Data collected in residential care units as part of larger data set. | Need for supports: recorded using a Manageability index. | Crowley felt that 57% likely to accept routine dental care; 23% may require sedation or GA for more extensive treatment and 19% would require GA for invasive dental treatment; 1% |</p>
<table>
<thead>
<tr>
<th>Name</th>
<th>Year</th>
<th>Design</th>
<th>Sample Size</th>
<th>Sampling Method</th>
<th>Disease</th>
<th>Dental Health Needs</th>
<th>Treatment Needs</th>
<th>Sedation Methods</th>
<th>Supporting Evidence</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gray, 2005, NI</td>
<td></td>
<td>Cross-sectional survey</td>
<td>n=269</td>
<td>Sampling unclear</td>
<td>ID over 13 years</td>
<td>Clinical survey in four day centres and a school in summer 2005, alongside routine examinations. Single, trained assessor assessed oral health and the community dentist recorded need for adjunct. Postal questionnaires to carers.</td>
<td>Need for supports: The referring dentist noted whether the treatment found to be needed was likely to be conducted with local anaesthetic (LA), intravenous sedation (IV Sedation) or general anaesthetic (GA).</td>
<td>29% LA, 19% sedation and 31% GA and 21% required no treatment in the dentists’ survey arm focusing on patients. Removing those who do not need treatment, this amounts to 36.7% LA; 24.1% sedation and 39.2% GA of those needing treatment. Data presented in a non-peer reviewed report.</td>
<td>Gray reported subjective recording of adjunct needed: 29% LA, 19% sedation and 31% GA and 21% required no treatment in the dentists’ survey arm focusing on patients. Removing those who do not need treatment, this amounts to 36.7% LA; 24.1% sedation and 39.2% GA of those needing treatment. Data presented in a non-peer reviewed report.</td>
</tr>
<tr>
<td>Pradhan et al., 2009, AUS</td>
<td></td>
<td>Cross-sectional survey</td>
<td>n= 485 adults with physical or intellectual disabilities aged 18-44 years using disability services in Australia. Exhaustive sampling applied.</td>
<td>Need for supports: Recording unclear: Item on survey.</td>
<td>Pradhan reported that 68.1% of participants did not need pharmacological adjuncts, while 18.8% required general anaesthesia for routine dental examination and treatment, and 13.1% were usually treated in the chair under oral sedation. GA and oral sedation mainly for behaviour management. Gradient observed across residential settings. Reporting of item in methods is somewhat unclear.</td>
<td>Pradhan reported that 68.1% of participants did not need pharmacological adjuncts, while 18.8% required general anaesthesia for routine dental examination and treatment, and 13.1% were usually treated in the chair under oral sedation. GA and oral sedation mainly for behaviour management. Gradient observed across residential settings. Reporting of item in methods is somewhat unclear.</td>
<td>68.1% of participants did not need pharmacological adjuncts, while 18.8% required general anaesthesia for routine dental examination and treatment, and 13.1% were usually treated in the chair under oral sedation. GA and oral sedation mainly for behaviour management. Gradient observed across residential settings. Reporting of item in methods is somewhat unclear.</td>
<td></td>
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<tr>
<td>Whyman et al., 1995, NZ</td>
<td></td>
<td>Cross-sectional survey</td>
<td>207 people (91% of population) in residential care; about three quarters had ID.</td>
<td>Need for supports: Examiner assessed feasibility of dental treatment in dental surgery, need for escort nurse and type of sedation and anaesthesia needed.</td>
<td>Whyman found feasibility as follows: 39.6% for LA, 28% for sedation and LA and 32.4% for GA. Subjective measure.</td>
<td>Whyman found feasibility as follows: 39.6% for LA, 28% for sedation and LA and 32.4% for GA. Subjective measure.</td>
<td>Whyman found feasibility as follows: 39.6% for LA, 28% for sedation and LA and 32.4% for GA. Subjective measure.</td>
<td>Whyman found feasibility as follows: 39.6% for LA, 28% for sedation and LA and 32.4% for GA. Subjective measure.</td>
<td></td>
</tr>
<tr>
<td>Reference</td>
<td>Study Type</td>
<td>Study Design/Methodology</td>
<td>Study Objectives</td>
<td>Sample Size/Description</td>
<td>Reported Use of GA</td>
<td></td>
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<tr>
<td>Stanfield et al., 2001, UK</td>
<td>Cross-sectional survey &amp; retrospective chart review</td>
<td>To report frequency of GA as part of larger set of aims including to investigate changes in the oral healthcare of adults with ID after transference from long stay hospital care to community-based care.</td>
<td>Survey post-deinstitutionisation; chart review pre-deinstitutionisation.</td>
<td>n=106 adults with ID, who were in transition from hospital to community care from 1995 – 1998.</td>
<td>Reported use of GA: Survey of GA within one year of discharge and just over 30% had used LA. This is an atypical sample but shows a heavy reliance on pharmacological support.</td>
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<tr>
<td>Feldberg et al., 2014, Israel</td>
<td>Review of surveys undertaken by research team over decades in Israel.</td>
<td>To report frequency of behaviour supports, such as GA as part of larger aim to present the development of current dental services for people with ID in Israel.</td>
<td>Varied data collection methods applied over time. Most recently, based on a standard assessment procedure since 2002. Focus has shifted over the years. Findings discussed focus on use of GA.</td>
<td>n=6,988 people with ID in residential care in Israel in 2008 compared to n=6,022 in 1998.</td>
<td>Reported use of GA: Review of reported use of GA in primary studies by the same team.</td>
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<tr>
<td>Holland et al., 1986, Ire</td>
<td>Cross-sectional survey</td>
<td>To report frequency of GA as part of larger set of aims</td>
<td>WHO standardised methods.</td>
<td>n= 194 people with disabilities attending three institutions in Cork, Ireland</td>
<td>Reported use of GA: Holland reported that 20% of participants needed GA for treatment, while 67% were treatable by students or junior staff.</td>
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</table>
Three studies reported cooperation scores, each using different indices (Morgan et al., 2012, Pregliasco et al., 2001, Meurs et al., 2010). These indices ranged in scoring complexity from good/fair/poor to more elaborate Likert-like indices, with five or seven defined points. Pregliasco et al. simply scored the level of cooperation without elaborating on what this meant; the Cooperation Level Scale reported by Morgan et al. was developed by Tufts Dental Facilities Serving Persons with Special Needs and a Behaviour Rating Scale was reported by Meurs, as developed by van Grunsven, in an unobtainable article cited by Meurs (155), for which inter-rater reliability statistics were reported. Validation was not reported for any index. Pregliasco reported cooperation as fair for most and Morgan et al (81) reported that a quarter of their whole sample would require advanced behaviour management techniques. In total, depending on how the spectrum of coping capacity was categorised, these studies demonstrate that about 40% – 60% of subjects, from two dental patient cohorts and an institution based near Milan, could be classified as having poor cooperation (Morgan et al., 2012, Pregliasco et al., 2001, Meurs et al., 2010).

Four studies reported the differential need for supports to receive future care or care normally for people with ID (Pradhan et al., 2009b, Crowley et al., 2005, Gray, 2005, Whyman et al., 1995). This estimation was undertaken variably and by imagining different treatments. Gray’s estimates were made by treating dentists who knew their patients, while Crowley’s and Whyman’s data were estimated by examiners. Pradhan’s estimates were based on usual need for support, though the exact wording of the variable is unclear. Acknowledging this variation, which limits the validity of any assimilation, these studies are, nonetheless, considered together. By extracting the percentage estimated to need either non-pharmacological support or local anaesthesia, sedation and GA, in each of these studies and developing an unweighted mean, on average, these studies suggested that 50.4% of adults with ID might or normally need non-pharmacological support or LA only (range 36.7%-68.1%), 22% might or normally require sedation (range 13.1%-28%) and 27.6% might or normally need GA (range 18.8%-39.2%), in order to receive a range of dental treatments (Pradhan et al., 2009b, Crowley et al., 2005, Gray, 2005, Whyman et al., 1995).
Lastly, three studies reported the use of GA, as an adjunct to dental care, in the range of 0.5% to 70% (Feldberg and Merrick, 2014, Holland and O'Mullane, 1986, Stanfield et al., 2003). The variation in these proportions reduces the meaningfulness of any average.

**2.5.2.3 Discussion**

The literature reviewed cannot be meaningfully assimilated to identify how often pharmacological adjuncts are needed or used by adults with ID. Based on these articles, about half of people with ID present with “poor cooperation” and a ballpark estimate of 50% might or normally, need pharmacological supports. The use of GA as an adjunct is so variable as to make such ballpark estimates meaningless.

This review highlights a number of issues in the cited literature. Apart from studies reporting on the use of GA, scoring was essentially subjective and at times projectoral. Studies often used ‘judgment’ or non-validated behaviour scores (Gray, 2005, Holland and O'Mullane, 1986, Pregliasco et al., 2001, Morgan et al., 2012, Crowley et al., 2005, Meurs et al., 2010). This highlights the need for consensus and validation of measures of behaviour and support in dental care of people with disabilities. Examples of what is needed can be seen in related fields, such as the Index of Sedation Need (Coulthard et al., 2011). In addition, there were sociodemographic, geographic, chronological and cultural differences between populations and samples, meaning that comparison between studies was fraught. See Feldberg’s reflections for further comment on this element (Feldberg and Merrick, 2014). Study samples were also different in that settings ranged from specialist dental services to accessible care homes.

Aside from the variation observed within the literature reviewed, the review process itself also affects what can be taken from these data. Firstly, the studies reviewed were selected based on non-systematic identification and selection. There is likely to be a much larger literature on this topic, especially in the grey literature. As well, the articles in which these data were observed did not clearly identify themselves as reporting on the topic at hand and therefore selection of studies was difficult. A systematic review on this topic would clarify the results of this section.

In conclusion, the literature has failed to reliably categorise people’s coping capacity for dental treatment (referred to as cooperation or simply, behaviour), which exists across a spectrum. The place of an individual upon this spectrum varies depending on many
contextual variables. The efforts to validly categorise the variables of interest have not led to consensus within the literature. It is impossible to achieve consensus from the literature on how frequently pharmacological adjuncts are needed or used by people with ID: a ballpark estimate of 50% of the time arises from the literature reviewed. There is therefore likely to be a significant but unknown need for both pharmacological and non-pharmacological supports among this group. Therefore, there is a need for research to measure the use and demand for dental sedation and GA for adults with ID. The use of agreed, validated indices would be a good start.

2.5.3 Non-pharmacological behaviour support strategies

2.5.3.1 Introduction

Intellectual disability describes a state of being whereby a person develops impairment in cognitive function as they grow, limiting their ability to adapt behaviour according to their environment. In challenging conditions, this can test coping capacity and limit learning of skills that are vital for autonomy and independence for people with ID. The foregoing indicated that 37%-68% of people with ID, involved in research, rely on non-pharmacological behaviour support alone to receive much of their dental care. The effective use of such approaches, therefore, deserves attention so that practitioners can deliver effective care and reduce reliance on restrictive approaches. There is a need to understand what behaviour support strategies can be applied, for whom, in what situations, for what reasons and with which skills and resources. However, it is not clear what these behavioural support techniques actually are. In this section I report a systematic review that identifies which non-pharmacological behaviour support strategies are reported or recommended specifically for dental care of people with ID and what is the evidence for these strategies.

2.5.3.2 Methods

Study selection

A systematic review was undertaken according to a protocol that was registered with Prospero, which is available at the international prospective register of systematic reviews (Mac Giolla Phadraig and Nunn, 2017). See Appendix 1 for Prisma Checklist. Adhering to this protocol, the following search string was entered into PubMed on 31/12/2016:(((((((behaviour OR behavior)) AND ((dental OR dentist)) AND ((intellectual* OR Learning OR Mental* OR Developmental)) AND ((Disabilit* OR Disabled OR Impair* OR Retard*))))) AND
The search was limited by date due to the changing approaches to behaviour support; studies including children and adults with ID were also included to increase the pool reviewed and in recognition of the prominence of paediatrics in this field. Other sources of literature included authors’ databases, in-article citation searching and consultation with experts. Following title/abstract screening by two reviewers (JN and CMGP) independently, according to criteria below (Table 2.4), full texts were retrieved for articles meeting the selection criteria. Data were extracted and tabulated.

**Table 2.4 Inclusion and exclusion criteria**

<table>
<thead>
<tr>
<th>Population</th>
<th>Inclusion</th>
<th>Exclusion</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Adults or children with ID, or terms likely to include this population a</td>
<td>General population without disabilities; Conditions, specifically identified as not ID e.g. autism, dementia, etc.</td>
</tr>
<tr>
<td>Intervention</td>
<td>Study reports, or recommends, non-pharmacological behaviour support strategies</td>
<td>Study does not report or recommend non-behavioural support strategies</td>
</tr>
<tr>
<td>Context</td>
<td>Focus on people with ID in the dental clinical environment.</td>
<td>Not specifically focused on dental clinical environment</td>
</tr>
<tr>
<td>Date</td>
<td>1996/08/31 to 2016/12/31</td>
<td>&gt; 20 years old</td>
</tr>
<tr>
<td>Design</td>
<td>Clinical Guidelines b, Narrative Reviews, Intervention studies b, Opinion and editorials, Observational studies, Case Series, Qualitative studies</td>
<td>Case reports</td>
</tr>
<tr>
<td>Language</td>
<td>English</td>
<td>Others</td>
</tr>
</tbody>
</table>

*a Including Special Healthcare Needs, Special, Disabled etc.; b These studies were considered when exploring the quality of evidence supporting the use of strategies.

**Quality assessment**

Quality assessment was undertaken for primary and secondary studies if their design allowed for the recommendation of specific support strategies. Therefore, all clinical guidelines (CGs), narrative reviews (NRs) and experimental designs were quality assessed with scoring by two assessors, independently (CMGP and JN). CGs were assessed for quality using AGREE II; NRs were quality assessed using the International Narrative Systematic Assessment Tool, a consensus generated index in which a study is judged on seven criteria. For each criterion, one point can be assigned. A review awarded at least 5 points was considered good (La Torre et al., 2015). Intervention studies were quality assessed using criteria according to the Cochrane Handbook (Higgins and Green, 2011).
Disagreements between the review authors, over the risk of bias in particular studies, was resolved by discussion.

**Synthesis**

A narrative synthesis was structured according to study design and support strategy. Due to the absence of a unique classification system, strategies were categorized based on an emergent mutually exclusive framework of behaviour supports to allow meaningful synthesis. The coding categories were developed inductively as strategies were assimilated, according to the mechanism of action of individual strategies by CMGP and JN. This process was guided by a previously described classification scheme (Glassman et al., 2009). Figure 2.5 offers an outline of the taxonomy emerging from this process, in order to group the strategies identified in the literature. In this synthesis, whether studies reported or recommended strategies was considered as well as whether techniques were defined / well described, or not.

**Confidence in cumulative evidence**

Level of evidence is graded for each technique studied using GRADE. It is important to acknowledge that this synthesis focused on the identified strategies in a dental context, with people with ID only and does not grade the level of evidence for these techniques as they are applied more general, in different contexts or populations.
Figure 2.5 A taxonomy of behaviour support developed for this systematic review

Behaviour support

- Pharmacological support
- Communicative support
- Environmental support
- Physical support

- Behavioural strategies
  - Cognitive strategies
  - Relaxation and distraction-based strategies
  - Control and expectancy-based strategies
  - Communicative strategies

- Physical strategies
  - Social strategies
  - Structural strategies
2.5.3.3 Results

Included articles

Of the 276 articles identified in PubMed, 207 were published within the last 20 years. All 207 were screened by title/abstract. A further 15 articles were identified from other sources (seven from the authors’ database, five from in-article citation searching, and three from consultation with experts). In total, 43 articles were selected for full-text review and 34 were included for synthesis. Studies were excluded based on intervention (n=8) and population criteria (n=1). The Prisma Statement in Figure 2.6 outlines the study flow. A summary of included studies is outlined in Table 2.5.

Figure 2.6 Modified Prisma Statement
### Table 2.5a Summary of Clinical Guidelines

<table>
<thead>
<tr>
<th>Study</th>
<th>Aim</th>
<th>Design</th>
<th>Sample/Population (n)</th>
<th>Data collection</th>
<th>Main focus</th>
<th>Findings</th>
</tr>
</thead>
<tbody>
<tr>
<td>BSDH, 2012</td>
<td>To produce guidance for dental care.</td>
<td>Clinical Practice Guideline</td>
<td>People with ID across the life course</td>
<td>Standard Guideline development assessed, according to the Scottish Intercollegiate Guideline Network (SIGN) classification</td>
<td>General</td>
<td>While specific behavioural approaches such as distraction and reinforcement are suggested for managing SIB or drooling, these are not referred to for supporting dental behaviour. Rather, most suggestions for behaviour support are given as alternatives to clinical holding. Limited focus on this element.</td>
</tr>
</tbody>
</table>

SIB = Self Injurious Behaviour
<table>
<thead>
<tr>
<th>Study</th>
<th>Aim</th>
<th>Design</th>
<th>Sample/Population (n)</th>
<th>Data collection</th>
<th>Main focus</th>
<th>Findings</th>
</tr>
</thead>
<tbody>
<tr>
<td>Connick, et al. 2000</td>
<td>Offer guidance on need for and appropriate use of restraint for people with profound ID</td>
<td>Narrative review</td>
<td>Focus on adults and children with profound ID who require support in specific conditions</td>
<td>Selection strategy clear: Focused review of relevant law and literature.</td>
<td>Restraint</td>
<td>Connick et al. offer an extensive and authoritative discussion on the use of physical intervention for dental care, and related issues. Article endorsed by National Association of Protection and Advocacy Systems (NAPAS)</td>
</tr>
<tr>
<td>Connick, et al. 1999</td>
<td>Consider the strengths and limitations of desensitisation in dentistry for the patient with severe and profound ID</td>
<td>Narrative review</td>
<td>Focus on adults and children with severe and profound ID</td>
<td>Selection strategy clear: Detailed discussion based on classic literature on systematic desensitisation</td>
<td>Systematic Desensitisation</td>
<td>Connick et al. do not recommend systematic desensitisation. Desensitization is explored as modeling, shaping, cueing, prompting, fading, distraction, and reinforcement. Connick et al. separate strategies into communicative and behavioural strategies</td>
</tr>
<tr>
<td>Estrella and Boynton 2010</td>
<td>Offer guidance to dentists on range of issues including behaviour support</td>
<td>Narrative review</td>
<td>Focus on children with special needs</td>
<td>Selection strategy clear: literature cited to support recommendations identified in AAPD guidelines and broader literature.</td>
<td>General</td>
<td>A broad and general article that covers a lot of topics, with a rich discussion of behaviour support techniques.</td>
</tr>
<tr>
<td>Glassman, et al. 2009</td>
<td>Model the decision-making process for choosing support strategies</td>
<td>Narrative review</td>
<td>Focus on adults and children with special needs</td>
<td>Selection strategy clear: Reviewed literature and sought consensus from group of professionals and users</td>
<td>Overview of support strategies</td>
<td>Glassman et al. review position statements and, in some places, guidelines to give an overview of supports explored in subsequent articles. The focus does not reflect the given aim or title.</td>
</tr>
<tr>
<td>Hollingsworth and Kalambouka, 2015</td>
<td>Inform dentists about communication with people with ID who have communication impairments.</td>
<td>Narrative review</td>
<td>Focus on adults and children with IDD with communication problems</td>
<td>Selection strategy unclear: Reviewed literature, policy, and legislation.</td>
<td>Communication</td>
<td>Hollingsworth and Kalambo discuss communication with people with ID, the relevant legal framework in UK and introduce concepts of augmentative communication as a means of behaviour support.</td>
</tr>
<tr>
<td>Ivanoff and Ivanoff, 2014</td>
<td>To make dentists aware of Phelan-McDermid Syndrome and provide recommendations</td>
<td>Narrative review</td>
<td>Focus on children with Phelan-McDermid Syndrome</td>
<td>Selection strategy clear: literature cited to support recommendations identified in NIDCR</td>
<td>General</td>
<td>Ivanoff and Ivanoff provide a brief overview regarding PM Syndrome with some reference to behaviour support, based on limited supporting literature.</td>
</tr>
<tr>
<td>Author, Year</td>
<td>Overview</td>
<td>Focus</td>
<td>Selection Strategy</td>
<td>Behavioural Support</td>
<td>Comments</td>
<td></td>
</tr>
<tr>
<td>-------------</td>
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</tr>
<tr>
<td>Kemp, 2005</td>
<td>Review of general and specifically behavioural approaches that appear in the dental literature</td>
<td>Focus on adults and children with special needs</td>
<td>Selection strategy clear: Expansive in-depth discussion on “representative and selective (not exhaustive or all-inclusive)” literature.</td>
<td>Behavioural support</td>
<td>Broad review considering behavioural approaches to decrease resistance and increase cooperation with appraisal of individual studies. Common characteristics of effective treatments are outlined and their limitations discussed. Strong psychological perspective with practical suggestions.</td>
<td></td>
</tr>
<tr>
<td>Lyons, 2009</td>
<td>Offer expert guidance on the principles of basic behavioural support.</td>
<td>Focus on adults and children with special care needs</td>
<td>Selection strategy unclear: Strategies identified from AAPD document; Clear outline of search strategy in some sections and not in others.</td>
<td>Behavioural support (non-restrictive)</td>
<td>Extended discussion on range of non-invasive, non-pharmacological behavioural techniques, applied to adults with developmental disabilities.</td>
<td></td>
</tr>
<tr>
<td>Nathan, 2001</td>
<td>To act as a practical reference guide regarding pharmacological support for children with disabilities.</td>
<td>Focus on children with disabilities</td>
<td>Selection strategy clear: literature cited to support recommendations</td>
<td>Sedation</td>
<td>Article presents a person-centred focus. Despite a comprehensive menu of approaches with detailed discussion on sedation, the author places strong emphasis on non-restrictive approaches.</td>
<td></td>
</tr>
<tr>
<td>Newton, 2009</td>
<td>To review literature on non-restrictive supports.</td>
<td>Focus on adults with ID and challenging behaviours</td>
<td>Selection strategy unclear: Mainly studies of dental behaviour management in individuals with ID</td>
<td>Behavioural support (non-restrictive)</td>
<td>Newton emphasises the unacceptable nature of restrictive physical supports. Newton’s review highlights that there is a need for research into non-restrictive behaviour management of individuals with intellectual disabilities who require dental treatment.</td>
<td></td>
</tr>
<tr>
<td>Peltier, 2009</td>
<td>Offer expert knowledge regarding dental phobia from literature and experience as applied to people with disabilities</td>
<td>Focus on people with disabilities who have dental fear (Age unclear)</td>
<td>Selection strategy clear: Detailed narrative review of dental phobia literature supporting recommendations</td>
<td>Behavioural support</td>
<td>Introduces techniques commonly applied in dental fear/phobia literature, as applied to adults with disabilities. Many of Peltier’s techniques are transferred from studies of dental phobia. Concludes that while psychological methods with great potential are available, research is lacking, even among those without disabilities.</td>
<td></td>
</tr>
<tr>
<td>Rada, et al, 2015</td>
<td>Offer guidance to orthodontists regarding</td>
<td>Focus on adults and children with IDD</td>
<td>Selection strategy unclear: literature</td>
<td>Sedation</td>
<td>Guidance for orthodontists in delivering care with a focus on pharmacological support. Limited emphasis on</td>
<td></td>
</tr>
<tr>
<td>Author, Year</td>
<td>Title</td>
<td>Focus</td>
<td>Selection Strategy</td>
<td>Behaviour Support</td>
<td>Summary</td>
<td></td>
</tr>
<tr>
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<td></td>
</tr>
<tr>
<td>Raposa, 2009</td>
<td>To offer expert guidance on specific behaviour support techniques available for use with people with IDD</td>
<td>Narrative review</td>
<td>Focus on adults and children with IDD</td>
<td>Selection strategy unclear: literature cited to support recommendations with extended discussion of some references.</td>
<td>Raposa presents a comprehensive range of suggestions, systematically from assessment to treatment for people with disabilities; Recognises lack of evidence base for effective selection of approaches. Raposa uniquely combines a parental and dental perspective.</td>
<td></td>
</tr>
<tr>
<td>Romer, 2009</td>
<td>Expert guidance on physical intervention with people with ID: To review of the literature and applicable laws pertaining to consent issues for people with special needs.</td>
<td>Narrative review</td>
<td>Focus on adults and children with special needs.</td>
<td>Selection strategy clear: systematic approach taken to summarise legislation, case law, and literature.</td>
<td>Romer briefly lists alternatives to physical intervention after a comprehensive and thoughtful review on clinical holding and related issues with list of alternative techniques from paediatric literature. This article covers many aspects of restrictive practice relevant to dentists in the field of Special Care Dentistry.</td>
<td></td>
</tr>
</tbody>
</table>

NIDCR = National Institute of Dental and Craniofacial Research; AAPD = American Association of Paediatric Dentists
<table>
<thead>
<tr>
<th>Study</th>
<th>Aim</th>
<th>Design</th>
<th>Sample/Population (n)</th>
<th>Data collection</th>
<th>Focus</th>
<th>Findings</th>
</tr>
</thead>
<tbody>
<tr>
<td>Faulks et al, 2007</td>
<td>Prospective, longitudinal multi-centre study, to assess use of inhalation sedation in a population with special needs</td>
<td>Pre-experimental design (One shot case study) without control using exhaustive sampling</td>
<td>n=349 Children and adults with ID</td>
<td>Posttest only: Standardised forms measuring indication and outcome of treatment; French modified Venham scale; treatment successfully completed and adverse events.</td>
<td>Sedation</td>
<td>Faulks offers a description of nitrous oxide administration and outcomes. Minimal mention of non-pharmacological strategies.</td>
</tr>
<tr>
<td>Collado et al, 2008</td>
<td>Description of postgraduate study on nitrous oxide training in France</td>
<td>Pre-experimental design (One shot case study) without control using exhaustive sampling</td>
<td>n=45 trainees and 5 experts in the use of conscious sedation, who undertook 1,108 sessions of conscious sedation using nitrous oxide inhalation sedation in hospitals in France over two years: 40% of sessions were undertaken on adults and children with ID</td>
<td>Posttest only: Standardised forms measuring indication and outcome of treatment; French modified Venham scale; treatment successfully completed and adverse events.</td>
<td>Sedation</td>
<td>Collado concludes that Nitrous Oxide / Oxygen sedation, at 50% oxygen, is effective and safe. Levels of adverse effects reported are somewhat higher than those published in similar studies. Minimal mention of non-pharmacological strategies.</td>
</tr>
</tbody>
</table>
| Shapiro et al, 2009   | Evaluate effectiveness of a sensory-adapted dental environment (SADE) on anxiety, relaxation, and cooperation. | Cross-over experimental design with random allocation using convenience sampling with random allocation | n=16 children with disabilities | Pre/post: Behavioural and psychophysiological variables | Environmen
tal sensory strategies v. routine care | Children with disabilities could potentially benefit from SADE. Small sample: References for power calculation are provided but details of calculation unclear. Statistical management of sequence effect reported. Adequate washout interval reported; No blinding but objective measure (EDA) included as outcome. |
<p>| Conyers et al., 2004 | To assess the effectiveness of in-vivo desensitization and video modeling for increasing compliance with dental procedures. | Multiple baseline design across participants, with unclear randomisation using purposive sampling. | n=6 adults with severe to profound ID requiring sedation for dental examination; four required clinical holding; age ranged from 33-54 yrs. | Multiple time points: Number of steps completed in dental procedure adopting task analysis. | Desensitisation v. modeling | Conyers reported a small experiment studying the effect of two interventions on compliance at mocked up dental procedure: Desensitization increased compliance for all 5 participants who used it, whereas video modeling increased compliance for only 1 of 3 participants. This study has limited generalizability because of lab conditions; Also intervention involved resource intensive desensitization. It was not possible to blind, there was a small sample and the impact of crossover effect is not addressed. |
| Meurs et al., 2010 | Investigate whether having background information about a patient with ID would have a positive effect on the level of cooperation during a first dental visit. | Post-test only experimental design with exhaustive sampling with random allocation | n=57 consecutive dental patients (M=24.3 yrs., Range: 4 to 69) with ID, who received a first oral examination at a center for special dental care; randomly assigned to a condition in which the dentist either received information about the patient prior to a dental visit (n=29) or not (n=28). | Posttest only: Level of cooperation displayed, using a behaviour-rating scale. | Information v. control | Meurs found that receiving prior information about patients with intellectual disabilities before the oral examination had no effect on the cooperation scores. Non-random selection limits generalisability but sample reportedly typical of patients seen on waiting list. |
| Altabet, 2002 | To evaluate the effectiveness of desensitisation programme, relative to control | Non-randomised, controlled trial using purposive sampling | n=35 individuals who had been evaluated for dental desensitization v. n=28 on waiting list control | Pre-post: Number of steps completed in dental procedure adopting task analysis, use of sedation, and restraint. | Desensitisation v. Waiting list control | Desensitisation led to increased procedures completed for mocked up routine dental cleanings but no difference in use of sedation or clinical holding. Benefit extended to those who partially completed programme. Desensitisation was intensive: twice a week for 8 weeks minimum. The small sample decreases power and unequal baselines were observed. |</p>
<table>
<thead>
<tr>
<th>Cajares, et al. 2016</th>
<th>Investigate effectiveness of animal assisted therapy in a dental practice caring for individuals with IDD</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pre - posttest design, (non-controlled, nonrandom) using convenience sampling</td>
<td>n=30 patients with ID attending an outpatient setting clinic receiving sedation for scaling; Sixty percent of the patients had a profound level of disability.</td>
</tr>
<tr>
<td>Pre-post: Anxiety scored through anxiety subscale of ADAMS scale Pre-test recorded on entering surgery, post-test after the individual spent 10 minutes with a support dog. Also chart review to score need for assistance entering room, sedation and behavioural record.</td>
<td>Animal assisted therapy</td>
</tr>
<tr>
<td>Cajares reports reduction in anxiety in this pilot. There is no control group or control of sequence effect; inferential statistical methods for continuous data not reported. Clinical impact of a reduction in ADAMS is unknown. Non-randomised; pretest data for 2 of three variables taken from chart at previous visit, which introduces risk of bias.</td>
<td></td>
</tr>
</tbody>
</table>

EDA = electrodermal activity
<table>
<thead>
<tr>
<th>Study</th>
<th>Aim</th>
<th>Design</th>
<th>Sample/Population (n)</th>
<th>Data collection</th>
<th>Focus</th>
<th>Findings</th>
</tr>
</thead>
<tbody>
<tr>
<td>de Castro et al., 2013</td>
<td>Compare acceptance of strategies between parents of children with and without IDD.</td>
<td>Cross-sectional Survey</td>
<td>Eighty parents (40 v 40) of children between 4-8yrs of age shown techniques and asked to score acceptability.</td>
<td>Likert-scale measuring acceptability of presented strategies.</td>
<td>Acceptability of behaviour supports</td>
<td>Basic techniques showed higher rates of acceptance than advanced techniques; Study presents comprehensive menu of techniques taken from AAPD.</td>
</tr>
<tr>
<td>Elango et al., 2012</td>
<td>Compare acceptance of BGTs between parents of children with and without disabilities.</td>
<td>Cross-sectional Survey</td>
<td>Parents of children with and without Special healthcare needs; n=102 divided in three groups.</td>
<td>Acceptability scored on visual analogue scale</td>
<td>Acceptability of behaviour supports</td>
<td>10 behaviour management techniques demonstrated. HOM should be used with great caution.</td>
</tr>
<tr>
<td>Humza Bin Saeed et al., 2012</td>
<td>Measure dentists' knowledge and practice BGTs for adults with ID.</td>
<td>Cross-sectional Survey</td>
<td>Dentists throughout UK: n=53; 37 specialists and 16 non-specialists</td>
<td>Likert-scale measuring acceptability of 15 BGTs.</td>
<td>Knowledge of behaviour supports</td>
<td>All dentists' knowledge of the principles of non-pharmacological BGTs was low. Study presents comprehensive menu of techniques. These included 10 behavioural strategies and five other techniques (pharmacological and physical interventions) derived from the literature. Largely focuses on ethical dilemma of use of restraint, which was found to be more acceptable with use of sedation.</td>
</tr>
<tr>
<td>Marks et al, 2012</td>
<td>Evaluate ethical considerations expressed by dentists in the Benelux towards the use of physical restraint for people with ID</td>
<td>Cross-sectional Survey</td>
<td>Dentists attending specialist SCD meetings in Holland and Flanders: Response rate 66 %; (n = 172) in the Netherlands and 95 % (n = 44) in Belgium. n= 216</td>
<td>Survey measuring reported frequency of use and attitudes towards a number of methods including nitrous oxide sedation and restraint by carers and dental staff.</td>
<td>Use and acceptability of behaviour supports</td>
<td>Newton finds that acceptability is related to outcome. List of ten techniques listed.</td>
</tr>
<tr>
<td>Newton and Sturmey, 2003</td>
<td>Compare acceptability of BGTs among dental students</td>
<td>Cross-sectional Survey</td>
<td>Dental Students in London; n=131 dental students</td>
<td>Standardised measure of the acceptability of behavioural treatment using vignettes in educational setting.</td>
<td>Acceptability of behaviour supports</td>
<td>Becker found that 63% of cases showed improved cooperation and decreased anxiety over the course of</td>
</tr>
</tbody>
</table>
survey mental disability under 21 yrs. orthodontic care. treatment. Limited discussion on non-pharmacological behaviour support.

BGT = Behaviour Guidance Technique; HOM = Hand over mouth technique

<table>
<thead>
<tr>
<th>Study</th>
<th>Aim</th>
<th>Design</th>
<th>Sample/Population (n)</th>
<th>Data collection</th>
<th>Focus</th>
<th>Findings</th>
</tr>
</thead>
<tbody>
<tr>
<td>Chaushu and Becker, 2000</td>
<td>Study the mode of behaviour management used in orthodontic treatment</td>
<td>Retrospective</td>
<td>n=49 children with disabilities who received orthodontic care.</td>
<td>Chart review, extracting scores for standardised behaviour rating scales.</td>
<td>Pharmacological support</td>
<td>While this study aimed to study behaviour management, it only listed sedation, GA and behaviour management explicitly. Study does not expand on what is meant by behaviour support, but highlights the need for a mixture of non / pharmacological approaches in complex care.</td>
</tr>
<tr>
<td>McKelvey et al., 2014</td>
<td>To review GA service</td>
<td>Retrospective cohort/Mixed methods</td>
<td>Adults treated under GA over five years.</td>
<td>Audit of clinical data, 13 interviews of patients /carers.</td>
<td>General Anaesthesia</td>
<td>Study reveals good outcomes from general anaesthesia and makes recommendations to improve experience. A short reference in one paragraph to carer-provided techniques.</td>
</tr>
<tr>
<td>Becker et al., 2009</td>
<td>Expert opinion and narrative review.</td>
<td>Case Series</td>
<td>Orthodontics in children with special needs</td>
<td>Authors use two case reports to illustrate points. Interviews with carers</td>
<td>Pharmacological support</td>
<td>Emphasis is placed on the use of pharmacological modalities.</td>
</tr>
<tr>
<td>Grant et al., 2004</td>
<td>Interviews with carers</td>
<td>Qualitative study</td>
<td>4 vignettes of adults with ID</td>
<td>Interviews with carers</td>
<td>General</td>
<td>Multiple strategies listed in quantitative literature emerge from data in this qualitative study.</td>
</tr>
</tbody>
</table>
Design

Of the 34 included studies, there were: 2 clinical guidelines (CGs); 14 narrative reviews (NRs); 7 experimental designs; 6 cross-sectional surveys; 2 retrospective cohort studies; 1 expert opinion without literature review; 1 case series and 1 qualitative design. These studies are described and quality assessed below according to their study design.

Description and quality of studies

Clinical guidelines

Two CGs offered guidance on behaviour support for children with Special Healthcare Needs and people with ID (Table 2.5a). Both studies focused generally on oral healthcare delivery, rather than specifically on behaviour support techniques, but did make relevant recommendations. The American Academy of Paediatric Dentistry (AAPD) guideline presents a range of support strategies (American Academy of Pediatric Dentistry, 2012). The British Society for Disability and Oral Health (BSDH) guideline recommended strategies across the range of management, particularly as alternatives to clinical holding (British Society for Disability and Oral Health/Faculty of Dental Surgery of Royal College of Surgeons of England, 2012). No evidence supporting the use of the strategies suggested is presented in either guideline so they were not taken into account when considering the strength of evidence further. As Table 2.6 shows, both CGs had areas of strength and weakness, with variable quality, as assessed by two raters.
Table 2.6 Quality assessment of Clinical Guidelines applying Agree II

<table>
<thead>
<tr>
<th>Domain</th>
<th>AAPD</th>
<th>BSDH</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>C</td>
<td>J</td>
</tr>
<tr>
<td></td>
<td>M</td>
<td>N</td>
</tr>
<tr>
<td>Domain 1: Scope and Purpose (Scaled Domain score %)</td>
<td>75%</td>
<td>83%</td>
</tr>
<tr>
<td>The overall objective(s) of the guideline is (are) specifically described.</td>
<td>7</td>
<td>7</td>
</tr>
<tr>
<td>The health question(s) covered by the guideline is (are) specifically described.</td>
<td>3</td>
<td>3</td>
</tr>
<tr>
<td>The health question(s) covered by the guideline is (are) specifically described.</td>
<td>7</td>
<td>6</td>
</tr>
<tr>
<td>Domain 2: Stakeholder Involvement (Scaled Domain score %)</td>
<td>31%</td>
<td>100%</td>
</tr>
<tr>
<td>The guideline development group includes individuals from all relevant professional groups</td>
<td>2</td>
<td>1</td>
</tr>
<tr>
<td>The views and preferences of the target population (patients, public, etc.) have been sought</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>The target users of the guideline are clearly defined</td>
<td>6</td>
<td>6</td>
</tr>
<tr>
<td>Domain 3: Rigour of Development (Scaled Domain score %)</td>
<td>22%</td>
<td>45%</td>
</tr>
<tr>
<td>Systematic methods were used to search for evidence</td>
<td>5</td>
<td>5</td>
</tr>
<tr>
<td>The criteria for selecting the evidence are clearly described.</td>
<td>3</td>
<td>2</td>
</tr>
<tr>
<td>The strengths and limitations of the body of evidence are clearly described</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>The methods for formulating the recommendations are clearly described</td>
<td>4</td>
<td>3</td>
</tr>
<tr>
<td>The health benefits, side effects, and risks have been considered in formulating the recommendations</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>There is an explicit link between the recommendations and the supporting evidence.</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>The guideline has been externally reviewed by experts prior to its publication</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>A procedure for updating the guideline is provided</td>
<td>2</td>
<td>2</td>
</tr>
<tr>
<td>Domain 4: Clarity of Presentation (Scaled Domain score %)</td>
<td>25%</td>
<td>61%</td>
</tr>
<tr>
<td>The recommendations are specific and unambiguous.</td>
<td>1</td>
<td>3</td>
</tr>
<tr>
<td>The different options for management of the condition or health issue are clearly presented</td>
<td>3</td>
<td>3</td>
</tr>
<tr>
<td>Key recommendations are easily identifiable</td>
<td>3</td>
<td>2</td>
</tr>
<tr>
<td>Domain 5: Applicability (Scaled Domain score %)</td>
<td>0%</td>
<td>0%</td>
</tr>
<tr>
<td>The guideline describes facilitators and barriers to its application.</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>The guideline provides advice and/or tools on how the recommendations can be put into practice.</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>The potential resource implications of applying the recommendations have been considered.</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>The guideline presents monitoring and/or auditing criteria.</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Domain 6: Editorial Independence (Scaled Domain score %)</td>
<td>11%</td>
<td>42%</td>
</tr>
<tr>
<td>The views of the funding body have not influenced the content of the guideline.</td>
<td>2</td>
<td>1</td>
</tr>
<tr>
<td>Competing interests of guideline development group members have been recorded and addressed.</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Rate the overall quality of this guideline</td>
<td>2</td>
<td>3</td>
</tr>
</tbody>
</table>

65
**Narrative reviews**

Narrative review (NR) was the most commonly adopted design in the literature reviewed. A narrative review summarises primary studies into a holistic synthesis shaped in part by the reviewers’ experience. Fourteen NRs offered recommendation based on the literature for dentists, orthodontists or dental care professionals (See Table 2.5b). Four reviews focused on a variety of behavioural or psychological supports (Lyons, 2009, Newton, 2009, Peltier, 2009, Kemp, 2005) and two on sedation (Nathan, 2001, Rada et al., 2015). Two were more general reviews, which considered behaviour support as a sub-section of the study topic (Estrella and Boynton, 2010, Ivanoff and Ivanoff, 2014), while others were more focused, exploring, for example, systematic desensitization (Connick et al., 1999), communication (Hollingsworth and Kalambouka, 2015), and physical restraint (Connick et al., 2000, Romer, 2009). One review summarised a broader set of guidance documents under general headings such as behavioural support and physical support (Glassman et al., 2009). Eight of these studies met the criteria for high quality (Table 2.7). The extent to which these studies reviewed the literature varied greatly. Reference lists ranged from 10 to 150 citations. Some authors, such as Raposa, relied heavily on personal perspective in shaping their report (Raposa, 2009), while others, such as Kemp (168), Newton (167) and Peltier (149) gave detailed appraisal of select primary research to support their recommendations. Many of the authors acknowledge a lack of relevant scientific evidence for the use of behaviour support among people with disabilities (Kemp, 2005, Nathan, 2001, Newton, 2009, Peltier, 2009).
Table 2.7 Quality assessment of narrative reviews

<table>
<thead>
<tr>
<th>Review</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Ivanoff and Ivanoff, 2014</td>
<td>0</td>
<td>1</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Raposa, 2009</td>
<td>0</td>
<td>1</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Rada et al., 2015</td>
<td>0</td>
<td>1</td>
<td>0</td>
<td>0</td>
<td>1</td>
<td>0</td>
<td>2</td>
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<td>Hollingsworth and Kalambouka, 2015</td>
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<td>Connick et al. 2000</td>
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<td>Connick et al. 1999</td>
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<td>Kemp, 2005</td>
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<td>Lyons, 2009</td>
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<td>Nathan, 2001</td>
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<td>Newton, 2009</td>
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<td>Pelletier, 2009</td>
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<td>Romer, 2009</td>
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</tbody>
</table>

1=Background of the study clearly explained / state of the art; 2=Objective is clear a;
3=Description/Motivation of selection of studies; 4=Description of study characteristics included is clear; 5=Presentation of results (paragraphs, tables, synthesis of data); 6=Conclusion is clear;
7=Conflict of interest is stated (if existing and if no statement bad). Score (>5=Good)

**Intervention studies**

As Table 2.5c demonstrates, seven experimental studies were identified (Altabet, 2002, Collado et al., 2008, Conyers et al., 2004, Faulks et al., 2007, Meurs et al., 2010, Shapiro et al., 2009, Cajares et al., 2016). Two pre-experimental studies, adopting one-shot case study design, measured the effectiveness of 50% nitrous oxide among adults and children with ID. These clearly had a focus on pharmacological support (Collado et al., 2008, Faulks et al., 2007) and were included only because they also reported or recommended non-pharmacological approaches. Given their main focus on pharmacological supports, they are not considered further here. Of the five, non-pharmacological intervention studies reviewed, four were controlled (Conyers et al., 2004, Shapiro et al., 2009, Meurs et al., 2010, Altabet, 2002) and one was not (Cajares et al., 2016). All adopted non-random selection, mainly due to issues regarding appropriate care management. Two applied random allocation (Meurs et al., 2010), while allocation was unclear in one study (Conyers et al., 2004). One study adopted a pre-experimental, one-shot case study design (Meurs et al., 2010), while the rest included measurement of the dependent variables on at least one occasion, pre- and post-test. All studies had elements at high risk of bias (Table 2.8).
Table 2.8 Quality assessment of intervention studies

<table>
<thead>
<tr>
<th>Study</th>
<th>Random sequence (selection bias)</th>
<th>Allocation concealment (selection bias)</th>
<th>Blinding - Patient</th>
<th>Blinding – Operator/Outcome assessor</th>
<th>Incomplete outcome assessment</th>
<th>Free of selected reporting</th>
<th>Free of other bias</th>
</tr>
</thead>
<tbody>
<tr>
<td>Shapiro et al. 2009</td>
<td>+</td>
<td>-</td>
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<td>-</td>
<td>+</td>
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<td>Conyers et al. 2004</td>
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<td>Meurs et al., 2010</td>
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<tr>
<td>Altabet, 2002</td>
<td>-</td>
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<td>-</td>
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<td>+</td>
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<td>-</td>
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<tr>
<td>Cajares et al. 2016</td>
<td>-</td>
<td>-</td>
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<td>-</td>
<td>-</td>
<td>+</td>
<td>-</td>
</tr>
</tbody>
</table>

- = High risk of bias, + = Low risk of bias, NA = Not applicable due to no control or non-blinding.

Cross-sectional surveys

The quality of these studies was not formally assessed. Of the 6 cross-sectional surveys reviewed (Table 2.5d), three aimed to measure knowledge, practice or attitudes towards physical, pharmacological or communicative behavioural supports among dentists or dental students (Humza Bin Saeed et al., 2012, Marks et al., 2012, Newton and Sturmey, 2003), while two measured attitudes of parents whose children did or did not have disabilities (de Castro et al., 2013, Elango et al., 2012). These studies presented between two and fifteen behaviour support techniques to between 80 and 216 participants for scoring, based on the variable of interest. Comparisons between subgroups were made where appropriate. One study listed definitions for the techniques tested (Elango et al., 2012). Two reported that they undertook a literature review to identify the techniques investigated (Humza Bin Saeed et al., 2012, Marks et al., 2012), while one reported strategies taken from AAPD guidelines (de Castro et al., 2013). One other study reported the difficulties identified in treating 37 children and young adults with ID, concluding that most orthodontic care was managed successfully and to completion with a mixture of support techniques, including gaining the patients' trust (rapport); acclimatization, general anaesthesia (GA) and sedation (Becker et al., 2001).
Opinion, case series, retrospective, qualitative and mixed methods studies.

These studies were not formally quality assessed. Emphasizing the use of pharmacological support to deliver orthodontic care, a case series of two people with ID undergoing orthodontics was reported, offering expert guidance for the management of orthodontic treatment for children with ID (Becker et al., 2009). Scheduling of appointments; Tell-show-do, positive and negative reinforcement, Sedation/GA, were recommended as options. The study by Chaushu et al., of 49 children with disabilities, advocated a behaviour management approach in orthodontic care, simply reporting "behaviour management" as an alternative to pharmacological support, without further explanation (Chaushu and Becker, 2000).

All of the orthodontic literature reviewed was from this same group, who mostly emphasised that orthodontic appliances (braces) can be provided to people with disabilities, particularly with the appropriate use of sedation.

McKelvey and colleagues in New Zealand reported the outcomes from 168 patients with ID who received GA, alongside qualitative interviews in a concise mixed methods study (McKelvey et al., 2014). The authors highlighted the importance of leveraging carers and family members to support behaviour in the dental environment. In a qualitative study of ten “key players” in Australia, Grant and colleagues (194) identified a number of strategies to achieve positive, minimally restrictive outcomes from dental care. Strategies emerging from the data included "giving it a go"; maintaining consistency; taking as much time as needed; respecting and encouraging choice making, good communication, scheduling appointments; assisting the person with disability to learn skills and desensitisation.

One opinion piece, produced by the National Institute of Dental and Craniofacial Research and reviewed by a panel of experts, was developed to provide practical advice for those interested in the oral care of people, without reference to the literature (National institute of Dental and Craniofacial Research, 2009).

Synthesis

This synthesis summarises the strategies reported or recommended in the literature to support people with ID, in order to receive dental care before
reviewing the strength of the supporting evidence. Strategies identified in the literature are listed in Table 2.9.

Table 2.9 Reported or recommended strategies of non-pharmacological behaviour support

<table>
<thead>
<tr>
<th>Support Behaviour</th>
<th>Strategy</th>
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<tbody>
<tr>
<td>Behavioural</td>
<td><strong>Reinforcement</strong> (Raposa, 2009, Connick et al., 1999, Kemp, 2005)</td>
</tr>
<tr>
<td></td>
<td>Behaviour modification (British Society for Disability and Oral Health/Faculty of Dental Surgery of Royal College of Surgeons of England, 2012, Connick et al., 1999)</td>
</tr>
<tr>
<td></td>
<td>Negative reinforcement / Contingent escape (Humza Bin Saeed et al., 2012, Elango et al., 2012, Lyons, 2009, Newton, 2009, Becker et al., 2009)</td>
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<tr>
<td></td>
<td>Differential reinforcement (Newton, 2009, Kemp, 2005)</td>
</tr>
<tr>
<td></td>
<td>Cueing, prompting and fading (Connick et al., 1999)</td>
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<tr>
<td></td>
<td>Escape extinction (Lyons, 2009, Kemp, 2005)</td>
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<td></td>
<td>Positive punishment (Kemp, 2005)</td>
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<td></td>
<td>In vivo modeling (Elango et al., 2012)</td>
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<td></td>
<td>Video modeling (Conyers et al., 2004)</td>
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<td></td>
<td>Systematic Desensitisation (Peltier, 2009, Connick et al., 1999)</td>
</tr>
<tr>
<td></td>
<td>Stepwise introduction to office and procedures (British Society for Disability and Oral Health/Faculty of Dental Surgery of Royal College of Surgeons of England, 2012, Rada et al., 2015, Ivanoff and Ivanoff, 2014, Becker et al., 2001)</td>
</tr>
<tr>
<td></td>
<td>Cognitive restructuring (Peltier, 2009)</td>
</tr>
<tr>
<td></td>
<td>Normalise anxiety (Peltier, 2009)</td>
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<td></td>
<td>Reduce distractions (National institute of Dental and Craniofacial Research, 2009)</td>
</tr>
<tr>
<td></td>
<td>Relaxation techniques (Faulks et al., 2007, Collado et al., 2008, Newton and Sturmey, 2003)</td>
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<td></td>
<td>Breathing exercises (Peltier, 2009, Kemp, 2005)</td>
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<td></td>
<td>Guided imagery (Marks et al., 2012, Peltier, 2009, Lyons, 2009, Kemp, 2005)</td>
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<td></td>
<td>Hypnotherapy (Marks et al., 2012, Peltier, 2009, Lyons, 2009, Kemp, 2005)</td>
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<tr>
<td></td>
<td>Embedded commands (British Society for Disability and Oral Health/Faculty of Dental Surgery of Royal College of Surgeons of England, 2012)</td>
</tr>
</tbody>
</table>
| Control and expectancy based | Give control (Peltier, 2009, Kemp, 2005, Connick et al., 1999)  
Stop signals (Peltier, 2009)  
Non-contingent escape (Humza Bin Saeed et al., 2012, Lyons, 2009, Newton, 2009)  
Countdown (Raposa, 2009, Peltier, 2009)  
Information (Ivanoff and Ivanoff, 2014, Collado et al., 2008, Kemp, 2005, Meurs et al., 2010)  
Consistency (Grant et al., 2004, British Society for Disability and Oral Health/Faculty of Dental Surgery of Royal College of Surgeons of England, 2012, Lyons, 2009, National Institute of Dental and Craniofacial Research, 2009)  
Manageable discomfort (Connick et al., 1999) |
| --- | --- |
Good verbal contact (Collado et al., 2008)  
Simple commands (Estrella and Boynton, 2010)  
Requests (Kemp, 2005)  
Reassurance (Collado et al., 2008, Faulks et al., 2007)  
Para verbal (Kemp, 2005, Peltier, 2009)  
Sign language, body gestures, photographs, symbols, drawings, widgets (Hollingsworth and Kalambouka, 2015)  
Eye contact and facial expression (Raposa, 2009, Kemp, 2005)  
Augmentative approaches (British Society for Disability and Oral Health/Faculty of Dental Surgery of Royal College of Surgeons of England, 2012)  
Rapport  
Gain trust (Becker et al., 2001, Becker et al., 2009)  
Show interest (Peltier, 2009)  
Show affection (Kemp, 2005)  
Humanistic approach (respect patients’ dignity as a human being) (Kemp, 2005) |
| Environmental strategies | Physical environment  
Dental home (American Academy of Pediatric Dentistry, 2012)  
Sensory Adapted Dental Environment (SADE) (Shapiro et al., 2009)  
Environmental adaptation - toys, fish tank, music, posters (Kemp, 2005)  
Prosthetic dental environment (Kemp, 2005)  
Soothing atmosphere (Peltier, 2009)  
Social environment  
Support from carer (McKelvey et al., 2014)  
Animal assisted therapy/companion animal (Kemp, 2005, Cajares et al., 2016)  
Behaviour management specialists from outside dental profession (Connick et al., 2000)  
Structural environment  
Appointment length and timing (Raposa, 2009, National institute of Dental and Craniofacial Research, 2009)
Flexibility (Lyons, 2009)
Treatment postponement / suspension (Kemp, 2005)

<table>
<thead>
<tr>
<th>Physical strategies</th>
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<tbody>
<tr>
<td>Patient positioning (Estrella and Boynton, 2010)</td>
</tr>
<tr>
<td>Immobilisation (Ivanoff and Ivanoff, 2014, National institute of Dental and Craniofacial Research, 2009)</td>
</tr>
<tr>
<td>Manual fixation by carer (holding hand) (Marks et al., 2012)</td>
</tr>
<tr>
<td>Hand over mouth with airway restriction (Kemp, 2005, Humza Bin Saeed et al., 2012, Newton, 2009)</td>
</tr>
</tbody>
</table>

*Literature cited does not necessarily recommend techniques. See text below for expanded discussion. Reported strategies not included in the list include Behaviour management / behaviour support (American Academy of Pediatric Dentistry, 2012, Chaushu and Becker, 2000, Glassman et al., 2009), Psychological support (Pelletier, 2009, Glassman et al., 2009), Communicative supports (British Society for Disability and Oral Health/Faculty of Dental Surgery of Royal College of Surgeons of England, 2012), Combined multi-component interventions within a single approach (Newton and Sturmey, 2003, Kemp, 2005)*

**Reinforcement**

Behaviour modification (British Society for Disability and Oral Health/Faculty of Dental Surgery of Royal College of Surgeons of England, 2012, Connick et al., 1999) describes the systematic use of principles of learning to increase the frequency of desired behaviours. It is applied in real world settings, such as in dental care, by applying a range of strategies that operate according to the contingencies of behaviour. These contingencies hold that behaviour is learned under the influence of antecedents and consequences, which can be manipulated to reinforce behaviour through operant conditioning. Some antecedents observed in this review, such as prompting (Connick et al., 1999) and modeling (Humza Bin Saeed et al., 2012, Romer, 2009, Lyons, 2009, Conyers et al., 2004, Newton, 2009, Kemp, 2005, Connick et al., 1999), are introduced before the desired behaviour to increase the likelihood of it occurring.

Within this context, the literature mainly reports consequences of behaviour. Many studies report reinforcement (Raposa, 2009, Connick et al., 1999) particularly positive (Ivanoff and Ivanoff, 2014, de Castro et al., 2013, Humza Bin Saeed et al., 2012, Elango et al., 2012, Raposa, 2009, Becker et al., 2009, Romer, 2009, Collado et al., 2008, Faulks et al., 2007, Grant et al., 2004, Newton and 72
Sturmey, 2003, Lyons, 2009, Kemp, 2005) and negative (Becker et al., 2009) to increase the likelihood of preferred behaviour occurring. The literature transfers these principles to the context of supporting people with ID in dental care by recommending rewards (Raposa, 2009, National institute of Dental and Craniofacial Research, 2009), with Newton offering an often used example: stickers (Newton and Sturmey, 2003). This explains the “positive” aspect by the positive application of a reinforcer. Kemp emphasises the importance of contingency when giving reward by reminding readers to be discriminant in how rewards are applied and avoiding non-contingent reward (Kemp, 2005). The “negative” element of reinforcement implies the removal of an (aversive) antecedent, once the preferred behaviour occurs (Becker et al., 2009) and is more often referred to as contingent escape in the literature reviewed (Humza Bin Saeed et al., 2012, Elango et al., 2012, Lyons, 2009, Newton, 2009). While Newton considers it restrictive (Newton, 2009), Kemp recommends punishment (Kemp, 2005) within the technical, rather than lay, meaning of the word – giving the example of applying verbal reprimands.

These basic principles, of behaviour modification, are applied in a number of related ways in the literature. Shaping is recommended by a number of authors (Raposa, 2009, Lyons, 2009) and positively not, by another (Connick et al., 1999). Shaping describes the process of reinforcing successive approximations of the preferred behaviour (Kazdin, 2012). This is somewhat contrary to escape extinction, which involves removing the reinforcement received from avoiding a task or situation, by engaging in a disruptive behaviour (Kemp, 2005).

Newton and Kemp advise that, by responding discriminately to behaviour, it is possible to differentially reinforce other behaviour as a means of conditioning behaviour for learning (Newton, 2009). According to Kemp, the principle of differential outcomes “refers specifically to the increase in [learning] that occurs when each of two or more discriminative stimuli is correlated with a particular outcome” (Kemp, 2005). Raposa (Raposa, 2009) recommends a programme called D-Terminated, developed by Tesini, which is a multicomponent programme involving chaining and reinforced practice. Reinforced practice involves learning by repetition and reinforcement (Kazdin, 2012). The reviewed literature seems to
infer this process by reporting repetitive tasking (Raposa, 2009, Lyons, 2009, Kemp, 2005), and “massed practice” (Kemp, 2005).

**Desensitisation**

Desensitisation (Ivanoff and Ivanoff, 2014, Raposa, 2009, Romer, 2009, Grant et al., 2004, Estrella and Boynton, 2010, Lyons, 2009, Conyers et al., 2004, Newton, 2009, Kemp, 2005, Conners et al., 1999) is one of the most commonly reported behavioural supports in the literature reviewed. However, there is no clear agreement as to what it actually is. Kemp (168), who is also cited by Lyons (150), approaches this from a psychologists’ rather than dentists’ perspective and describes a process similar to Systematic Desensitisation as described by Wolpe: “the gradual exposure of the patient to the feared object or situation, with the concurrent training of and reinforcement of relaxation as a response incompatible with anxiety or fear. It may or may not include active coping skills, and can be conducted in imagination, by videotape, or live.”

Conyers et al. maintain that there are two basic psychological principles relevant to their version of desensitization: demand fading and differential reinforcement (Conyers et al., 2004). Demand fading describes a process of engaging in subsequent steps only when compliance was observed with previous steps; reinforcement is considered below. Connick (Connick et al., 1999), who tends to use the terms desensitization, systematic desensitization and behaviour modification interchangeably, explains desensitization as a mix of modeling, shaping, cueing, prompting, fading, distraction and reinforcement. Clearly not a fan, Connick goes on to describe the use of desensitisation as a “dangerous experiment”, when applied to people with disabilities. However, desensitization as a technique, appears to be accepted by parents and practiced by many dentists (Elango et al., 2012, Humza Bin Saeed et al., 2012).

Two studies, adopting task analysis, found desensitization effective in increasing tolerance for dental care (Conyers et al., 2004, Altabet, 2002). However, the test conditions were prosthetic and the time allocated extensive, bearing little resemblance to how this technique can be, or often is, applied in dental practice as per Connick et al., as cited by Lyons (Lyons, 2009). Rather, in general dental practice, desensitization is ongoing and integrated into the process of delivering
care (Roberts et al., 2010). In practice, the classic step of constructing an hierarchy of aversive stimuli is skipped, and rather stimuli are gradually exposed to the patient, adopting a typical, implied hierarchy such as: attending the surgery; entering the operatory; sitting on the dental chair; visual examination; digital examination, prophylaxis, topical anaesthetic etc. In these ways, the process of desensitization, as used in dentistry for people with ID, is not synonymous with systematic desensitisation. Rather, it fits more closely with the term acclimatisation (British Society for Disability and Oral Health/Faculty of Dental Surgery of Royal College of Surgeons of England, 2012, National institute of Dental and Craniofacial Research, 2009, Becker et al., 2001, Rada et al., 2015) The latter describes a stepwise approach of exposing patients to the dental office (Ivanoff and Ivanoff, 2014) and procedures (Rada et al., 2015, British Society for Disability and Oral Health/Faculty of Dental Surgery of Royal College of Surgeons of England, 2012) to promote low anxiety and build coping capacity.

**Modeling**

Modeling (Humza Bin Saeed et al., 2012, Romer, 2009, Lyons, 2009, Conyers et al., 2004, Newton, 2009, Kemp, 2005, Connick et al., 1999) involves learning by observation of the desired behaviour in another. This technique adopts concepts of Bandura’s Social Learning Theory (Bandura and Walters, 1977), and is applied, within an operant conditioning lense, as an antecedent to increase the likelihood of appropriate behaviours occurring. The literature gives examples of both live (Elango et al., 2012) and video modeling (Conyers et al., 2004). Raposa (Raposa, 2009) extends this concept when recommending “educational modeling”, which includes clear, understandable directions, adopting a broader concept of modeling.

**Cognitive strategies**

In general, the literature reports the use of psychological support (Peltier, 2009, Glassman et al., 2009). In this context this is understood to mean a range of cognitive approaches. Cognitive strategies reported in the literature include restructuring (Peltier, 2009), whereby negative thoughts are identified, challenged and reframed. This is similar, in some ways to the cognitive component of Cognitive Behaviour Therapy, which is recommended for adults with ID (Peltier, 2009, Kemp, 2005, Humza Bin Saeed et al., 2012). One of the studies reviewed discussed some difficulties regarding such cognitive approaches with people with
ID due to impaired attention and difficulty adhering to “homework” (Kemp, 2005). Indeed, some people with severe to profound ID in particular, may be unable to attend to, comprehend, verbalise, rationalise, or conceptualise and therefore engage with their thought processes surrounding dental anxiety and other associated experiences. Therefore, it may be necessary to focus on the behavioural elements of such therapies in this group. Other, more general psychological support strategies include normalising anxiety (Peltier, 2009).

**Relaxation and distraction based strategies**

Relaxation and distraction are reported as further strategies to support adults with ID to receive dental care. Simple relaxation techniques are reported by a number of authors (Faulks et al., 2007, Collado et al., 2008, Hinchliffe et al., 1988, Sale et al., 2002, Newton and Sturme, 2003). Specific examples include breathing exercises (Peltier, 2009, Kemp, 2005) and guided imagery (Peltier, 2009). In a similar manner, hypnotherapy is also recommended (Marks et al., 2012, Peltier, 2009, Lyons, 2009, Kemp, 2005). The BSDH specifically refer to embedded commands (British Society for Disability and Oral Health/Faculty of Dental Surgery of Royal College of Surgeons of England, 2012), an Ericsonian approach to subliminal suggestion. Distraction (Ivanoff and Ivanoff, 2014, de Castro et al., 2013, Humza Bin Saeed et al., 2012, Romer, 2009, Faulks et al., 2007, Nathan, 2001, Peltier, 2009, Lyons, 2009, Kemp, 2005, Connick et al., 1999) is recommended by a number of studies, while NIDCR opinion recommends the opposite: reducing distractions (National institute of Dental and Craniofacial Research, 2009).

**Control and expectancy based strategies**

By giving patients control and information, so that they can better understand what is asked of them, patients can develop strategies to deal with the demands this may present. One commonly cited strategy is giving or transferring locus of control to the patient (Peltier, 2009, Kemp, 2005, Connick et al., 1999, Collado et al., 2008, Faulks et al., 2007). Given the inherent aversive nature of some dental procedures, discomfort may not be avoidable, rather efforts can be made to make it manageable (Connick et al., 1999). In the literature reviewed, the use of stop signals for people with ID is one example how dentists can reduce anxiety, by giving patients control (Peltier, 2009).
The literature also recommends or reports (Humza Bin Saeed et al., 2012, Lyons, 2009, Newton, 2009), non-contingent escape, whereby the cessation of an aversive stimulus is not dependent on response, but is offered regardless, such as by offering a break. This can be interspersed by counting, to let patients know when to expect these breaks and to increase coping capacity (Raposa, 2009, Peltier, 2009).

Anxiety can also be reduced by letting patients know what to expect. Strategies in the literature that adopt this approach include Tell-Show-Do (TSD) (Ivanoff and Ivanoff, 2014, de Castro et al., 2013, Humza Bin Saeed et al., 2012, Elango et al., 2012, Raposa, 2009, Becker et al., 2009, Faulks et al., 2007, Estrella and Boynton, 2010, Lyons, 2009, Kemp, 2005, Connick et al., 1999). A number of studies recommend delivering care in a consistent manner that is, therefore, predictable to the patient (Grant et al., 2004, British Society for Disability and Oral Health/Faculty of Dental Surgery of Royal College of Surgeons of England, 2012, Lyons, 2009, National institute of Dental and Craniofacial Research, 2009). Another approach to supporting behaviour was sharing information regarding the treatment (Ivanoff and Ivanoff, 2014, Collado et al., 2008, Kemp, 2005, Meurs et al., 2010). Kemp felt that the literature he reviewed was equivocal regarding the impact of providing information to patients (Kemp, 2005). Meurs et al. experimentally studied the impact of prior information for the dentist and found it to be ineffective (Meurs et al., 2010).

**Communicative strategies**

2009) and non-verbal (Hollingsworth and Kalambouka, 2015, Humza Bin Saeed et al., 2012, Raposa, 2009, Collado et al., 2008, Kemp, 2005, Connick et al., 1999) aspects of communication. Non-verbal communication is emphasised in this literature and includes strategies such as using sign language, body gestures, photographs, symbols, drawings, widgets (Hollingsworth and Kalambouka, 2015), judicious use of eye contact (Raposa, 2009), facial expression (Kemp, 2005) and more general augmentative techniques (British Society for Disability and Oral Health/Faculty of Dental Surgery of Royal College of Surgeons of England, 2012).

Rapport (Becker et al., 2001) describes the development of a relationship between patient and dentist built on mutual trust. The literature recommends this as a means of support. Kemp (168) suggests showing affection and adopting a humanistic approach, that respects the dignity of the patient as a human being in order to promote this relationship. Peltier suggests showing a genuine interest in the patient with intellectual disability (Peltier, 2009).

Environmental strategies

The literature reports strategies that may work by manipulating the physical, social and structural environment for dental visits. One article suggests the application of the ‘dental home’ concept (American Academy of Pediatric Dentistry, 2012). One cross-over experiment found evidence for a Sensory Adapted Dental Environment (SADE), which involved modifying the sensory environment through lighting, sound, smell, as well as pressure using a “Butterfly wrap” (Shapiro et al., 2009). One other study suggested a more natural environmental adaptation including fish tank, music, posters (Kemp, 2005), while Peltier recommends more generally, a soothing atmosphere (Peltier, 2009).

Fidgets, toys and comforters were also suggested by other studies (Ivanoff and Ivanoff, 2014, Raposa, 2009, Kemp, 2005, National institute of Dental and Craniofacial Research, 2009). One study discussed the use of a mocked-up dental environment to allow practice in a simulated setting (Kemp, 2005), which would seem rather resource intensive. Social supports reported in the literature include seeking support from carers (McKelvey et al., 2014) while one study recommended the consultation of behaviour management specialists from outside the dental profession (Connick et al., 2000). A number of authors advised the
selective presence of others through parental or carer presence or absence (de Castro et al., 2013, Raposa, 2009, Lyons, 2009, National institute of Dental and Craniofacial Research, 2009). The use of animals was studied by Cajares in a pilot study (Cajares et al., 2016) that showed promise and has led to ongoing research. Kemp also recognises the value of companion animals (Kemp, 2005).

The structure and scheduling of dental appointments can be modified to offer support to people with ID (Hollingsworth and Kalambouka, 2015, Ivanoff and Ivanoff, 2014, Raposa, 2009, Becker et al., 2009, Estrella and Boynton, 2010, American Academy of Pediatric Dentistry, 2012, British Society for Disability and Oral Health/Faculty of Dental Surgery of Royal College of Surgeons of England, 2012, National institute of Dental and Craniofacial Research, 2009). Examples include adjusting appointment length and timing (Raposa, 2009, National institute of Dental and Craniofacial Research, 2009). Appointments can also be scheduled to accommodate other appointments, medication and other aspects of daily routine to maximise coping capacity (British Society for Disability and Oral Health/Faculty of Dental Surgery of Royal College of Surgeons of England, 2012). Equally, a flexible approach is also recommended (Lyons, 2009), giving the option to postpone or suspend treatment if necessary (Kemp, 2005).

**Physical strategies**

Physical supports listed in the literature mostly involved limiting movement of the person with ID in order to receive dental care. The only exception suggested using patient positioning to support behaviour (Estrella and Boynton, 2010), while mouth props were recommended by two groups (Elango et al., 2012, Nathan, 2001).

In the literature reviewed, multiple definitions for procedures, which aim to restrict movement were described. It was often difficult to differentiate between descriptions of restrictive physical supports, which included clinical holding and physical restraint (Rada et al., 2015, Romer, 2009, Nathan, 2001, Connick et al., 2000, British Society for Disability and Oral Health/Faculty of Dental Surgery of Royal College of Surgeons of England, 2012, Newton, 2009, Kemp, 2005, Glassman et al., 2009, American Academy of Pediatric Dentistry, 2012), defined as “any manual method, physical, or mechanical device, or material, or equipment attached or
adjacent to the resident's body, which the individual cannot remove easily and restricts freedom of movement or normal access to one's body” (Connick et al., 2000), which includes the use of devices, or “the use of physical holds (clinical holding), to assist or support a patient to receive clinical dental care or treatment in situations where their behaviour may limit the ability of the dental team to effectively deliver treatment, or where the patient's behaviour may present a safety risk to themselves, members of the dental team or other accompanying persons” which excluded devices (British Society for Disability and Oral Health/Faculty of Dental Surgery of Royal College of Surgeons of England, 2012). Immobilization (Ivanoff and Ivanoff, 2014, National institute of Dental and Craniofacial Research, 2009) was also reported, as was protective or supportive stabilization (Connick et al., 1999, de Castro et al., 2013, Estrella and Boynton, 2010), with limited use recommended (Raposa, 2009, Newton, 2009) or implied (Newton and Sturmey, 2003). It seems that holding, restraint and stabilization were broadly similar, although some authors focused on who applied restriction: either applied by a dentist or nurse (Newton and Sturmey, 2003), or parent (de Castro et al., 2013); what was used to apply this restriction, such as mechanically by Papoose board (de Castro et al., 2013, Nathan, 2001, Estrella and Boynton, 2010); and which body part was held: Marks and colleagues reported manual fixation as hand-holding by a carer (Marks et al., 2012).

Although its use should be restricted (Rada et al., 2015, Newton, 2009, Nathan, 2001, Connick et al., 2000, British Society for Disability and Oral Health/Faculty of Dental Surgery of Royal College of Surgeons of England, 2012), the literature is generally supportive or at least neutral towards the judicious use of physical restraint, stabilisation or clinical holding for certain people in certain situations. Such decisions are based on risk – benefit assessments weighing potential harm to the patient, urgency and extent of treatment need, and likelihood of success against viable alternatives. Given the contentious nature of physically restrictive supports, Connick et al. and Romer, who emphasise risk reduction by safe restriction of the patient to obviate risks of pharmacological side effects, falls, accidents and harm to self and others during dental care, offered guidance for practitioners in their use, in the context of relevant legislation (Connick et al., 2000, Romer, 2009). Newton on the other hand made the case for alternatives to reduce restrictive practice and the BSDH, who also publish guidelines for clinical holding separately, offered suggestions for behaviour support, mainly as alternatives to holding (Newton, 2009).
2009, British Society for Disability and Oral Health/Faculty of Dental Surgery of Royal College of Surgeons of England, 2012). Such alternatives are important for older adults with ID, who may present higher risk of physical harm from physical restriction, due to physical decline with age, behavioural difficulties requiring greater use of restriction, and accrued treatment need over the life course. There are no Irish Guidelines regarding clinical holding

The literature regarding Hand over mouth (HOM) exercises were less accepting. While Kemp (Kemp, 2005) offered a balanced discussion of HOM, many studies explicitly or implicitly suggested limiting, restricting or abolishing HOM, with and without airway restriction (HOMAR) (Elango et al., 2012, Newton, 2009, Marks et al., 2012, Newton and Sturmey, 2003). In fact most reports of HOM and HOMAR in the literature were in studies of the acceptability of support techniques, possibly due to their unacceptability. Therefore, these techniques were often reported neutrally (Humza Bin Saeed et al., 2012) as part of larger lists of techniques under assessment, whereas the literature, as a whole, does not support their use.

**Multi-component interventions**

As Kemp notes, and as evidenced in the literature, many of the interventions adopt multiple strategies to support behaviour, and are often adopted within a single approach (Newton and Sturmey, 2003). For example, relaxation training and reinforcement with stickers were adopted in one combined, multi-component interventions (Kemp, 2005), while Raposa outlines the multiple strategies in Tesini’s D-Termined approach.

**Effectiveness of behaviour support strategies**

**Desensitisation**

This review finds low quality evidence supporting the use of desensitization (in two specific formats) for improving the number of dental tasks achievable by patients with ID (Table 2.5). In two controlled studies, a total of 40 participants underwent desensitisation. The first study measured the effectiveness of in-vivo desensitization compared with video modeling, among adults with severe-profound ID (Conyers et al., 2004). This small study found in-vivo desensitization
effective at increasing tolerance for dental procedures for five out of six participants (compared to 1 out of 3 for video modeling). Multiple, non-blinded raters undertook data collection, with satisfactory reliability statistics reported. In this study, desensitization essentially referred to positive reinforcement contingent upon completion of each of 18, defined procedural steps within a task analysis, using a mock-up of a dental practice (Conyers et al., 2004). In a larger, non-blinded experiment, comparing a group who received desensitization with a waiting list control (n=35 v n=28), desensitization was again found to be effective at increasing tolerance for dental procedures but was not effective at reducing the need for physical or pharmacological restriction (Altabet, 2002). In this instance, desensitization was used interchangeably with systematic desensitization and involved developing a personalised hierarchy, with the help of modeling, shaping, paired relaxation, and reinforcement. The interventions were different in both studies and neither truly approximated clinical dental practice conditions, limiting their generalizability. These studies offer weak evidence that desensitization was more effective than routine care or video modeling for increasing tolerance of dental procedures.

**Information**

One study compared patient background information versus routine care and found that providing the dentist with detailed prior information on patients with ID did not affect the patients’ behaviours (Table 2.5). Using a blinded rating of video-based data, patients’ behaviour during dental care was found to be similar for control and intervention groups, applying a Dutch behaviour rating scale as an outcome measure. The results of this well-reported randomised, controlled trial of 57 adults and children with ID, showed that patient background information, given to the treating dentist prior to the episode of care, did not affect outcome (Meurs et al., 2010). The authors concluded that dentists were similarly prepared to facilitate cooperation for people with disabilities with or without background information. This review finds moderate level evidence that does not support the use of pre-informing dentists as a means of supporting behaviour.

**Environment**

Two studies investigated environmental interventions (Table 2.5). One study measured the effectiveness of visual, auditory and tactile sensory adaptation on
behavioural and physiological outcomes. Involving 16 children with developmental disabilities, in an open, cross-over intervention trial, this study demonstrated the effectiveness of sensory environmental modifications (Shapiro et al., 2009). Potential bias from allocation sequence was accounted for, statistically. This study outlines the benefits of this technique, which includes physical support in the form of “friendly immobilization wrap” as an alternative to psychological or pharmacological approaches, “without side-effects”. One pilot study (184) aimed to investigate the outcomes of animal-assisted therapy for 30 individuals with IDD, who were to receive sedation and scaling, adopting a pre/post non-controlled non-randomised design. Anxiety levels were recorded using the mean Anxiety Depression and Mood Scale (ADAMS) anxiety subscale score. Anxiety was reduced from entry to the surgery to post the interaction, with the specially trained dog. This study design did not allow for a control group, and therefore, it is not possible to separate the effect of the intervention from confounds within the study environment. The clinical impact of a reduction in ADAMS score is not reported (Cajares et al., 2016). Further research is ongoing. This review offers low level of evidence supporting Sensory Adapted Dental Environment to reduce behavioural and physiological signs of anxiety in 16 children with ID. The results of the study by Cajares et al (184), at high risk of bias, gives very low level of evidence that Animal Assisted Therapy may decrease anxiety for people with IDD in dental environments.

2.5.3.4 Discussion

Behaviour support strategies

This is the first systematic literature review that aimed to identify the non-pharmacological behaviour support strategies reported or recommended for use with adults with ID, when receiving dental care. The review identified communicative, environmental, physical (and pharmacological) behaviour supports, for which 76 strategies were identified. Communicative Supports can be further categorised as behavioural, cognitive, distraction and relaxation-based, control and expectancy-based and communicative strategies and environmental supports can be considered as physical, social or structural supports. The most commonly cited specific strategies were desensitization, positive reinforcement, distraction, tell-show–do, physical restraint, communicative guidance/skills, modeling and scheduling of appointments, representing just a fraction of the 76
diverse techniques observed in the literature. Other, less commonly cited strategies, included use of a mouth prop, fidget toys, and showing affection.

There were a number of limitations within the literature reviewed that affected the collating of these techniques, including inadequate definition / description of strategies, interchanging terminology within and between studies and the babushka-like nesting of strategies within strategies. Perhaps these limitations together create a lack of clarity for knowledge users. While there were exceptions (Elango et al., 2012, Peltier, 2009, Newton, 2009, Lyons, 2009), in many instances, the strategies described were poorly defined or not defined at all. Some articles simply listed approaches, while others described approaches in varying degrees of detail but, did not define their approach. Raposa, for example, described the process of acclimatisation in her recommendations but does not explicitly use this term (Raposa, 2009).

In addition to this, techniques were also often given different or inaccurate terms. For example, when describing physical restriction, protective stabilization was used in places, while restraint was used in others. Further, desensitization meant many things between different studies in the literature, and was generally difficult to differentiate from the process of acclimatisation. Even within individual studies, terms were used interchangeably. In the study by Connick et al, which termed desensitization a “dangerous experiment”, terms were interchanged with systematic desensitization and behaviour modification. This can potentially cause confusion for knowledge users, for whom desensitization is more likely to mean the adaptation of contingencies into routine dental interactions during visits, as a means of behaviour support (Allen et al., 1992, Roberts et al., 2010). This meaning is far more relevant for dental professionals, rather than the lengthy practice sessions and formal behavioural processes, to which Connick et al may have referred.

On a related issue, the literature contained babushka-like nesting of strategies within strategies, and multiple mechanisms within single strategies. This accordion-like compression of strategies and principles makes it difficult to identify component strategies, when appraising the literature or identifying behavioural support strategies. This nesting is inherent. For example, behaviour
modification is an umbrella term that encompasses many strategies to modify behaviour. As an example of multiple mechanisms within single dental strategies, Kemp (168) discussed distraction as a means of alleviating fear and, within this, discussed breathing exercise and listening to music, which in other studies were considered separately or under relaxation technique and music therapy. Raposa’s study described Tesini’s D-Terminated programme, as a repetitive tasking exercise with familiarization. This programme seems to integrate many principles of behaviour modification such as chaining, positive reinforcement and desensitisation.

It is clear from the literature that the strategies listed are not mutually exclusive and that in practice, a combination of strategies will work together rather than in isolation. Kemp outlines the merit of comprehensive multi-component treatment packages, involving many strategies at the same time. These, he says, are the rule rather than the exception (Kemp, 2005). Together, these issues mean that there is a need for interpretation when identifying strategies. This review also highlights the need to develop consensus on the classification of behaviour support. The review held herein would offer a good start for such a process.

**Effectiveness**

This systematic review also aimed to identify the level of evidence supporting the non-pharmacological behaviour support strategies identified, using GRADE (Guyatt et al., 2008). The clinical guidelines included in this study were not based on strong evidence and, therefore, did not inform the effectiveness of strategies. The narrative reviews that recommended many techniques were of fair quality, but by design, offer low level of evidence. There were only five primary studies identified in the literature review, testing five strategies. All experiments included were limited by sampling bias. Randomisation was an issue in all studies reviewed, perhaps reflecting the ethical issue of randomly assigning a person to a test group when they are in need of effective care.

Based on two studies, the level of evidence for the use of desensitization in dental settings, to increase ability to tolerate the stages of dental procedures, compared to no treatment is low; and very low compared to video modeling. All other quality assessment of the evidence was from single studies. There was a low level of
evidence against the use of pre-informing dentists in order to improve cooperation of people with intellectual disabilities. The level of evidence for the use of animal-assisted therapy, to reduce anxiety, was very low. The level of evidence for the use of a sensory adapted environment was low. None of the other strategies identified were based on evidence specific to dental care of people with ID, though it is acknowledged that they were often based on extrapolation from the paedodontic or dental phobia literature, where evidence does exist. However, this literature was outside the scope of this review, because the transferability of these strategies toward adults with ID is largely unknown.

**Limitations**

When considering the outcomes of this study, there are a number of issues to consider that may affect the validity of our conclusions. Firstly, the search strategy only included a single search engine and it is likely that there are other studies relevant to consider for inclusion. The author addressed this by engaging experts and snowballing. However, this search strategy falls short of expected standards. The trustworthiness of a synthesis depends on both the quality and the quantity of the evidence base upon which it is built. For the maintenance of standards, researchers should think carefully about the strength of the evidence from non-experimental studies, in order to assess the effectiveness of an intervention and how it should be interpreted, because of the risk of bias (reviews and dissemination, 2009). This review, nevertheless, included articles of methodological design and quality that would not normally enter systematic review inclusion criteria, because this was essential to answer the research questions. For example, the decision to include narrative reviews and case series, considered as low levels of evidence even when conducted well, was made following a scoping exercise that identified a limited base of intervention studies, which would not adequately capture the use of the terms under consideration. The strategies this study aimed to identify simply resided in these designs and we therefore decided to include these studies.

Given the lack of a classification system, it is not surprising that many of the terms or descriptions used were hard to classify or were used interchangeably. As part of the process of extracting and synthesizing the strategies identified, we developed a taxonomy, broadly similar to that adopted previously by Glassman et
al. (Glassman et al., 2009), who used the term support in compliance with dominant, person-centred concepts. However, the term support may make the techniques needed seem deceivingly easy to learn and apply and this literature review highlights the often technical and complex techniques that underlie the simple concept of support. For the purpose of completeness, although this review intended to study non-pharmacological supports, when studies were included according to the selection criteria above, a number of them described GA (Rada et al., 2015, de Castro et al., 2013, Humza Bin Saeed et al., 2012, Elango et al., 2012, Becker et al., 2009, Becker et al., 2001, American Academy of Pediatric Dentistry, 2012, Estrella and Boynton, 2010, British Society for Disability and Oral Health/Faculty of Dental Surgery of Royal College of Surgeons of England, 2012, Kemp, 2005), conscious sedation (Becker et al., 2009, Becker et al., 2001, Estrella and Boynton, 2010, American Academy of Pediatric Dentistry, 2012, British Society for Disability and Oral Health/Faculty of Dental Surgery of Royal College of Surgeons of England, 2012), relative analgesia (Rada et al., 2015, de Castro et al., 2013, Humza Bin Saeed et al., 2012, Nathan, 2001, Marks et al., 2012, Estrella and Boynton, 2010, British Society for Disability and Oral Health/Faculty of Dental Surgery of Royal College of Surgeons of England, 2012, National institute of Dental and Craniofacial Research, 2009), oral sedation (Rada et al., 2015, Elango et al., 2012, Nathan, 2001, British Society for Disability and Oral Health/Faculty of Dental Surgery of Royal College of Surgeons of England, 2012), IV sedation (Rada et al., 2015, Humza Bin Saeed et al., 2012, Nathan, 2001, British Society for Disability and Oral Health/Faculty of Dental Surgery of Royal College of Surgeons of England, 2012) and transmucosal sedation (Nathan, 2001) as supports. This demonstrates the complementary nature of such techniques. This review does not, however, purport to consider the entire literature on pharmacological supports.

Conclusions

In conclusion, non-pharmacological behaviour support is an umbrella term for a multitude of strategies. The literature reviewed here suggests that non-pharmacological behaviour support can be considered comprehensively under the headings pharmacological, communicative, environmental and physical, supports. These in turn contain various strategies. In the literature regarding people with ID that was reviewed in this study, these strategies were unreliably defined and
described, and often nested within other terms or definitions. The outcomes from such strategies are unknown, outside of limited evidence for the effectiveness of sensory adaptation, animal-assisted therapy, desensitization and the ineffectiveness of video modeling and pre-operatively informing dentists with background information on their patients. The paucity of evidence limits the fit of behavioural support strategies with modern, evidence-based dentistry. From the amount and quality of evidence reviewed in this study, no particular approach can be definitively recommended. Therefore, there is a need to develop evidence to substantiate the use of non-pharmacological support strategies for people with ID undergoing dental care, from a fundamental level so as such strategies meet the high standards required for the practice of modern dentistry.

**Recommendations**

This study highlights the need for consensus and, arising from this, clinical guidelines, specifically for dentists to use in the care of adults with ID. A lack of a common language within and between professions creates problems when trying to research, understand, teach, design and apply these principles. There is a need for standardisation regarding the terminology used to describe support strategies: that is, definitions, description and an agreed classification system for the use of these strategies, specifically in this context.

Much basic research is needed to develop this field of dentistry, as applied to adults with ID. There is a need to initiate research using standardised methods and, importantly, outcomes in this field. Sufficiently powered, randomised controlled trials of multi-element interventions are needed. So too, are qualitative studies, to explore how strategies are developed and selected. To begin, there is a need for exploratory research to investigate dentists’ use of supports among people with ID: What they actually do in practice, how they choose these strategies and how they are learned. Ultimately, to ensure tangible benefits for people with an ID, curricula and Clinical Practice Guidelines need to be developed ensuring effective translation from research.

**2.5.4 Conclusion regarding service use.**

In conclusion, people with ID are disproportionately high users of dental services in general, especially when living in supported, residential settings. The frequency
and type of service use varies greatly depending on level of ID, age and residential setting. Consideration of the demographics of this population is therefore important when researching dental service use. For the majority of care, non-pharmacological behaviour supports are applied. This is an umbrella term for a multitude of communicative, physical, social and environmental supports. Their effectiveness is unclear. There is a need for standardisation regarding the terminology used to describe behavioural approaches to support and much basic research is needed to develop this field of dentistry.

2.6 Conclusion of literature review

This literature review demonstrates that edentulism is an irreversible disability that increases with age. Estimates vary widely among adults with ID, and it is unknown how commonly it affects adults with ID in Ireland. Nor is it known what impact it has on this population. Edentulism also acts as both a marker of oral disease burden and a marker of the experience of dental services over a lifetime. It is unclear how often and in what way adults with ID access dental care as they age.

There is a need to understand how adults with ID are supported to receive dental care, so that appropriate planning of services, as well as delivery of relevant care, can be undertaken. Without data on the dental utilization rates for people with ID and knowledge of the factors that affect utilization of services, funding bodies, managers and policy makers face challenges planning and evaluating oral health services (Brister et al., 2008). While it is recognised that people with ID require a range of general and specialised services to meet their oral health needs (Gallagher and Fiske, 2007), the proportion receiving or requiring mainstream, GA or sedation-assisted services for dental treatment are unknown. From policy, clinical, service and workforce planning perspectives, it is essential to understand how often and by whom, services such as routine care, IV sedation and general anaesthesia are used and needed.

A lack of high quality research into edentulism and service use among adults with ID limits practice, research and policy in this field. The absence of such data inhibits monitoring of oral disease burden and prevents the establishment and assessment of comprehensive oral health goals for this population; it also limits the ability to plan and monitor oral health service outcomes, training for dentists,
workforce planning and service models over time. All this compounds inequalities. Therefore, this research was designed to address these issues.

2.7 Aims, objectives and research questions

2.7.1 Aim

The thesis that this PhD aims to demonstrate is that dentate status among people with ID is poor and consequential and that this poor outcome occurs in the presence of dental service provision. This will demonstrate that oral health outcomes are inequitable for people with ID and that dental services are inappropriate.

The aim of this study is to explore total tooth loss and oral health service use among older adults with intellectual disabilities in Ireland. Specific research objectives and questions are presented in Figure 2.6.
Objective 1.
To understand the frequency, sequelae and impact of edentulism among older adults with intellectual disabilities in Ireland.

- 1.1 What is the reported dentate status and complete denture use profile of older adults with ID in Ireland, compared to the general population? *(Chapter 4)*
- 1.2 Why do edentulous adults with ID not wear dentures? *(Chapter 5)*
- 1.3 Does treated and untreated edentulism predict difficulty eating for older adults with ID? *(Chapter 6)*

Objective 2.
To understand the frequency of dental attendance and support for older adults with intellectual disabilities

- 2.1 Do older adults with ID in Ireland attend dental services regularly? *(Chapter 7)*
- 2.2 Why do some older adults with ID not attend dental services? *(Chapter 7)*
- 2.3 What behavioural supports do older adults with ID reportedly use, when accessing dental care? *(Chapter 8)*
- 2.4 How do dentists working with adults with ID develop their skills in communicative behaviour support, why do they do so and how do they select and apply the different strategies available to them? *(Chapter 9)*
Chapter 3 Methods
3.1 Introduction

Like a beaming light that cuts the dark, research can offer an incremental revelation of the unknown. Depending on the particular object of inquiry, researchers select from a range of lenses to illuminate the phenomena in focus. This PhD study adopts multiple methods of inquiry to shine such a light, together forming essential components of one research programme. This structure is sometimes referred to as multi-method design (Morse, 2003). The “multi” methods that this term here evokes, includes quantitative-, mixed- and qualitative- methods.

It is important to note that each of these methodologies are framed within specific paradigms of inquiry or world-views that signal distinct ontological (view of reality), epistemological (view of knowing and the relationship between knower and to-be-known), methodological (view of mode of inquiry), and axiological (view of what is valuable) positions (Sandelowski, 2000a). Figure 3.1 gives an introductory overview of Guba and Lincoln’s perspective on what constitutes a paradigm, their concepts of reality, knowledge and inquiry, and how they relate to the methods used in research (see Figure 3.1). This framework is presented for clarity, though it is acknowledged that a broader literature exploring such philosophical assumptions exists (Creswell, 2003, Mackenzie and Knipe, 2006, Sandelowski, 2000a).

In this chapter, we look at how three methodologies are applied to answer the seven research questions contained herein. Specific methodological details are held within the corresponding chapters and the discussion here applies to methods and methodology as applied across the thesis. This chapter summarises these methodologies sequentially. Each section starts with a brief discussion on the paradigms upon which the methodology is based. The section on quantitative methods introduces IDS-TILDA, the major source of quantitative data in this thesis. The chapter then discusses features of qualitative research applied here before considering mixed-methods elements. The role of primary and secondary research is briefly summarised before concluding comments. But first, a word on Multiple Methods of inquiry…
• Basic belief system or worldview that guides inquiry by defining the nature of the world to the researcher. In this sense, a paradigm houses the philosophical assumptions that underpin research including epistemology, ontology and methodology.

• The ontological question defines what is meant by reality and as such, what is within the realm of legitimate scientific inquiry. Ontology refers to the form and nature of reality and therefore, what can be known about it.

• The epistemological question defines the relationship between knowledge and the knower. This provides a philosophical background for deciding what kinds of knowledge are legitimate and adequate.

• Methodology refers to the form that inquiry takes to let the researcher identify what can be known about reality, as they hold it to be.

as per Guba and Lincoln (Guba and Lincoln, 1994)
3.1.1 Multi-method Research

Multiple methods are commonly applied in health research to offer multiple lenses on a topic and thus offer a broader perspective of reality (Sale et al., 2002). A *multi-method design*, according to Morse at least, involves multiple methods of inquiry, most often qualitative and quantitative projects, that are complete on their own but used together to form essential components of one research programme. Thus, each study is planned and conducted to answer a particular sub-question, and the results inform a comprehensive whole (Morse, 2003). It is clear that such a design will meet the objectives of this research programme.

It is important to note that multiple and mixed-methods are generally not considered to be the same, though the distinction can be unclear even between those expert in this field (Johnson et al., 2007). The difference between multiple and mixed methods is underpinned on their ontological and epistemological assumptions (Sale et al., 2002). As these terms are used in this PhD, *multi-method design* allows for the adaptation of multiple paradigms, given the independent nature of the constituent components, whereas *mixed-methods* research has come to adopt pragmatism as a developing philosophy. Whereas multi-methods makes no claim on whether paradigms should be mixed or considered at all (Morse, 2003), more recent discussion within the pragmatic world-view recommends dropping philosophical focus completely, which pragmatists, rather pragmatically, see as unhelpful (Morgan, 2016). This places these perspectives somewhat at odds. For the purpose of this thesis, we consider the relevant epistemologies while, here at least, acknowledging the pragmatic perspective that this may not be necessary or helpful. Therefore we will consider the world views that shape the “multiple” perspectives held within this multi-methods study because they need to be considered and addressed, particularly in this thesis (Morgan, 2016). Therefore, this chapter frames each methodology by their philosophical underpinnings, despite the pragmatist philosophical argument to ignore such concepts. We start with quantitative methodology.

3.2 Quantitative methodology

Quantitative methods predominate in this Thesis (Table 3.1). The quantitative methods described in this section were applied within the context of Waves 1 and 2 of the Intellectual Disability Supplement to The Irish Longitudinal Study on Ageing (IDS-
TILDA). This section describes the quantitative methods applied. Further details of IDS-TILDA can be found in Appendix 2.

3.2.1 Paradigm

The quantitative methods applied across this thesis are derived from the post-positivist paradigm. Post-positivism is built largely on the positivist world-view, which ontologically, assumes that an external and universal reality exists. Epistemologically, a positivist reality can be observed objectively and independently meaning that it is therefore measurable. This reality lends itself to quantification by the researcher through observation (Gray, 2013). Post-positivism maintains the core assumptions of positivism but recognises that all observation is inherently fallible and that truth can only be approximated rather than perfectly explained. Therefore, post-positivist research “lays emphasis on inferential statistics with its emphasis on assigning probabilities that observed findings are correct (not certainties)” (Gray, 2013). This perspective has influenced the methods used in this study. In other words, post-positivism has influenced the design, sampling, data collection and quantitative analyses applied in the current PhD in both quantitative chapters (Chapters 4-6) and the quantitative phases of the mixed-methods chapters (Chapters 7&8).
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### 3.2.2 Methods

#### 3.2.2.1 Design

The Intellectual Disability Supplement to The Irish Longitudinal Study on Ageing (IDS-TILDA) was designed as a longitudinal cohort study of a nationally representative sample of adults with ID over the age of 40 years in Ireland. IDS-TILDA explores ageing among older adults with ID: their ageing profile, physical and behavioural health, health services needs, psychological health, social networks, living situations and community participation. This study is undertaken in recognition that there is a lack of longitudinal and incidence studies addressing health issues of elderly people with intellectual disability (Haveman, 2009) and a need for mainstream policy and the evidence collected to inform and evaluate such policies, does not take into account the specific needs of older adults with ID. So far, there have been two waves of data collection (McCarron et al., 2011, McCarron et al., 2014) with the third wave of data collection complete March 2017.

This study was initiated in 2008, and designed to compliment The Irish Longitudinal Study on Ageing (TILDA), a nationally representative, prospective cohort study on ageing in Ireland, established in 2006 (Kenny et al., 2010). TILDA’s aim is to make Ireland the best place in the world to grow old. TILDA focuses on the economic circumstances, health and well being of those over 50 years of age, living independently in Ireland. To date this study has seen three waves of data collection. Wave one included a stratified clustered sample of 8178 individuals, 6995 of whom completed an interview at wave 2 (Nolan et al., 2014). Wave 3 data collection has concluded and is due to be analysed shortly.

Despite the longitudinal nature of IDS-TILDA, the quantitative analyses in this thesis concentrate on a specific point in time (Chapters 4&7 are based on data from Wave 1 and Chapters 5, 6 & 8 are based on data from Wave 2). As used in the current thesis, the design is best conceptualised as repeated cross-sectional surveys rather than a longitudinal cohort study. Longitudinal analyses will grow in importance as policy is implemented and time passes but were not prioritised at this stage because of the limited interval between waves (3 years) and the
modification of dental specific items from Wave 1 to 2 (See Appendix 2, Table S3).

**IDS-TILDA Team and ethos**

IDS-TILDA is a longitudinal cohort study coordinated by Professor Mary McCarron and visiting Professor Philip McCallion from the University at Albany, Center for Excellence in Aging & Community Wellness. The IDS-TILDA team consists of a broad range of experts from ID nursing, psychology, psychiatry, sociology, statistics, economics, dentistry and pharmacology, who work from Clare Street, Dublin. It is a busy office with a lot of students passing through. A Scientific Advisory Group oversees the project, which was developed with the support of people with ID. According to the Wave 1 report: “The underpinning ethos of promoting the inclusion and participation of people with an intellectual disability (ID) guided the design of the study as did maximizing comparability with the Irish Longitudinal Study on Ageing (TILDA) and other European and international studies on ageing. In addition, the study included measures and topics that are particularly and uniquely relevant to people with ID.”(McCarron et al., 2011)

**3.2.2.2 Population and Sample**

Within the quantitative paradigm, samples sizes are large, compared to other modes of inquiry so as statistical methods can be applied to ensure that samples are representative. This ensures external validity and generalizability to the population, which is normally the subject of interest to the researcher, rather than the sample, per se.

**Population**

In this study the population of interest is older adults with ID in Ireland. Ireland holds a rather unique position of maintaining a database, with compulsory registration for those assessed as needing or in receipt of specialised services in Ireland. The NIDD objective is to record this information for every individual known to have an intellectual disability and assessed as being in receipt of, or in need of, an intellectual disability service. These data are collected by service providers, school principals and health service providers along standardised methods and these data are passed on annually through regional database
directors for reporting purposes. People are maintained on this database as long as they are considered in need of or in receipt of services and their profiles are updated annually. Chapter 1 offers further details of this database.

**Wave 1 sample**

The Wave 1 IDS-TILDA sample included 753 people who met inclusion criteria: (A) Age ≥40 years with ID, (B) registered with NIDD, and (C) written consent to participate and/or family/guardian written agreement, where required (McCarron et al., 2011). The sample was drawn from the National Intellectual Disability Database (NIDD), which collates information on all people with ID in Ireland who have been assessed as eligible for, or who receive ID services (Kelly et al., 2008). Potential participants were invited to participate randomly (see below).

Respondents represented 8.9% of the corresponding population. From the 1,800 registrants who were invited to participate, and who were found to be representative of the larger database population, a response rate of 47% was found, which was within the anticipated range of 45%-50% (McCarron et al., 2011). This response rate does introduce the risk of systematic differences between participants and those who refused to participate. In comparison to the 2008 NIDD cohort (Kelly and Kelly, 2011), where the population of people with ID over 40 years is 51% male and 49% female, in this IDS TILDA sample 45% of participants were male and 55% were female. Regarding Wave 1 IDS TILDA sample, 24% of the sample had mild ID (NIDD=27.6%), 46% moderate (NIDD=44.3%), 24% severe (NIDD=20.5%) and 5% (NIDD=5.5%) profound level of ID. For approximately 5% of the IDS TILDA sample and 2% of the NIDD population, their level of ID was not verified. Therefore, the sample can be considered representative based on level of ID, while some gender imbalance existed in the initial cohort.

**Wave 2 sample**

For Wave 2, all living Wave 1 participants (N=719) were invited and the overall response rate was 94% (n=708). Eleven Wave 1 participants refused to participate in Wave 2 and 34 were deceased in the interval meaning that 45
participants were lost to follow up. This sample was largely comparable to both the Wave 1 sample and the NIDD database (McCarron et al., 2014).

3.2.2.3 Ethical Issues
This research is based on principles of inclusion, person-centred care, empowerment and choice, contribution to the lives, and promotion, of people with ID. In line with these principles people with ID were involved at all stages of this research project.

Safeguarding and information sharing
Given their potentially vulnerable status as both older adults and adults with ID a gatekeeper system was applied to remove potential for undue pressure to participate in the study. Therefore, potential participants interacted with regional disability database administrators (RDDAs) until their registration was at an advanced stage. RDDAs distributed participant packs containing an easy read summary, explaining the project and consent forms, for both the potential participant and those who supported them (McCarron et al., 2011). At the same time, a proactive information sharing drive was underway including DVDs, presentations, website and data collector delivered information sessions. As such, steps were taken to both include and safeguard this especially vulnerable group. More on the values framework is offered in Appendix 2.

Consent
Process consent was adopted whereby potential participants’ consent to partake was reviewed at multiple stages and the person’s right to withdraw was upheld. Initially, those who received an invitation pack were encouraged to read the study material with support if needed and consent if they were willing to participate. Where people could not self-consent, a family member/guardian was requested to review the materials and to sign a letter of agreement supporting participation in the study. The research team contacted the participant or their supporting person upon receipt of completed consent forms to clarify the research process. From the Wave 1 sample, 285 participants (38%) self-consented; 468 (62%) were unable to self-consent and a letter of
agreement/consent to participate was received from a family member/guardian in Wave 1.

**Ethical Approval**

In 2008, IDS-TILDA was granted ethical approval by Trinity College Dublin Faculty of Health Sciences Research Ethics Committee and all 138 intellectual disability service providers throughout Ireland, involved in supporting people with ID to take part in this study. This followed extensive piloting of survey instruments and procedures.

### 3.2.2.4 Data collection

Data collection for Wave 1 spanned February 2010 to July 2011. Data collection for Wave 2 spanned from April 2013 to February 2014. Following analysis of Wave 2 data, the qualitative study was designed. Figure 3.2 summarises the sequence of data collection. Data collection for Wave 3, spanned from September 2016 to March 2017: these data are not yet analysed.

**Figure 3.2 Sequence of sampling, recruitment and data collection**

- **WAVE 1**
  - Ethical approval and pilot
  - 1600 PINs distributed to RDDAs
  - 753 consented Wave 1
  - PIQ completed
  - CAPI Completed

- **WAVE 2**
  - Ethical Approval confirmed
  - 708 consented Wave 2 participants
  - PIQ completed
  - CAPI completed

- **QUALITATIVE DATA**
  - Ethical approval confirmed
  - Sample generated
  - Focus group 1
  - Follow up interviews
  - Member checking

PIN = Personal Identification Number; RDDA = Regional disability database administrators acting as gatekeepers; PIQ = Personal information questionnaires, CAPI = Computer assisted personal interview.
Following rigorous training, data were collected by researchers who had experience of working with people with ID at both waves. Using a two-stage data collection technique, a postal pre-interview questionnaire (PIQ) was completed with or for each participant, which offered the opportunity to draw data from existing records. These pre-interview questionnaires were sent to each participant before the computer assisted personal interview. This questionnaire covered demographic information, health status, healthcare utilization and medication usage. The purpose of this preliminary questionnaire was to give respondents time to source the information required thereby increasing reliability of data.

This was then followed up with a face-to-face computer assisted personal interview (CAPI) consisting of 17 sections administered as a face-to-face computer assisted interview with each participant. Questions covered additional demographical information, such as type of residence and religion; cognitive health; happiness; physical health; instrumental activities of daily living and support needed to undertake these activities; mental health; employment situation; lifelong learning; day services; behavioral health; social participation; social connectedness; life satisfaction; aging perceptions; personal choices; sources of income; evaluation questions and a final checklist for interviewers. The second wave saw the introduction of a Health Fair including the collection of directly measured health parameters (McCarron et al., 2014). Dental measures were not included. Where necessary, a proxy who knew the participant well completed the interview jointly with or on behalf of the participant. IDS-TILDA required that proxy informants have known the person with ID for a minimum of six months. Based on whether the participant had support in responding or not, respondents were categorised as respondent only, respondent and proxy, or proxy only.

Items relating to oral health related parameters have changed from Wave to Wave, with the total number increasing from five in Wave 1 to eleven in Wave 2 and thirteen in Wave 3. In Appendix 2, Tables S3a-S3c report the format of dental items from Wave 1, and 2 and report the items planned for Wave 3. These items will continue to undergo data-driven development into future waves.
3.2.2.5 Variables

While the IDS-TILDA survey has been presented up to this point as a purely quantitative tool, there were multiple open-ended items, mainly to explain quantitative responses. Specific items used in this thesis are presented and discussed in the appropriate chapters and items relating to oral health parameters, from the three waves of IDS-TILDA are presented in Table S3a-c (See Appendix 2), which demonstrate the growth of the “dental section” and data driven selection of items.

3.2.2.6 Quantitative Analyses

All quantitative data were entered into SPSS v.20® for the purpose of analysis. R was used for advanced analyses. In IDS-TILDA, data were cleaned and checked for the dataset as a whole.

Data set matching

When comparing edentulism to the general population living independently (Chapter 4), participants were paired to the TILDA sample, using propensity score matching. Both datasets were first cleaned and variables recoded to ensure uniformity in the data. Extraneous variables (and for IDS-TILDA, cases under 50 years) were deleted and the two datasets merged. Propensity score matching was then completed in SPSS 20 using the R plug-in and the “ps matching” custom dialog (Thoemmes, 2012). Nearest neighborhood matching without replacement was used based on a greedy matching algorithm with a caliper of 0.15 of the standard deviation of the logit of the propensity score (to reduce potential imbalances among matches). Given that several covariates were represented, a single propensity score was generated, which can be viewed as the absolute difference between individuals in each group.

Descriptive and inferential analyses

Generally, summary statistics and counts with percentages were presented for demographic and descriptive data. Pearson’s Chi Square and similar tests of association were calculated to test for association between variables, which of course varied depending on the specific research questions. Where suitable, the level of statistical significance was set at an accepted probability of $p<0.05$ with
correction for multiple tests applied using the rough false discovery rate, where appropriate (Benjamini and Yekutieli, 2001).

**Logistic Regression**

Perhaps the central analytic procedure in this PhD was Logistic Regression. This is a form of Generalised Linear Model that is applied in cross sectional survey analyses, used to determine the effect of independent variables (predictor or IV) on a dichotomous dependent variable (outcome or DV). Logistic regression considers odds ratios (OR) as a measure of likelihood per unit change in the dependent variable, relative to a reference category for each independent variable: Odds being the ratio of the probability that the outcome of interest occurs to the probability that it does not (Bland and Altman, 2000). The 95% confidence interval (CI) tells of the precision of the OR: a large 95%CI indicates low precision while low 95%CI indicates higher precision. In practice, the 95% CI is often used as a proxy for the presence of statistical significance if it does not overlap the null value (e.g. OR=1) (Szumilas, 2010).

In this study, regression modeling allowed control (or adjustment) for the effect of multiple covariates when measuring the relationship between the predictor(s) and the outcome of interest. So, in this way, regression was used to measure the association of age and residential setting with the DV, edentulism, in Chapter 4, while controlling for the effect of the other variable in the model. This method is extended to include a much larger range of covariates with specified predictor variables in analyses seen in Chapters 6 and 8.

**Principles and sample size**

Parsimonious modeling was applied whereby the simplest explanation of the data was sought with the fewest variables because adding more variables tends to only slightly improve the model, while increasing the degrees of freedom (Tabachnick and Fidell, 2013). This meant that models were purposefully kept as simple as possible (more on this below). Recoding was also kept to a minimum, to avoid an over-fit to the sample data to the extent that results no longer generalise to a population (16). As per default in SPSS V.20, missing cases were deleted
automatically in the analyses. In R Studio V.1.0.44, row-wise deletion was undertaken.

Specifically for Logistic Regression, Peduzzi suggests that at least 10 events per variable are required to ensure parameter estimates are unbiased (Peduzzi et al., 1996). This means that, the sample sizes in all regression models used in this PhD provided adequate power for all models used in this study.

**Selecting independent variables**

Successful modeling of a complex data set is “part science, part statistical methods and part experience and common sense.” (Hosmer and Lemeshow, 2005). The regression models used here were built theoretically and statistically to test specific hypotheses. Candidate IVs were identified based on theoretical and empirical relationship to the outcome in each model. For example, for the simple model developed in Chapter 4, unadjusted, bivariate analyses were tested and where significant ($p<0.05$), candidate IVs progressed for further testing a part of the model.

The models in Chapters 6 and 8 were more complex. To build these models, missing data were removed and all candidate variables and were then entered into R and a full model developed. To test for multicollinearity, the General Variance Inflation Factor (GVIF) was calculated (Fox and Monette, 1992). GVIFs consist of the Variance inflation factors (VIF) corrected by the number of degrees of freedom (df) of the predictor variable: $\text{GVIF} = \text{VIF}^{[1/(2*df)]}$. As a rule of thumb, GVIF below 4 indicates that variables do not present multicollinearity. Collinearity refers to the problem, which arises in regression models when independent covariates are strongly correlated. This can lead to both Type I and Type II error, which may be indicated by inflated confidence intervals of the regression coefficient. This can also highlight redundant IVs, which can reduce the power of the overall model. Most significant statistical problems from collinearity only arise with strong correlation between covariates (Tabachnick and Fidell, 2013). Reporting of collinearity is recommended in dental regression models (Tu et al., 2005). In this thesis collinearity was not an issue.
Optimising models

In Chapters 6 & 8, once the full models were defined, these models were fitted to include all variables useful in predicting the outcome while minimizing the number of degrees of freedom. It was assumed that these models offered greatest parsimony. Parsimony describes the concept that regression models should be as simple as possible to avoid both under- or overfitting the data. Inference with too few variables can be biased, while models with too many variables suffer poor precision or spurious correlation (Burnham and Anderson, 2004). Therefore, the models with the lowest Akaike information criterion (AIC) were selected as the final models p.720 (Tabachnick and Fidell, 2013). This entailed calculating AIC for each model under consideration and selecting the model with the minimum value of AIC as the “best,” approximation of the true model (assuming one exists). It was through this final model that the relationships between the dependent variables and their explanatory variables were eventually explored. Final model evaluation was determined using the receiver operating characteristic curve (ROC curve) and the Area Under the Curve (AUC) was calculated (Table 3.2).
<table>
<thead>
<tr>
<th>Chapter</th>
<th>Covariate selection</th>
<th>Model selection</th>
</tr>
</thead>
<tbody>
<tr>
<td>Chapter 4 (Table 4.4)</td>
<td>Associations found through bivariate analysis: Two variables were entered as predictor variables into a binomial logistic regression with dentate status as the outcome variable</td>
<td>Items not showing unadjusted association were excluded. Model designed to test the association of one IV, while controlling for the impact of one other.</td>
</tr>
<tr>
<td>Chapter 6 &amp; Chapter 8</td>
<td>Systematised literature search to identify candidate variables from the literature based on association with the dependent variable. Data transformation where necessary to generate suitable variables, exclusion when unsuitable.</td>
<td>Competing models were compared using Akaike information criterion (AIC) and the model with the lowest AIC was selected as offering the best fit for the data included. Evaluation of the final model was undertaken using the receiver operating characteristic curve (ROC curve) and the Area Under the Curve (AUC) was calculated.</td>
</tr>
</tbody>
</table>
3.3 Qualitative methodology

In keeping with the Multi-method design, qualitative methods were applied in the purely qualitative Chapter 9 and as part of the mixed methods reported in Chapters 7 and 8, though this element is considered under mixed methods later in the chapter.

3.3.1 Paradigm

Unlike quantitative methods which are situated firmly within a post-positivist world view, qualitative methodology is applied across many paradigms, though most often within a constructivist world-view (Mackenzie and Knipe, 2006). Within this paradigm, ontologically, it is accepted that reality is constructed by the human experience of existence, rather than there being an external constant reality. Therefore the understanding and knowledge of reality is unique to the individual and is therefore context dependent (Mackenzie and Knipe, 2006). This epistemological stance recognises the impact of the researcher’s own culture, background and experiences on the research process. Constructivists do not generally begin with a theory (as with post-positivists), rather they generate or inductively develop a theory or pattern of meanings during analysis (Creswell, 2013). Qualitative methods are normally applied to generate data, often through human interactions, as in Chapters 8 and 9, with open-ended questions tend to encourage a rich description of human experience.

3.3.2 Methods

3.3.2.1 Designs

A Qualitative Descriptive design (Sandelowski, 2000b) was applied in Chapter 9. Using an online, synchronous sequential focus group / interviews for data collection, Thematic Content Analysis, as described by Burnard et al., was applied (Burnard et al., 2008). This same design was applied for the qualitative element of Chapter 8, as part of a mixed methods study. Ethical approval for this element of the study was received through separate ethical approval from the Research Ethics Committee of the School of Dental Science, Trinity College Dublin.
As part of Chapters 7, in which mixed-methods were applied, qualitative methods were used to explore why some people with ID did not attend dental services. Text analysis, essentially a form of computer-assisted content analysis, was applied to explore this phenomenon. It is worth noting here though that some authors point out that content analysis based on frequency counts of responses to open-ended questions is not qualitative research (Sale et al., 2002). However, Krippendorff (p.16) argues that all reading of text is essentially qualitative, even if this text is later quantified, even by computers (Krippendorff, 2004). Further, Morgan posits that such distinctions of method may not be useful or even possible, especially in mixed method designs incorporating closed and open ended questions, as seen here (Morgan, 2007). For the purposes of clarity, text analysis is presented as part of the qualitative methodology section, because of the qualitative features of this method but with recognition of the “bluriness” of this fit. Data came from responses to an open-ended question in the IDS-TILDA Wave 1 dataset. As such, much of the ethical, population, sampling and data collection issues have been addressed above and are not repeated here. This element makes a brief re-appearance later in 3.3.2.4 below.

3.3.2.2 Sample

Sampling

In contrast with quantitative methods, qualitative research often applies non-probability sampling techniques. This is considered *purposive sampling* and encompasses a number of techniques which generally lead to inclusion of either similar or contrasting perspectives in a study, having selected from a larger sampling frame (Teddlie and Yu, 2007). However, our sampling frame was only very slightly higher than the sample collected and therefore could be seen as a *convenience sample*, but not in the opportunistic sense described by Marshall (Marshall, 1996). To distinguish from the indiscriminant or opportunistic selection that convenience sampling evokes, the term purposive sampling is perhaps more apt, though I acknowledge this indistinction, as per Marshall. In fact, what Marshall terms “key informant sampling” (Marshall, 1996) may better describe the sampling strategy here because, the sampling strategy generated a focus group of participants who were selected based on their highly specialised and specific roles, experiences and perspectives. All were drawn from Ireland,
which matched the sample in IDS-TILDA and had broadly similar clinical specialisation and training, which limited contextual variation.

**Sample size**

There are multiple perspectives on how large a sample is needed in qualitative research. This depends on many factors including purpose of the study, methods applied and theoretical perspective. This topic is considered in depth elsewhere (Mason, 2010a). As is argued in later chapters, it would have been better to have had a larger sampling frame and ultimately, sample for the qualitative elements of Chapters 8 and 9. Chapter 8 considers sampling issues through a mixed methods lense.

### 3.3.2.3 Data collection

Data were collected from a series of sequential focus groups / interviews with the same group of dentists. This approach was not selected *a priori* in this project, rather it was adopted to meet the shifting conditions of real world research. Participants had originally planned to meet in a face-to-face focus group at an annual conference of the Irish Society for Disability and Oral Health. However, the conference programme over-ran meaning that most participants were delayed in attending and it was reluctantly canceled. Given the geographic dispersal of participants the researcher explored the utility of interviews, synchronous and asynchronous online focus groups. A synchronous online focus group was selected because it offered the advantages of focus group methodology while addressing the difficulties in convening such a geographically dispersed information rich group. The researcher found that an online focus group also raised barriers for the group. While participants were visible and audible to each other the absence of material non-verbal communication and real-life atmosphere meant that discussion was somewhat stunted at times. This meant that the facilitator’s role as “traffic cop” was more involved than one expects to find in face-to-face focus groups. This diminished the depth of interaction that researchers hope to generate from intra-group dynamics. Following this focus group is was decided to return to participants to increase the depth of exploration of the research topic and give time for narrative...
accounts to fully unfold. Serially collecting data in this way been shown carry such advantages (Jacklin et al., 2016, Murray et al.).
3.3.2.4 Analyses

Text analysis

Open-ended items were transcribed verbatim and exported into PASW Text Analytics for Surveys 4.1® (IBM, 2010). This software uses natural language processing to transform qualitative data from survey text into terms for analysis, thus allowing extraction of core concepts, enabling automated linguistic analysis. Core terms were first extracted and grouped into categories and by concept automatically. Then categories were refined further through an iterative process of joint manual/automated refinement. Text analysis exposed commonalities among core concepts and categories. Associations between categories were visualised using category web graphs, to help explain relationships. In this way data were analysed descriptively, without much abstraction, by categorizing and quantifying their relationships.

Thematic content analysis

Data in chapters 8 and 9 were analysed using qualitative Thematic Content Analysis (Burnard et al., 2008). This method was selected over other qualitative analytic frameworks, such as framework, discourse and phenomenological analysis, as it met the aims of the research question best: This is considered the least interpretive of all qualitative analysis approaches, in that there is no mandate to re-present the data in any other terms but the respondents’ own. Nevertheless, it is often the method of choice when “straight descriptions of phenomena are desired”, especially when using qualitative methods to find out “the who, what, and where of events” (Sandelowski, 2000b). Overtones of grounded theory were applied throughout as evidenced by the use of constant comparative method and the application of a theoretical lense. Memo-ing was also adopted, throughout the process to allow auditing of code and theme development and conceptual interpretation of the data.

Theory development

This study led to the development of theory – namely theory around decision-making and communication in the delivery of dental care to adults with ID (Chapter 9 for details). However, it is important to note that these are not
theories in the Grounded Theory sense (Strauss and Corbin, 1994). In fact, it was not planned to generate theory, *a priori*: the final theory actually arose late in the research process. Rather, as Creswell illustrates in Figure 3.5 of his book, theory was derived from informant’s narrative - from patterns among categories after a visual model of inter-related categories was drawn and re-drawn with reference to experience and the literature (Creswell, 2013). These theories were validated and further enriched at member check.

### 3.3.2.5 Rigour

There are established and systematic approaches to establish validity and reliability in quantitative research. In contrast, issues arise when one considers the trustworthiness, validity or rigour of qualitative analyses (Burnard et al., 2008, Creswell and Miller, 2000). While Sale and colleagues go so far as to suggest that notions such as validity violate the philosophical underpinnings of qualitative research, which seeks multiple definitions of reality embedded in various respondents’ experiences (Sale et al., 2002), there are nevertheless multiple processes recommended and contested to achieve rigour in qualitative research. See Krefting for further discussion on this (Krefting, 1991). In relation to the analyses in Chapters 8 and 9, I have undertaken a number of procedures in an attempt to ensure rigour. These are adopted pragmatically, from across paradigms (Creswell and Miller, 2000).

#### Researcher reflexivity

Given the importance of the researcher’s cultural and personal context on qualitative analyses it was important to self-disclose my assumptions, beliefs, and biases, so as readers could appraise the validity of chapters 8 and 9. Readers are directed to these chapters for details.

#### Member-checking and peer review

There are multiple steps available to enhance the validity of qualitative research (Creswell and Miller, 2000). One such method is member checking, whereby the participants have a chance to react to both the data and the final narrative, thereby adding credibility. This method was applied in both chapters 8 and 9. In November 2016 two participants and the author reviewed code and category
development, interpretation of study excerpts and gave feedback on theoretical models. This process validated the analyses in chapter 8 and led to deeper understanding of how dentists communication with patients in Chapter 9, as well as unveiling the relationship between rational and intuitive decision making by dentists.

### 3.4 Mixed methods

Mixed methods as a methodology is in its infancy. The terminology used to describe the design, procedures and integration of data, results and methods in this field are taking shape (Johnson et al., 2007). Mixed methods research involves the intentional collection of both quantitative and qualitative data to offer a better understanding of a research question than either method alone, by combining the strengths of each (Creswell et al., 2010). Further, mixed-methods also involves the intentional integration of multiple forms of data purposely collected in a variety of ways (Fetters et al., 2013). Mixed methods, as understood here, were applied in Chapters 7 and 8.

#### 3.4.1 Paradigm

Mixed methods research is based on the pragmatic paradigm (Doyle et al., 2009, Sandelowski, 2000a, Creswell, 2013). The pragmatic approach is not confined by a particular world-view. Rather it is informed by the belief that the practicalities of research are such that it may not be exclusively driven by theory or data, rather “a process of abduction is recommended which enables one to move back and forth between induction and deduction through a process of inquiry” (Morgan, 2007). By combining methods as we do in these chapters, we also combine methodologies with differing and potentially opposing philosophical underpinnings. This is an argument that once predominated this field of research. Guba and Lincoln went so far as to say that the positivist and constructivist paradigms are so different that a combination of the two is not possible (Guba and Lincoln, 1994). Sandelowski reflects current mixed methods thinking by focusing on the practicalities of the methods applied rather than further fuel the debate on paradigms (Sale et al., 2002, Sandelowski, 2000a). This reflects the pragmatic approach that has come to guide mixed methods research (Doyle et al., 2009). This perspective frees pragmatist researchers to adopt what works best to
answer the research questions under consideration. This approach was adopted in Chapters 7 and 8 in particular.

3.4.2 Methods

3.4.2.1 Designs

There are a number of texts, which outline the range of ways in which mixed methods can be described. Adopting those described by Creswell et al. (Creswell et al., 2010), two designs were adopted. *Fixed Parallel* design was adopted in Chapter 7, where data from qualitative and quantitative perspectives were integrated to measure the frequency of poor dental attendance and concurrently explain why participants did not attend the dentist. This is not considered further in this section.

*Sequential explanatory* design was adopted in Chapter 8, whereby qualitative data helped to explain in more depth the mechanisms underlying the quantitative results (Creswell et al., 2010). This is considered further in the following section.

3.4.2.2 Sample

Typically in sequential mixed methods sampling within studies which are predominantly quantitative followed by a smaller qualitative phase (QUAN-qual studies), a subsample of the original sample is purposively selected for the qualitative phase (Teddlie and Yu, 2007). The researcher here felt that expert dentists with extensive experience of supporting dental care of adults with ID within an Irish context were best positioned to clarify the phenomena observed among the IDS-TILDA sample.

3.4.2.3 Data collection and reporting

In this study, data were essentially integrated in a process termed *connecting data* (Creswell et al., 2010), i.e. the analysis of results from the initial phase dictated the data collected in the second phase of research. By using a *weaving narrative* (Fetters et al., 2013), the results of the quantitative and qualitative elements were presented together in an enriched narrative in Chapter 8.
3.5 Primary versus secondary research

This section introduces the concept of primary and secondary data collection and analysis, in the context of this study. Secondary research can be described as answering new questions with old data (GLASS, 1976) and in a way, when this PhD study initiated, this is what was involved. The Wave 1 data reported in Chapters 4 and 7 and elsewhere (Mac Giolla Phadraig et al., 2014b) were already collected but not analysed or reported. The dental items had been selected, largely, to reflect items in the TILDA dataset prior to my involvement in this study. During these initial analyses, exploratory data analyses and recoding, I led the selection of Wave 2 dental items to explain and explore data arising from Wave 1. These were then collected by data collectors as part of the participant interview. In the same manner, my analysis of Wave 2 data informed the selection of items for the recently completed Wave 3. Some of these items, listed in Appendix 2, were selected to explore tooth brushing while others were selected to explore oral health and service use. By working closely with the dental research team in TILDA these items also reflected the new dental subsection of the TILDA dataset. Ensuring the inclusion of these items will allow timely comparisons between those with and without disabilities in the future, informing policy development. The increasing importance of dental items within the overall IDS-TILDA dataset is evident in Appendix 2, by following the flow of items from wave to wave. The qualitative research reported here was, of course, primary in nature.

3.6 Conclusion

This chapter summarises the methodologies and methods applied in this thesis. The major methodological issues, with which this thesis engages, have been summarised. Further detail is available in later chapters.
Chapter 4 Total tooth loss and complete denture use in older adults with intellectual disabilities in Ireland

The contents of this chapter are based on this publication:

Total tooth loss and complete denture use in older adults with intellectual disabilities in Ireland

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Keywords
aging; intellectual disability; mouth; edentulous; denture

Abstract

Objective: The objective of this study was to describe the reported dentate status and complete denture use of older people with intellectual disability (ID) and compare with those of older people in the general population in Ireland.

Methods: The first wave of the Intellectual Disability Supplement to The Irish Longitudinal Study on Ageing (IDS-TILDA) study provides opportunity to measure edentulism and complete denture use in a nationally representative sample of older people with ID in Ireland. Data drawn from the first wave of IDS-TILDA were matched using propensity score matching with data from The Irish Longitudinal Study on Ageing (TILDA), a study among older adults in Ireland. All IDS-TILDA variance showing significant association (P < 0.05) with edentulism were entered into a regression model to identify predictors of edentulism.

Results: The proportion of the 449 IDS-TILDA participants with no teeth was higher (34.1 percent) than the proportion of participants with no teeth in the 478 matched TILDA participants (14.9 percent). Only age was predictive of edentulism among older adults with ID. Edentulism was prevalent earlier for those with ID. Notably, 61.3 percent of edentulous older people with ID were without dentures.

Conclusion: Older people with ID are more likely to be edentulous than those without ID in Ireland and when they lose their teeth, they are unlikely to use dentures. This suggests a need for targeted measures to maintain the teeth of this group and, in the short term, the provision of replacement teeth in this population, where indicated.

Introduction

People with intellectual disabilities (ID) are living longer (1). Life expectancy for adults with mild ID is now similar to that of the general population and people with moderate or severe ID now routinely reach their late 40s and late 50s, respectively (2). As the population with ID ages, they experience age-related chronic diseases common with the general population. This aging among people with ID is said to present a challenge, by virtue of increasing numbers and heterogeneity in terms of health status and needs, to policy makers, educators, and clinicians alike (3).

Tooth loss increases with age in older adults with special needs (4). Longitudinal research suggests that periodontal disease is a greater source of tooth loss for people with ID than caries (5). This is not surprising as periodontal disease is far commoner among people with ID than the general population (6–8). In addition, even though people with ID often have similar or even lower levels of caries than the general population, the treatment of dental caries usually leads to extraction rather than restoration (6–9, 11). While edentulism has decreased dramatically in developed countries over the last decades (12, 13), it is accepted that people with ID have higher rates of edentulism than the general population (6, 13, 15). Although this finding is not universal (16). In 2003, an oral health survey conducted with adults with ID in residential care settings in Ireland found high levels of edentulism among participants. Additionally,
Summary of Chapter 4

**Purpose**  This chapter is the first of three chapters that explore total tooth loss and its treatment with complete dentures among adults with ID in Ireland. The purpose of this chapter is to describe the reported dentate status and complete denture use of older people with Intellectual Disability in Ireland and compare to those of older people in the general population.

**Methods**  The first wave of the *Intellectual Disability Supplement to The Irish Longitudinal Study on Ageing (IDS-TILDA)* study provides opportunity to measure edentulism and complete denture use in a Nationally representative sample of older people with Intellectual Disability in Ireland. Data drawn from the first wave of *IDS-TILDA* were matched using propensity score matching, with data from *The Irish Longitudinal Study on Ageing (TILDA)*, a study among older adults living independently in Ireland. All variables showing significant association ($p<0.05$) with edentulism were entered into a regression model to identify predictors of edentulism among the IDS-TILDA sample.

**Results**  The proportion of the 478 IDS-TILDA participants with no teeth was higher (34.1%) than the proportion of participants with no teeth in the 478 matched TILDA participants (14.9%). Only age was predictive of edentulism among older adults with intellectual disability (ID). Edentulism was prevalent earlier for those with ID. Notably, 61.3% of edentulous older people with ID were without dentures.

**Conclusions**  Older people with ID are more likely to be edentulous than those living independently, without ID in Ireland and when they lose their teeth, they are unlikely to use dentures. This suggests a need for targeted measures to maintain the teeth of this group and, in the short term, the provision of replacement teeth in this population, where indicated.
4.1 Introduction

People with intellectual disabilities (ID) are living longer (Doyle and Carew, 2016). Life expectancy for adults with mild ID is now similar to that of the general population and people with moderate or severe ID now routinely reach their late 60s and late 50s, respectively (Bittles et al., 2002). As the population with ID age, they experience age-related chronic diseases in common with the general population. This ageing among people with ID is said to present a challenge, by virtue of increasing numbers and heterogeneity in terms of health status and needs, to policy makers, educators and clinicians alike (Perkins and Moran, 2010).

Tooth loss increases with age in older adults with special needs (Chen et al., 2010). Longitudinal research suggests that periodontal disease is a greater source of tooth loss for people with intellectual disabilities than caries (Gabre et al., 1999, Gabre et al., 2001). This is not surprising as periodontal disease is far commoner among people with ID than the general population (Crowley et al., 2005, Scott et al., 1998, Machuca et al., 2007). In addition, even though people with intellectual disabilities often have similar or even lower levels of caries than the general population, the treatment of dental caries usually leads to extraction rather than restoration (Crowley et al., 2005, Shaw et al., 1990, Cumella et al., 2000, Whyman et al., 1995, Tiller et al., 2001). Other causes of tooth loss, such as traumatic injury, are also important contributors to edentulism, although their contributory significance may be lower (Gabre et al., 2001).

While edentulism has decreased dramatically in developed countries over the last decades (Polzer et al., 2010, Beltran-Aguilar et al., 2005), it is accepted that people with ID have higher rates of edentulism than the general population (Crowley et al., 2005, Hinchliffe et al., 1988, Whyman et al., 1995, Morgan et al., 2012), though this finding is not universal (Kendall, 1992). In 2003, an oral health survey conducted with adults with ID in residential care settings in Ireland found high levels of edentulism among participants. Additionally, many of these participants did not wear dentures to restore function or aesthetics. The authors concluded: “Lessons need to be learned to avoid perpetuating such an undesirable outcome for future generations of people with an intellectual disability” (Crowley et al., 2005).
4.1.1 Research question
Ten years on, this study measures current levels of edentulism and complete denture wear in a nationally representative sample of older adults with an ID in Ireland. This study asks the following research question: What is the dentate status and complete denture use profile of older people with Intellectual Disability in Ireland in comparison with the general population?

4.2. Methods
Data were drawn from the first wave of the Intellectual Disability Supplement to The Irish Longitudinal Study on Ageing (IDS-TILDA) (McCarron et al., 2011) a study designed to explore ageing among older adults with ID, their ageing profile, physical and behavioural health, health services needs, psychological health, social networks, living situations and community participation. These data were compared with data from The Irish Longitudinal Study on Ageing (TILDA). Data for both studies were collected in approximately the same time period and most data collection instruments were the same (Kenny et al., 2010, Whelan and Savva, 2013). Further data on the TILDA study sample are available upon request through http://www.ucd.ie/issda/data/tilda/ and are not presented in detail here. Ethical approval was gained from the Faculty of Health Sciences Research Ethics Committee in Trinity College Dublin and all participating services.

4.2.1 Sample
The sample reported in this study was drawn from a representative sample of people with ID (IDS-TILDA), matched to a sample of people drawn from TILDA.

IDS-TILDA Sample
The sample of older people with ID included in this study was taken from IDS-TILDA’s nationally representative sample of 753 people with intellectual disability over 40 years of age. The original sample was drawn from the population of people registered on the National Intellectual Disability Database (NIDD) (Kelly et al., 2008), which includes persons at all levels of ID, and the full range of residential circumstances. It is well established that the NIDD collates information on all people with ID in Ireland who are eligible for, or
receive services (Doyle and Carew, 2016). A systematic approach guided sample selection: expecting a 50% response rate, staff at NIDD, consistent with inclusion/exclusion criteria, randomly selected 1,800 invitees based on personal identification numbers (PINs), provided by regional disability database administrators (RDDA). RDDAs, acting as gatekeepers to maintain the anonymity and protect invitees from possible pressure to participate (as per ethical guidance), then mailed invitation packs explaining the project along with consent forms directed to the person with ID, their families and support staff. The packets included easy read versions of documents.

Where people could not self-consent, a family member/guardian was requested to review the materials and to sign a letter of agreement supporting participation in the study. Among the individuals who agreed to participate, 285 (38%) self-consented and a letter of agreement/consent to participate was received from a family member/guardian for 468 (62%) who were unable to self-consent.

Of the original 1,800 invitees, 753 participants fulfilled all inclusion criteria: 1) Age ≥40 years with intellectual disability, 2) registered with NIDD, and 3) written consent to participate and/or family/guardian written agreement, where required. Comparison with the published demographics of the 2008 NIDD cohort (Kelly et al., 2008) (from which they were drawn) confirmed that the IDS-TILDA random sample was representative of the population (McCarron et al., 2011).

Matched Sample
For purposes of comparison with the general population, those within the IDS-TILDA sample aged 50 years and older were matched with a TILDA sample using propensity score matching (Thoemmes, 2012). A dataset of 956 matched participants (478 in each study) was therefore generated. This paper uses this matched sample of 478 IDS-TILDA participants for non-comparative analysis and comparative analyses with 478 matched participants from TILDA.

Propensity Score Matching
This is a method of matching participants in one group in an observational study with participants in a second group (in this case, matching participants from IDS-TILDA and TILDA), based on observed covariates (Thoemmes, 2012). The current study matched participants based on the covariates age, gender and geographic location.

Given that the TILDA dataset is based on older adults in the general Irish population aged 50 years and over, IDS-TILDA participants aged under 50 years were excluded from analysis, resulting in 478 persons with ID in the current sample. Geographic location was included because the TILDA sample, drawn from the Irish Geodirectory, was stratified based on geographic location, whereas the IDS-TILDA sample was purposefully a random rather than a geographically stratified sample as it was known that geographic location clusters would reflect service provision issues rather than characteristics of people with ID. Nevertheless, both samples were then compared to their sampling frames and in the case of TILDA to census data to further confirm representativeness (McCarron et al., 2011, Kenny et al., 2010, Whelan and Savva, 2013).

4.2.2 Data collection

The research team provided concurrent information seminars to raise awareness about the study and its purposes. Following rigorous training, data were collected by researchers who had experience of working with people with ID. We used a two-stage data collection technique. The first stage involved a postal pre-interview questionnaire completed with or for each participant, which included the opportunity to draw data from existing records. This was then followed up with a face-to-face interview using a standard set of questions. Where necessary, a proxy who knew the participant well completed the interview jointly with or on behalf of the participant. IDS-TILDA required that proxy informants have known the person with ID for a minimum of six months and post-hoc analysis found that this was true for all proxies used. Data relating to the general older population came from secondary analysis of TILDA study data, whose data collection methods are previously published (Kenny et al., 2010).
4.2.3 Variables

Background variables included gender and age. Type of residence (independent/family or community group home or residential setting) and severity of intellectual disability (mild or moderate or severe/profound) are also presented for the IDS-TILDA matched sample. Severity of ID (mild / moderate / severe or profound) was established in the pre-interview and confirmed in the face-to-face interview. Respondents in this group received support in answering questions, where needed, by using proxy respondents. Based on whether the participant had support in responding or not, respondents were categorised as respondent only, respondent and proxy, or proxy only.

Self-reported dental status and denture use were recorded for both samples using 5 scoring options, as used in similar research (National Council on Ageing and Older People, 2004, Kenny et al., 2010). To enable comparison of dentate and edentulous respondents, the three options referring to dentate individuals (1. I have all my own natural teeth - none missing; 2. I have my own teeth, no dentures - but some missing; 3. I have dentures as well as some of my own teeth) were coalesced into a single category considering all people reporting some teeth (referred to as dentate) and two variables considering all people reporting no teeth (1. I have full dentures; 2. I have no teeth or dentures) were coalesced into another category (referred to as edentulous). The result was a dichotomous main outcome variable for analysis.

4.2.4 Analysis

Matching Approach  Both datasets were first cleaned and variables recoded to ensure uniformity in the data. Extraneous variables (and for IDS-TILDA, cases) were deleted and the two datasets merged. Propensity score matching was then completed in SPSS 20 using the R-plug-in and the “ps matching” custom dialog (Thoemmes, 2012). Nearest neighbourhood matching without replacement was used based on a greedy matching algorithm with a caliper of .15 of the standard deviation of the logit of the propensity score (to reduce potential imbalances among matches). Given that several covariates were represented, a single propensity score was generated which can be viewed as the absolute difference between individuals in each group.
**IDS-TILDA Analyses** Data from the IDS-TILDA matched sample were analysed using SPSS v.20®. Summary statistics and counts with percentages are presented for demographic data. Pearson’s Chi Square was calculated to test for association between the dependent variable describing dentate / edentulous status and independent variables within the group with ID. Independent variables with a significant association ($p < 0.05$) were included in a binary logistic regression model to regress variables while adjusting for covariates.

**Comparative analyses** Pearson’s Chi Square tested for any association between dentate / edentulous status and study allocation.

### 4.3 Results

#### 4.3.1 Demographics and self-reported dentate status

There were more females than males in this study. Most participants were between fifty and fifty nine years of age. Demographic data for the matched IDS-TILDA and TILDA samples are summarised in Table 4.1

<table>
<thead>
<tr>
<th></th>
<th>IDS-TILDA a</th>
<th>TILDA b</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Total</strong></td>
<td>478 (100)</td>
<td>478 (100)</td>
</tr>
<tr>
<td><strong>Gender</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>203 (42.5)</td>
<td>190 (39.7)</td>
</tr>
<tr>
<td>Female</td>
<td>275 (57.5)</td>
<td>288 (60.3)</td>
</tr>
<tr>
<td><strong>Age</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>50-59</td>
<td>266 (55.6)</td>
<td>259 (54.2)</td>
</tr>
<tr>
<td>60-69</td>
<td>150 (31.6)</td>
<td>151 (31.6)</td>
</tr>
<tr>
<td>70+</td>
<td>61 (12.8)</td>
<td>68 (14.2)</td>
</tr>
</tbody>
</table>

*IDS-TILDA = Intellectual Disability Supplement to The Irish Longitudinal Study on Ageing; b TILDA = The Irish Longitudinal Study on Ageing*

Table 4.2 demonstrates that the majority of participants from the IDS-TILDA sample lived in either residential care or community group homes with only 14.6% living independently or with family. Half of participants (48.7%) had moderate ID. A minority of respondents (n=86) replied to the interview without any support while almost half (n=219) responded jointly with a person involved in their care (proxy). Responses were completed solely by a proxy family...
respondent or staff, who worked regularly with the individual (that is without any
direct response from the participant) in about one third (n=173) of cases. Two
thirds of the sample (n=314, 65.7%) had some teeth (Table 4.2). A complete lack
of teeth showed initial association with being older, residential setting and who
responded (p<0.05) but not with level of ID or gender (p>0.05), using bivariate
correlations.

Table 4.2. Association of IDS-TILDA sample variables with dentate status (%)

<table>
<thead>
<tr>
<th></th>
<th>Total</th>
<th>Dentate</th>
<th>Edentulous</th>
<th>p Value ^d</th>
</tr>
</thead>
<tbody>
<tr>
<td>Total^b</td>
<td>477 (99.8)</td>
<td>314 (65.7)</td>
<td>163 (34.3)</td>
<td></td>
</tr>
<tr>
<td>Gender</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>203 (42.5)</td>
<td>137 (67.8)</td>
<td>65 (32.2)</td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td>275 (57.5)</td>
<td>177 (64.4)</td>
<td>98 (35.6)</td>
<td>p&gt; 0.05</td>
</tr>
<tr>
<td>Age</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>50-59</td>
<td>266 (55.6)</td>
<td>201 (75.6)</td>
<td>65 (24.4)</td>
<td></td>
</tr>
<tr>
<td>60-69</td>
<td>151 (31.6)</td>
<td>92 (61.3)</td>
<td>58 (38.7)</td>
<td></td>
</tr>
<tr>
<td>70+</td>
<td>61 (12.8)</td>
<td>21 (34.4)</td>
<td>40 (65.6)</td>
<td>p &lt; 0.001</td>
</tr>
<tr>
<td>Type of Residence</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Independent/Family</td>
<td>70 (14.7)</td>
<td>50 (71.4)</td>
<td>20 (28.6)</td>
<td></td>
</tr>
<tr>
<td>Community ^b</td>
<td>169 (35.2)</td>
<td>119 (71.3)</td>
<td>48 (28.7)</td>
<td>p &lt; 0.05</td>
</tr>
<tr>
<td>Residential</td>
<td>239 (50.1)</td>
<td>143 (60.1)</td>
<td>95 (39.9)</td>
<td></td>
</tr>
<tr>
<td>Level of Intellectual Disability</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mild</td>
<td>99 (22.8)</td>
<td>68 (68.7)</td>
<td>31 (31.3)</td>
<td></td>
</tr>
<tr>
<td>Moderate</td>
<td>212 (48.7)</td>
<td>138 (65.1)</td>
<td>74 (34.9)</td>
<td></td>
</tr>
<tr>
<td>Severe/Profound</td>
<td>124 (28.5)</td>
<td>84 (67.7)</td>
<td>40 (32.3)</td>
<td>p&gt; 0.05</td>
</tr>
<tr>
<td>Response type</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Respondent only</td>
<td>86 (18.0)</td>
<td>62 (72.1)</td>
<td>24 (27.9)</td>
<td></td>
</tr>
<tr>
<td>Respondent and proxy</td>
<td>219 (45.7)</td>
<td>147 (67.4)</td>
<td>71 (32.6)</td>
<td></td>
</tr>
<tr>
<td>Proxy only</td>
<td>173 (36.3)</td>
<td>105 (60.7)</td>
<td>68 (39.3)</td>
<td>p &gt; 0.05</td>
</tr>
</tbody>
</table>

^a One observation did not have a valid response for the dependent variable and was therefore excluded from this analysis; ^b Community = Community Group Home; ^c Residential = Residential Care Home; ^d p = Pearson's Chi Square test

4.3.2 Dentate status and denture use

Table 4.3 compares dentate status and denture use for IDS-TILDA and TILDA
matched samples. Among adults over 50 years, 34.1% of those with ID were
missing all teeth and 14.9% among the matched sample without ID. This
association was highly statistically significant (p < 0.0001). This compares to
17.7% (n=1502) of the overall TILDA sample of older people living
independently in Ireland. Where participants had only some teeth missing, only
19.3% of the IDS-TILDA and 45.9% of the TILDA matched samples had partial dentures. Contrastingly, 61.3% of edentulous older people with ID were without dentures compared to 5.2% of edentulous adults in the general population.

| Table 4.3 Dentate status and denture use of IDS-TILDA and TILDA matched datasets (%) | |
|---------------------------------|-----------------|-----------------|
| Which best describes the teeth you have? | IDS-TILDA | TILDA |
| Total respondents | 477 (99.8) | 477 (99.8) |
| I have all my own natural teeth – none missing | 45 (9.4) | 51 (10.7) |
| I have my own teeth, no dentures - but some missing | 217 (45.5) | 192 (40.3) |
| I have dentures as well as some of my own teeth | 52 (10.9) | 163 (34.2) |
| Total Dentate | 314 (65.8) | 406 (85.1) |
| I have full dentures | 63 (13.2) | 69 (14.5) |
| I have no teeth or dentures | 100 (20.9) | 2 (0.4) |
| Total Edentulous | 163 (34.1) | 71 (14.9) |

Figure 4.1 allows comparison of level of edentulism by banded age. The presence of edentulism increased stepwise with age. This was higher for the sample with ID, going from 24.4% (n=65) of 50-59 year olds, through 38.7% (n=58) of those 60-69 years old to 65.6% (n=40) of those 70+. This compares to 6.2% (n=16) of 50-59 year olds, through 19.3% (n=29) of those 60-69 years 38.2% (n=26) of those 70+ in the TILDA sample.

When associations found through bivariate analysis were entered as predictor variables into a logistic regression with dentate status as the outcome variable, increasing age appeared to be predictive of having no teeth, while controlling for residential setting (Table 4.4).
Table 4.4 Predictors of Edentulous Status Among People with ID

<table>
<thead>
<tr>
<th></th>
<th>B</th>
<th>OR</th>
<th>CI</th>
<th>p Value</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Age</strong>&lt;sup&gt;a&lt;/sup&gt;</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>50-59</td>
<td>1.00</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>60-64</td>
<td>.627</td>
<td>1.87</td>
<td>(1.18 – 2.97)</td>
<td>.008</td>
</tr>
<tr>
<td>70+</td>
<td>1.951</td>
<td>7.04</td>
<td>(3.64 – 13.60)</td>
<td>.000</td>
</tr>
<tr>
<td><strong>Residential setting</strong>&lt;sup&gt;a&lt;/sup&gt;</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Independent/home</td>
<td>1.00</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Community</td>
<td>-.147</td>
<td>.86</td>
<td>(0.42 – 1.78)</td>
<td>.690</td>
</tr>
<tr>
<td>Residential</td>
<td>.112</td>
<td>1.12</td>
<td>(0.54 – 2.31)</td>
<td>.762</td>
</tr>
</tbody>
</table>

<sup>a</sup> Adjusted for gender and level of ID; This model shows that age had a significant independent positive effect on edentulous status, while controlling for residential setting. B = Regression coefficient; OR = Odds Ratio; CI = Confidence Interval

Figure 4.1 Percentage of older people in matched sample with (IDS-TILDA) and without (TILDA) who are edentulous in Ireland, banded by age.

4.4 Discussion
We found that a complete lack of natural teeth is common in older people with ID in Ireland. Over a third of this representative sample of people with ID over age 50 was without any teeth. Comparison with TILDA data suggests that being
edentulous (14.9% of the matched sample and 17.7% of the TILDA sample as a whole) was more common for people over 50 years of age with ID than among those without ID in Ireland. As a further comparison, 19.4% of the general public over 60 years were reported to be edentulous in the USA (Beltran-Aguilar et al., 2005).

The fact that edentulism is high among this group is disappointing, but not surprising (See Section 2.2.3). The current study mirrors the trend noted by Crowley and colleagues (Crowley et al., 2005). In their study of adults with ID in residential services only, 14% of 35-54 year olds (compared to 19.9% of those 50-54 years old in the IDS-TILDA sample) and 61% of 55+ year olds (compared to 38.6% over 55+ years old in this study) had total loss of teeth. Differences in approach to selecting their samples notwithstanding, there was an important and unique opportunity for comparison given this is the only benchmark available in Ireland. With those limitations noted, the comparison does suggest that there are lower levels of edentulism among adults with ID in Ireland in 2013 than in the sample assessed in 2003 and confirms the need to further measure incidence and rates of edentulism on a longitudinal basis. Concerningly, the findings here confirm that all people with ID and not just those in residential settings are more likely to lose all their teeth than those without ID and that tooth loss starts earlier in life for the population as a whole.

Edentulism increases with age and is associated with features including race, literacy, sex, smoking, and social class (Starr et al., 2008, Mendes et al., 2012). This study showed some initial association between lack of teeth and age, residential setting and who responded on behalf of the participant. However, among the variables entered into the logistic regression model, only increasing age was found to be a predictor of edentulism. Age has been previously associated with tooth loss in a similar population (Chen et al., 2010).

The current study highlights the need to understand the impact of loss of teeth on older people with disabilities, regarding both their health and quality of life. This is important, as research has associated edentulism with many notable consequences such as reduced masticatory function, poor dietary selection and
psychosocial sequelae, as well as serious health conditions such as cardiovascular disease, and even death (Polzer et al., 2010, Allen and McMillan, 2003).

The second major finding of this study is that almost two thirds of edentulous participants with ID did not have dentures. This compares to 5.2% of edentulous participants in the paired TILDA data and 8.8% of edentulous participants over 55 years in the SLAN study (National Council on Ageing and Older People, 2004). The contrast is stark and perhaps reflects a failure of dental services to provide a functional replacement of teeth and / or poor uptake of denture wear (Costello, 1990, Crowley et al., 2005, Hinchliffe et al., 1988). The complete loss of teeth and a lack of functional replacement is a poor outcome for older people with ID in the current study. These findings strengthen the case for targeted, evidence based programmes for people with ID throughout life so as to avoid succeedent complete tooth loss and lack of functional replacement. These programmes should include a range of appropriate preventive, conservative and rehabilitative primary and secondary services.

This study does not explain the reasons why dentures were not used by edentulous individuals. Findings here are of lower use of dentures among edentulous people with ID than people without ID (a comparative need). The assumption that a lack of teeth constitutes need for dentures is fraught, however, as there is a distinction between what a professional or expert might consider need (normative need) and what a patient / service user may consider need (expressed need) (Bradshaw, 1972). Narby et al. stated that it is the interaction between clinician and individual that establishes need through a “communicative dialogue with mutual respect” (Narby et al., 2005). As such, we are unable to assume that a lack of dentures among edentulous individuals with ID means a failure to meet their need. Previous research found high levels of tolerance for prosthodontic treatment need among institutionalised elderly (Mojon and MacEntee, 1992). Crowley’s research suggests that as many as two thirds of edentulous people with ID not wearing dentures are unsuitable for denture wear (Crowley et al., 2005) while others suggest that need may be reduced by at least a half, once propensity for treatment and other factors are considered in this group (Mojon and MacEntee, 1994, Vigild, 1987b).
A further complication is that even if “suitable” and willing, edentulous people must undergo the extensive and often demanding denture fabrication process. Also once processed, it may be difficult to become accustomed to denture wear, even for people without cognitive issues, due to pain, discomfort, difficulty eating and looseness (Brunello and Mandikos, 1998, Kotkin, 1985). However, Crowley’s research found that few Irish adults with ID had dentures which they chose not to wear (Crowley et al., 2005). Such issues then make it difficult to draw firm conclusion about the lack of dentures among edentulous people with ID.

4.4.1 Limitations

There are several limitations to note. The first relates to sampling and participation. Given that only 753 out of 1800 original invitees (43%) were ultimately interviewed there is a possibility that those who did not participate, were somehow systematically different from those who did. There were a range of reasons for non-participation not under control of the researchers given the need for appropriate oversight by others to ensure adequate protections for an otherwise vulnerable population. Nevertheless, examination of key demographic variables found no significant differences between the profile of the group interviewed and NIDD, the sampling frame from which it was drawn (McCarron et al., 2011). In comparison to the 2008 NIDD cohort (Kelly and Kelly, 2011), where the population of people with ID over 40 years is 51% male and 49% female, in this IDS TILDA sample 45% of participants were male and 55% were female. Regarding Wave 1 IDS TILDA sample, 24% of the sample had mild ID (NIDD=27.6%), 46% moderate (NIDD=44.3%), 24% severe (NIDD=20.5%) and 5% (NIDD=5.5%) profound level of ID. For approximately 5% of the IDS TILDA sample and 2% of the NIDD population, their level of ID was not verified. Therefore, the sample can be considered representative based on level of ID, while some gender imbalance existed in the initial cohort.

Use of propensity scoring to control for the effects of confounding variables is well established (Austin, 2011). Here propensity scoring was used to address demographic variables such as age, gender and geographic dispersal (which has implications for dental service access) that might otherwise explain differences in
edentulism. Such an approach therefore increased the likelihood that any differences noted may instead be attributable to characteristics of having or not having an intellectual disability and/or to differential access to and use of dental services because of the presence or non-presence of intellectual disabilities. The process benefitted from beginning with samples (TILDA and IDS-TILDA) that were previously demonstrated to be representative of the populations from which they were drawn (McCarron et al., 2011, Kenny et al., 2010, Whelan and Savva, 2013), albeit that the initial sampling approaches used (stratified versus random sampling) were different. The IDS-TILDA sample (as the group to be matched to) remained representative of those in IDS-TILDA and NIDD over 50 years, but the TILDA sample, because they were matched to IDS-TILDA, became less representative (post-hoc analysis found some difference in geographic dispersal compared both to the larger TILDA sample and to Irish census data). The matched TILDA participants were also younger than the main TILDA dataset. Such differences do have implications for external validity.

Perhaps the major limitation of this study is the self reported nature of the measure of dentate status. Using self reported, rather than clinical measures facilitated the inclusion of oral health related measures without the need for training in specific indices among non-dental health data collectors who were collecting a large data set. It was felt that ethical approval was also facilitated without the inclusion of clinical measures for the first wave of this study. Although the validity of the current results, based on self reported measures, may be at risk of bias, they reflect those used in largescale epidemiological research previously and currently undertaken in Ireland (Kenny et al., 2010, National Council on Ageing and Older People, 2004).

Partial or total reliance on proxy respondents is a common data collection approach among older people with cognitive issues, recognised to reduce missing responses but potentially increase misattribution bias (Shardell et al., 2013). The proportion of self-only respondents who were edentulous was lower than for other groups, and while this showed initial borderline association ($p = 0.05$), this was not predictive of edentulism in our regression model, which suggests these
variables were not strongly correlated. We can assume from this that proxies did not misattribute either dentate or edentulous status consistently.

4.4.2 Future research

There is a need to further investigate the concept of need and demand for restoration of functional dentition, the tolerance of such procedures and the likelihood of desired outcomes amongst older people with intellectual disability. Additional studies where dentate status is clinically confirmed will help further understanding of the reliability of self and proxy responses in similar research. The IDS-TILDA protocol has been modified to consider these issues in future data collection waves.

4.5. Conclusions

Older people with ID across Ireland have higher levels of reported total tooth loss than the general population living independently. A lack of teeth was predicted by increasing age and not level of disability or residential setting. Most concerningly, when older people with ID lost all their teeth, there was little evidence that they were replaced with dentures. This suggests a need to study why dentures are not used by older adults with ID. There may be a need to offer targeted treatment services to address this identified need. The evidence suggests that prevention of tooth loss in people with ID is important throughout life so as to avoid this poor outcome when they become older. Therefore service developments aiming to prevent edentulism among people with ID are also needed, before it is too late.
Chapter 5 Why do edentulous adults with intellectual disabilities not wear dentures?

The contents of this chapter are based on this publication:
Summary of Chapter 5

**Purpose** This is the second of three chapters exploring total tooth loss and its treatment with complete dentures among adults with ID in Ireland. Older adults with intellectual disabilities (ID) are often edentulous. When total tooth loss occurs in this population, they are very unlikely to wear complete removable dentures (CRDs) to restore oral function in Ireland. The reasons for this are unclear, though opinion holds that this is because dentists do not offer prosthodontic treatment to this group. In this study we ask edentulous older adults with ID why they do not wear dentures.

**Methods** Cross-sectional survey data from Wave 2 of the Intellectual Disability Supplement to The Irish Longitudinal Study on Ageing (IDS-TILDA) was examined to study reported denture wear among edentulous older adults with ID.

**Results** Out of 692 participants, 186 were edentulous (26.9%), of whom 57 (30.6%) wore CRDs and 129 (69.3%) did not. Twelve of this 129 had dentures but did not wear them. Of the 117 respondents who reported that they did not have dentures, information was given by 107 as to whether they wanted dentures: 99 (valid % = 92.5%) did not want dentures, while only 8 did. No respondents in this study reported that they were denied denture therapy. Rather, they simply did not want dentures. Clinicians should understand that extra steps may be needed to ensure that consent is truly informed when patients opt for, or decline, complete denture therapy.

**Conclusions** While there is a high normative need for prosthodontic rehabilitation, expressed need is low. Extra steps may be necessary to ensure optimal outcomes for people with ID.
5.1 Introduction

Evidence continues to mount of the important relationship between total tooth loss and poor health as measured by nutritional status, cardiovascular disease, dementia, diabetes and respiratory disease (Felton, 2015). While more research is needed to fully understand these relationships, it is possible that edentulism indirectly increases risk of such co-morbid conditions. Many of these conditions are especially common among people with intellectual disabilities (ID) as they age (Evenhuis et al., 2001, Haveman, 2009), a group generally found to also have far higher levels of edentulism than the general population (Crowley et al., 2005, Whyman et al., 1995, Hinchliffe et al., 1988, Morgan et al., 2012). Taking Ireland as an example, adults over 50 years of age are about twice as likely to be edentulous if they have an ID (34% v 15%) (Mac Giolla Phadraig et al., 2015c).

There is increasing evidence showing a relationship between rehabilitation of edentulous adults with complete removable dentures (CRDs) and reduced risk of comorbid conditions. For example, malnutrition is less likely in edentulous older adults if they wear CRDs (Han and Kim, 2016, Saarela et al., 2014, Lamy et al., 1999), as is dementia (Paganini-Hill et al., 2012). Prosthodontic replacement of missing teeth also has potential to improve quality of life for adults with disabilities (Crowley et al., 2005). Yet, when adults with ID lose their teeth there is an unusually high tendency to not wear dentures (Costello, 1990, Naidu et al., 2001, Hinchliffe et al., 1988, Cumella et al., 2000).

Among the general population without ID, 95% of edentulous older adults report complete denture wear (Mac Giolla Phadraig et al., 2015c). In contrast, most research indicates that only about a third of edentulous adults with ID actually wear dentures (Crowley et al., 2005, Mac Giolla Phadraig et al., 2015c, Naidu et al., 2001) although some broader ranges of use are reported (Hinchliffe et al., 1988, Cumella et al., 2000, Gray, 2005), perhaps representing methodological and sampling differences between studies. Other researchers have established a working assumption that between a third and a half of such untreated adults and other dependent older adults are actually suitable for denture wear, once suitability for treatment and other factors are considered (Crowley et al., 2005, Mojon and MacEntee, 1994, Vigild, 1987a). While there is a
recognised need for objective assessment (Costello, 1990), these preliminary findings suggest a high unmet normative need. The reasons for this unmet need are poorly understood, meaning that this phenomenon requires further study (Mac Giolla Phadraig et al., 2015c, Gray, 2005, Crowley et al., 2005).

5.1.1 Research question
With this study, we ask older edentulous people with ID why they do not wear dentures? Perhaps this population has dentures and would simply rather not wear them or they do not want denture therapy? Perhaps they have been refused denture therapy? The answer to this question will inform policy and service design in this area. This answer will also help clinicians agree decisions with patients with ID, based on appropriate communication and assessment.

5.2 Materials and methods

5.2.1 Design
Cross-sectional survey design, using data from Wave 2 of the Intellectual Disability Supplement to The Irish Longitudinal Study on Ageing (IDS-TILDA) (McCarron et al., 2014).

5.2.2 Ethics statement
Ethical approval for this study was granted by the Research Ethics Committee of the Faculty of Health Sciences, Trinity College Dublin and all participating services.

5.2.3 Sample
The sample in this study included 708 people with ID participating in the second wave of this cohort study. This represented 94% retention from Wave 1 [20]. The sample was originally drawn randomly from the population over 40 years of age registered on the National Intellectual Disability Database (NIDD) [21]. Participants presented with mild (27%), moderate (49%) and severe/profound (23%) ID and resided in a range of residential settings. Inclusion criteria for the current study included: 1) Participants in Wave 1 of IDS-TILDA and 2) written consent to participate and/or family/guardian written agreement, where required.
This sample was largely comparable to both the Wave 1 sample and the NIDD database, from which the sampling frame was derived (McCarron et al., 2014).

5.2.4 Data collection
Data were gathered using a postal pre-interview questionnaire (PIQ), which drew data from self-report and available records. Level of ID was recorded in the pre-interview questionnaire and verified later at face-to-face interviews used to confirm the pre-interview data and gather additional self-report information. All data collectors underwent extensive training. Proxies supported some individuals in answering questions, where they could not respond independently. Respondent type was measured as either self-report only (n=142, valid%=20.5%), self-report and proxy (n=31.8, valid%=31.8%) or proxy only (n=331, valid%=47.7%). No clinical examination was included.

5.2.5 Variables
In addition to respondent type, background variables included age, residential setting, and severity of intellectual disability (mild or moderate or severe/profound). Self-reported dentate status and denture use were measured using a modification of a previously demonstrated self-report measure (National Council on Ageing and Older People, 2004, Kenny et al., 2010). In this instance there was a six point modification of the original five point scale, as used in Wave 1 data collection (Mac Giolla Phadraig et al., 2015c). Dentate respondents were excluded from further analysis. Edentulous respondents were re-categorised into dichotomous groups of complete denture wearing respondents (Table 5.1, Option 4) and respondents who did not wear CRDs (Table 5.1, Options 5 and 6). Participants were then asked about their denture history and preference for CRDs. Table 5.2 lists the question items.

5.2.6 Analysis
Analysis was completed using SPSS V.20. Descriptive statistics, proportions and rates are reported across variables. To understand the relationship between demographics of edentulous older adults with ID and denture wear, Pearson’s Chi Square was used to compare both complete denture wearing and non-denture wearing groups across age, level of ID, residential setting and respondent type variables.
Table 5.1 Which best describes the teeth you have? (n=708)

<table>
<thead>
<tr>
<th>Description</th>
<th>N</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Total respondents</td>
<td>692</td>
<td>100</td>
</tr>
<tr>
<td>1 I have all my own natural teeth – none missing</td>
<td>111</td>
<td>16.0</td>
</tr>
<tr>
<td>2 I have my own teeth, no dentures - but some missing</td>
<td>325</td>
<td>47.0</td>
</tr>
<tr>
<td>3 I have dentures as well as some of my own teeth</td>
<td>70</td>
<td>10.1</td>
</tr>
<tr>
<td>Total Dentate</td>
<td>506</td>
<td>73.1</td>
</tr>
<tr>
<td>4 I have full dentures</td>
<td>57</td>
<td>8.1</td>
</tr>
<tr>
<td>5 I have dentures but don’t wear them</td>
<td>12</td>
<td>1.7</td>
</tr>
<tr>
<td>6 I have no teeth or dentures</td>
<td>117</td>
<td>16.9</td>
</tr>
<tr>
<td>Total Edentulous</td>
<td>186</td>
<td>26.9</td>
</tr>
</tbody>
</table>

Table 5.2 Items included in this Chapter

1 Which best describes the teeth you have?  
2 Why do you not wear dentures?  
3 Have you had dentures fitted by a dentist?  
4 Would you like replacement of your missing teeth?  

* Used to categorise complete denture use status in the current study.

5.3 Results

5.3.1 Sample
As can be seen in Table 5.3 just under half of the sample had moderate intellectual disability and most lived in supported accommodation. There was no statistically significant relationship between complete denture wear for edentulous participants and age, level of ID or residential setting, although a trend for less denture wear was noted with increasing age, level of disability and unsupported living (Table 5.3). There was a highly significant relationship between those who responded and whether the participant had dentures, with most self-reporting respondents having dentures and most proxy only respondents not having dentures (Table 5.3).

5.3.2 Complete denture wear and need
Data on dentate and denture wearing status were available on 692 of the 708 participants: 506 (73.1% of the sample) with some teeth were not included in further analysis and the focus of further analyses was on the 186 respondents who were edentulous (26.9%). Of this edentulous subsample, 57 (30.6%) wore CRDs and 129 (69.3%) did not, and of these eight (4.3% of the edentulous
subsample) reported a desire for CRDs suggesting an expressed need (met or unmet) among 65 (34.9%) of edentulous participants (Figure 5.1).

Table 5.3: The relationship between denture wear and demographics

<table>
<thead>
<tr>
<th>Denture Wear</th>
<th>No</th>
<th>Yes</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>n</td>
<td>(%)</td>
<td>n</td>
</tr>
<tr>
<td><strong>Age range</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>44-49</td>
<td>30</td>
<td>76.9%</td>
<td>9</td>
</tr>
<tr>
<td>50-64</td>
<td>64</td>
<td>65.3%</td>
<td>34</td>
</tr>
<tr>
<td>65+</td>
<td>25</td>
<td>78.1%</td>
<td>7</td>
</tr>
<tr>
<td><strong>Level of ID</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mild</td>
<td>28</td>
<td>65.1%</td>
<td>15</td>
</tr>
<tr>
<td>Moderate</td>
<td>55</td>
<td>70.5%</td>
<td>23</td>
</tr>
<tr>
<td>Severe\Profound</td>
<td>27</td>
<td>73.0%</td>
<td>10</td>
</tr>
<tr>
<td><strong>Residential setting</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Independent Family</td>
<td>23</td>
<td>82.1%</td>
<td>5</td>
</tr>
<tr>
<td>Community group home</td>
<td>48</td>
<td>70.6%</td>
<td>20</td>
</tr>
<tr>
<td>Residential Care</td>
<td>48</td>
<td>65.8%</td>
<td>25</td>
</tr>
<tr>
<td><strong>Respondent type</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Self Report Only</td>
<td>6</td>
<td>17.6%</td>
<td>28</td>
</tr>
<tr>
<td>SR and Proxy</td>
<td>23</td>
<td>56.1%</td>
<td>18</td>
</tr>
<tr>
<td>Proxy Only</td>
<td>99</td>
<td>90.0%</td>
<td>11</td>
</tr>
</tbody>
</table>

** Statistically significant at $p<0.001$, using Pearson’s chi square
Figure 5.1 Participant flow

Edentulous n = 186 (100%)  
(26.9% of valid sample)

People who currently have dentures

I have full dentures  
n=57  
(30.6% of edentulous sample)

People who have no teeth or dentures  
n=117  
(62.9% of edentulous subsample)

I have dentures but don’t wear them  
n=12  
(6.5% of edentulous sample)

Reported previous dentures  
n=11  
(9.6% of edentulous subsample who have no dentures)

Did not report ever having dentures  
n=104  
(90.4% of edentulous subsample who have no dentures)

Why do you not wear dentures? n=23

Don’t like having dentures  
n=17

Dentures caused pain or discomfort  
n=4

other  
n=2

Would you like replacement of your missing teeth?  

No  
n=99  
(92.5% of valid respondents)

Yes  
n=8  
(7.5% of valid respondents)

(% = Valid %; * Dentate respondents excluded from further analysis in the current study; ** 2 respondents did not supply valid responses; *** 8 respondents did not supply valid responses.

5.3.3 Why do you not wear dentures?
Twenty-three respondents (12.4% of edentulous respondents and 28.8% of those who had received dentures) reported previously having CRDs, which they do not use; of these, 17 (74%) did not liking having dentures. Most of these were reported by proxies, though some self-reported. Of the remaining respondents, four self-reported that their CRDs caused pain or discomfort, one participant lost them and two reported a fear of choking.

5.3.4 Would you like dentures as replacement of your missing teeth?
Of the 23 respondents who previously had dentures but did not wear them at the time of the interview, only two reported that they would like a replacement. Of the 117 respondents who reported that they did not have dentures (12 had dentures but did not wear them, at the time of interview), further data were available for 107: 99 (valid% = 92.5%) did not want dentures, while only 8 (valid% = 7.5%) did.
5.4 Discussion

5.4.1 High normative but low expressed need

This article investigated the low rate of complete denture use among adults with ID. We found that most edentulous adults with ID never had dentures. When asked why they did not wear dentures, no participants reported that dentists had not offered or refused them dentures. Previous research had assumed that this was the most likely cause of low denture wear in this cohort (Naidu et al., 2001, Crowley et al., 2005). Rather, this study found that the majority simply did not want dentures.

There is a distinction between what an expert might consider need (normative need) and what a person says they need (expressed need) (Bradshaw, 1972). In this study, two thirds of those identified as having normative need for complete denture therapy had no expressed need, e.g. did not want dentures. According to Cumella et al. (Cumella et al., 2000), the extent to which needs for people with ID are met depends on many factors such as “the expectations which they and their carers have of health services, the degree of social support which they receive, their ease of access to services, and their ability to tolerate treatment”. They also rely on carers for decision-making in how they interact with oral healthcare services. In our study, those who had dentures were significantly more likely to have responded for themselves rather than rely on proxies to respond on their behalf. These data suggest an association between need expressed by proxy and the clinical decision not to make prostheses. People with ID can be disempowered in their interactions with oral health service providers (Mac Giolla Phadraig et al., 2015a) and their reliance on proxies may serve to disempower them further in the process therapeutic dialogue. This is compounded by a tendency towards suggestibility and acquiescence (Clare and Gudjonsson, 1993). Perhaps it is simpler for all involved to take a lack of self-expressed need at face value, making it easy for professionals to hide behind the concept of choice when justifying a lack of intervention (Pritchard, 2001). The data suggest that clinicians must ensure that people with ID are empowered to make informed choices when it comes to complete denture therapy, where possible.
5.4.2 Communication and time

Narby and colleagues state that need for prosthodontic treatment can only be established between clinician and patient through a “communicative dialogue with mutual respect” (Narby et al., 2005). However, it may be difficult for people with ID to problem solve and to conceive of abstract alternatives, of which they have no concrete experience (such as prostheses) (Arscott et al., 1999). This may subtly influence their decision not to request or receive prostheses (Cullen, 1999). This places responsibility on the clinician to ensure that information on denture wear is communicated effectively. For example, the patient may require time to get accustomed to real dentures and impression trays, which may offer vital visual, tactile and experiential cues. Easy read materials, pictures, diagrams, demonstration on others, allowing the patient to handle and explore equipment and responding according to their communication preferences are all potentially helpful (Lindsay, 2011).

Clinicians should also ensure adequate time for discussion and reflection by the patient with ID to support clinical decisions (Health Services Executive, 2014). This often necessitates sequential visits before a prosthodontic treatment plan is agreed. Even when it is agreed that denture therapy is preferred, it can be difficult to judge a person’s ability to tolerate the complexities of denture processing (Costello, 1990). A multi-step therapeutic assessment may help by using stepwise impression techniques as a definitive assessment of the patients’ tolerance for impression-making.

5.4.3 Most tolerated dentures

Clinicians and carers may also be concerned that the individual may not be able to manage wear and maintenance of a prosthesis (Naidu et al., 2001). Our study found that denture therapy, when provided, was tolerated by about two thirds of participants in the current study. Therefore CRDs can be seen as successful, or at least tolerated, when provided. Nevertheless, there are negative consequences associated with dentures.

5.4.4 Service considerations

The most appropriate response to these data is to prevent edentulism in this group (Mac Giolla Phadraig et al., 2015c). With regard to the 5,000 adults with ID who have neither teeth nor dentures in Ireland, it is essential that services ensure informed decisions by
empowered patients. Accessible denture processing skills are also necessary. In Ireland, where the bulk of care to older adults with ID is delivered by the pediatric-oriented Public Dental Services (PA Consulting Group, 2010), this may necessitate reorientation of dental services and/or up-skilling of service providers to respond to the needs of this emerging cohort. There is a similar argument for increasing special care training for undergraduate dentists and clinical dental technologists to maximise this cohort’s access to appropriate dental services. The provision of implant-retained prostheses could be also considered. However, such services are potentially expensive. The McGill Statement (Feine et al., 2002, Thomason et al., 2009) recognizes two-implant mandibular removable overdentures as a minimum treatment for edentulism. To provide this minimum standard of care for this population, at a conservative cost of €5000 per person, would cost €25,000,000 or a third of the national budget for the Public Dental Service. However, a demand led service is unlikely to cost anywhere near this as one study suggests: Targeted services offering implant-retained prostheses to edentulous older adults with disabilities in Scandinavia had extremely low uptake (Brahm et al., 2009). In addition, there are a number of contraindications to prostheses with or without implant support which will likely further reduce the numbers likely to avail of such care. This includes conditions such as poor oral hygiene, inability to tolerate the process of construction, inability to wear prosthetics due to poor neuromuscular control, complex medical history, extensive resorption of prosthesis bearing tissues as seen in those with periodontal disease or chronic edentulism.

5.4.5 Limitations
The results of this study should be considered in the context of its limitations. This study used self-report measures of denture wear with a risk of misattribution bias: participants may not correctly describe their denture wear status. The current design did not allow the research team to verify dentate status and the wear of dentures. We plan to measure the validity of such self-reported measures in Wave 4 of IDS-TILDA. Secondly, proxies were often used to report both dentate status and denture wear. The inclusion of proxy response was important so as those with greatest dependency were included and their experiences captured in the overall study. Without this, they would have been excluded leading to a skewed picture of this population. However, this means that one person is responding on behalf or in tandem with another and the degree to which this
communication is influenced by the proxy must be variable from respondent to respondent. This is a possible confound, which is why it was included in the study as a DV. In fact it was found to be a significant predictor of denture wear, which highlights the importance of supported communication for this group. Additionally, participants may not remember the reasons why they stopped wearing dentures: a recall bias. Some respondents relied on others to help them answer these questions, and this reliance on proxy respondents may influence the findings reported. Lastly, this data do not suggest that CRDs are a “best option” for all edentulous older adults with ID, rather they illustrate that clinicians must actively involve the patient in decision making and assessment regarding denture therapy so as the best choice for each patient can be agreed.

5.5 Conclusion

While there is a high normative need for prosthodontic rehabilitation among the older adult cohort with ID, the expressed need is low. The current study found that older edentulous people with ID do not appear to want prostheses. Extra steps might be needed to empower edentulous patients and ensure that consent is truly informed when they opt for or decline denture therapy. While this study highlights some issues in the imbalance between expressed and normative need, the reasons for low demand are still somewhat unclear. More research is needed, specifically studying factors, which influence decision making when planning care for edentulous older adults with ID. There is also a need to understand the impact of failing to restore oral function for this population. The next chapter explores the benefit of wearing dentures of this cohort.
Chapter 6 Total tooth loss is a risk factor for difficulty eating for older adults with intellectual disabilities – only if untreated.
Summary of Chapter 6

**Purpose**
This chapter is the third and final chapter that explores total tooth loss and its treatment with complete removable dentures among adults with intellectual disabilities in Ireland. This chapter aims to measure the functional impact of edentulism and its management on older adults with ID by quantifying the predictive value of dentate status on difficulty eating.

**Methods**
Cross-sectional survey data from Wave 2 of the IDS-TILDA study were entered into a multiple logistic regression model testing the relationship between the dependent variable, *Difficulty eating*, and one variable, *Dentate status*, with the effect of other independent variables statistically eliminated. This model offered the best fit of the data, based on Akaike's information criterion (AIC). The predictive value of the overall model was tested using a ROC Curve and Area Under the Curve Statistic.

**Results**
Of the 692 participants, 506 had some teeth (*Group 1*), 57 had no teeth and reported wearing complete removable dentures (*Group 2*) and 129 had no teeth or dentures (*Group 3*). A parsimonious regression model was developed including 406 responses. Using this model, compared to Group 1, it was found that the odds of difficulty eating was twice as great (OR=2.01, 95%CI=1.02-4.03) among people without teeth or dentures (Group 3). Conversely, edentulous participants who had dentures (Group 2) had far lower odds (OR =0.21, 95%CI=0.06-0.64) of reporting difficulty eating compared with those with natural teeth (Group 1). The overall model showed good discrimination, according to AUC statistic.

**Conclusions**
The study findings confirm that, for adults with ID, toothlessness is predictive of difficulty eating only when untreated. When treated, the risk of difficulty eating is actually reduced dramatically, even compared to those who report having natural teeth. Missing teeth should be replaced for edentulous adults with ID. Dental assessment should also be incorporated into the assessment of eating difficulties among adults with ID, especially as they age.
6.1 Introduction

6.1.1 Introduction
In the previous chapter, it was clear that people with ID do not always receive functional replacement of missing teeth when they become edentulous, something that people with ID do not demand. Indeed it seems that the option of such replacements is not presented to people with ID in a meaningful way (Mac Giolla Phadraig et al., 2016).

Given that dentists, applying principles of evidence based practice, will theoretically, frame the discourse for those who have capacity, and lead best interest decisions for patients who lack capacity, evidence is needed as to the benefits, or indeed not, of oral rehabilitation specific to this group. Therefore, this chapter assesses a basic function of dentition: eating, and specifically, whether total tooth loss, restored or unrestored, is a risk factor for difficulty eating among this population.

6.1.2 Background
Dental caries (tooth decay), occurs when dietary carbohydrates are fermented by bacteria in dental plaque causing demineralisation, cavitation, inflammation and infection of teeth. Periodontitis (gum disease) occurs when the gum and bone surrounding the teeth (periodontal tissues) become inflamed and leads to bone resorption, looseness and eventually loss of teeth. The cumulative outcome of these processes, and their mismanagement, is total tooth loss (edentulism).

The number and distribution of teeth affects chewing efficiency (Schimmel et al., 2015, Walls and Steele, 2004), an essential sensorimotor attribute for preparation of food for swallowing (van der Bilt et al., 2006). For people with no teeth at all, this may lead to sub-optimum food choice, food avoidance and, possibly, nutrient deficiencies (Moynihan et al., 2009). Walls and Steele found, in their review of the literature, that edentulism affects chewing efficiency, but more importantly it limits food choice, selection and preparation, especially of fruit and vegetables, which are rich in Vitamin C and fibre (Walls and Steele, 2004). In fact, nutritional changes like these (along with inflammation and infection) are seen as an important biological vehicle behind the relationship between tooth loss and mortality (Polzer et al., 2010).
People with no teeth present with chewing difficulty (Walls and Steele, 2004, Slade et al., 1996) and providing dentures alone may not lead to significant improvement in dietary choice or nutritional status (Moynihan, 2005, Sheiham and Steele, 2001). Denture wear offers functional replacement of teeth and is the norm for older edentulous populations without ID (Mac Giolla Phadraig et al., 2015c, Slade et al., 1996). Complete dentures have been shown to reduce the health (Polzer et al., 2010) and nutritional impact of edentulism by improving diet, and reducing both malnutrition and obesity (Han and Kim, 2016, Saarela et al., 2014, Lamy et al., 1999, Han and Kim, 2016). Yet they also present a challenge when chewing (Walls and Steele, 2004, Slade et al., 1996) and may not lead to significant improvement in dietary choice or nutritional status with denture therapy alone (Moynihan, 2005, Sheiham and Steele, 2001). In total, the evidence suggests that total tooth loss leads to difficulty eating in the older general population, as expressed through dietary choice and food modification, quality of life and nutritional outcomes. It appears that denture wear may reduce difficulty eating, though this picture is somewhat unclear.

The population with intellectual disabilities (ID) are aging (Bittles et al., 2002) and experience edentulism to a greater extent and at an earlier age, than the general population (Crowley et al., 2005, Whyman et al., 1995, Hinchliffe et al., 1988, Morgan et al., 2012, Mac Giolla Phadraig et al., 2015c). However, unlike their counterparts in the general population, they are very unlikely to wear complete dentures when they become edentulous (Costello, 1990, Naidu et al., 2001, Hinchliffe et al., 1988, Cumella et al., 2000). One study found people with ID to be twelve times less likely to wear dentures when they lose their teeth (Mac Giolla Phadraig et al., 2015c). How people with ID come to this decision, to not wear dentures, is unclear and there is a question as to whether they are supported to make informed decisions about dentures. A better understanding of the impact of denture wear on function, such as on eating, for people with ID would increase evidence to support informed and empowered treatment choices (Mac Giolla Phadraig et al., 2016). However, the relationship of dentition status, denture wear and difficulty eating among this population remains unclear.
The lack of clarity may be in part due to the multidimensional nature of the eating difficulty in this population. Eating and swallowing are complex behaviours involving volitional and reflexive activities of more than 30 nerves and muscles (Matsuo and Palmer, 2008) and among people with ID particularly, the term extends far beyond masticatory dysfunction, referring to neural impairment affecting chewing and swallowing, psychogenic vomiting, reflux, regurgitation, rumination, faddiness/refusal, hyperphagia, pica, binge eating, food stealing and many more (Clark and Griffiths, 2008, Gravestock, 2000). Put another way, for people with ID, the concept of difficulty eating covers an array of specific structural and functional impairments including food selectivity, feeding skills deficits, food refusal, risk of aspiration or behaviour problems (Gal et al., 2011, Matson and Kuhn, 2001). When researchers consider difficulty chewing specifically, among children with disabilities and populations often affected by ID, it seems to be a significant contributor to such eating difficulties (Sjögreen et al., 2015, Seiverling et al., 2011).

There a need to understand the complex underlying phenomena that contribute to eating disorders among people with ID (Gravestock, 2000). This is because difficulty eating may influence the choice of residence that adults with ID live in (Matson et al., 2006) and is predictive of dependency during meals (Ball et al., 2012), often making meal times lengthy and more difficult (Chadwick and Jolliffe, 2009). Another reason is that eating difficulties pose serious health risks. These include aspiration, poisoning, malnutrition (Matson and Kuhn, 2001) and asphyxiation (Samuels and Chadwick, 2006). Research supports the assumption that a functioning dentition can reduce the risk of asphyxiation in older adult populations, even in those without an ID (Kikutani et al.). Respiratory infections arising from aspiration are common (Perez et al., 2015) and a major cause of death in adults with ID (Tyrer and McGrother, 2009). Difficulty eating can even predict death among adults with ID (Heslop et al.).

Until now there have been no large, epidemiological studies to test the assumption that edentulism in adults with ID leads to difficulty eating or that dentures restore this function. Understanding the role of total tooth loss may lead to better assessment and management of difficulty eating in this population. There is also a need for evidence
regarding the functional impact of treating and not treating edentulism to determine if denture therapy is beneficial (Mac Giolla Phadraig et al., 2016). Therefore, this study aims to test whether edentulism is a risk factor for difficulty eating and whether replacement of total tooth loss reduces any functional impact.

### 6.1.3 Research questions

Is total tooth loss predictive of difficulty eating in adults with ID, with and without complete denture wear?

### 6.2 Methods

#### 6.2.1 Design

This is an observational study based on secondary analyses of the cross-sectional survey data from the Intellectual Disability Supplement to The Irish Longitudinal Study on Ageing (IDS-TILDA). The latter is a multi-wave longitudinal study exploring the ageing profile, physical and behavioural health, health services needs, psychological health, social networks, living situations and community participation of older adults with ID in Ireland (McCarron et al., 2014).

#### 6.2.2 Ethics statement

This study complies with the ethical standards and laws applicable in Ireland. This study received ethical approval from the Faculty of Health Sciences Research Ethics Committee in Trinity College Dublin and all participating services.

#### 6.2.3 Population and sample

The sample in this study included 708 older people with ID participating in the second wave of this cohort study. This figure represented 94% retention from Wave 1 (McCarron et al., 2014). The sample was originally drawn randomly from the population over 40 years of age registered on the National Intellectual Disability Database (NIDD) [20]. This sample was largely comparable to both the Wave 1 sample and the NIDD database, from which the sampling frame was derived [21].
6.2.4 Data collection

This study focuses on 2013-2014 data arising from Wave 2 of IDS-TILDA. Data were collected at two time points: Self-reported data captured in a pre-interview questionnaire and later, in a researcher administered Computer-Aided-Personal-Interview, with support from proxies where necessary.

6.2.5 Quantitative variables

Dependent variable Given the diverse structural and functional impairments that come under the term difficulty eating, the dependent variable focuses on difficulty eating as a general concept. Participants were asked to Please indicate the level of difficulty, if any, you have with eating such as cutting up your food, use of utensils, drinking from a cup/glass etc. For the 694 (92.2%) participants who gave a valid response, answers were coded as No difficulty (n=375, 54%) or either Some Difficulty (n=193, 27.8%), A lot of difficulty (n=50, 7.2%) or Cannot do at all (n=76, 11%). For purposes of analysis, these last three answer options were collapsed as Difficulty (n=319, 46%), creating a binary outcome variable.

Explanatory Variable Dentate status was recorded based on self-reported response to the item: Which best describes the teeth you have? Respondents were categorised based on their reported dentate status as having either some teeth (Group 1), no teeth (edentulous) and using complete dentures (Group 2) and edentulous, not using dentures (Group 3). Group 1 consisted of three collapsed categories: I have all my own natural teeth - none missing (n=111, 21.9% of Group 1); I have my own teeth but some missing - I have no dentures (n=325, 64.2% of Group 1) and I have dentures as well as some of my own teeth (n=70, 13.8% of Group 1).

Covariates Based on theoretical and conceptual association, factors in the literature reported or suggested to be associated with the general concept of difficulty eating for people with ID were included in the model. The model was built to focus on difficulty eating as a general and multidimensional concept and not the myriad of underlying impairments; to have done so would have led to an unwieldy model including superfluous independent variables, increasing the degrees of freedom and neglecting Occam’s razor. To illustrate this, pica is known to be associated with self-injury, among
other factors, but to include self-injury as a covariate in a model on difficulty eating, which is only partially constituted by pica, lacks conceptual rigour. For the model, demographic variables, gender and residential setting were included to allow for non-modifiable risk indicators. Level of ID and age were also included as non-modifiable factors, though they may also be independent predictors of eating problems (Gal et al., 2011) (Lazenby, 2008). Ball and colleagues, studying a group of adults with an intellectual disability, found that two thirds of those requiring mealtime support had additional disability or illness (e.g. visual impairment, poor dentition or dementia) and that half had psychological or behavioural issues, such as challenging behaviour or emotional disturbance (Ball et al., 2012). Speech and Language guidelines list congenital and acquired neurological conditions e.g. Cerebral Palsy, stroke, dementia and Down syndrome, as well as medications, anatomy, iatrogenic or behavioural issues as predictors of eating, drinking, swallowing problems (Irish Association of Speech and Language Therapists, 2010). Chadwick and Jolliffe (Chadwick and Jolliffe, 2009) identified an association between dysphagia and cerebral palsy, increased physical disability and cognitive impairment among 101 people with ID. Therefore all of these variables were also included as candidate covariates.

People who have eating problems may have had measures put in place to address these concerns such as routine mashing of their food and may therefore no longer report difficulties eating, despite an underlying impairment. This may hide any association with edentulism. To control for the potential ameliorating effects of such management strategies on eating difficulties, candidate covariates included modification of food texture, provision of adapted equipment, postural correction and prompting/pacing or encouragement/supervision (Ball et al., 2012). Table 6.1 lists the variables we included in the model, with their corresponding IDS-TILDA items together with citation from the supporting literature.

### 6.2.6 Statistical methods

Analysis was completed using SPSS V.20 and R Studio V.1.0.44. Firstly, sample descriptors gender; age; level of ID; type of residence; dementia, organic brain syndrome or senility; emotional, nervous or psychiatric condition; reported challenging behaviour; visual impairment; reported Down Syndrome; polypharmacy; dependency; activity level; 153
reported help eating; use of special utensils when eating; soft/liquidised diet and difficulty eating were divided according to dentition status and compared using Pearson’s $X^2$. To build the regression model, all candidate variables were first entered into an overall model. Covariates were tested for multicollinearity using General Variation Inflation Factor (GVIF) (Fox and Weisberg, 2011). Following exclusion of three candidate variables, crude and adjusted Odds Ratios (ORs) and corresponding 95% confidence intervals (95%CI) were reported using a binary logistic regression model for the 406 includable participants. This tested the effect of dentate status on difficulty eating, while controlling for the effect of covariates in a full model. Based on this full model, information criterion was used to select model parameters. Akaike’s information criterion (AIC) considers both error and the principle of parsimony. AIC penalises a model for too many parameters. The model with the lowest AIC was considered to be the optimal model and therefore selected in this analysis. The discriminatory value of the final model was then observed using the receiver operating characteristic curve (ROC curve) and the Area Under the Curve (AUC) was calculated.
Table 6.1: Predictive and ameliorating factors reportedly associated with difficulty eating among people with ID.

<table>
<thead>
<tr>
<th>Predictive parameters</th>
<th>IDS-TILDA Factor, transformation and scoring</th>
</tr>
</thead>
<tbody>
<tr>
<td>Non-modifiable demographics</td>
<td>PIQ, Gender, PIQ, Age Range, PIQ, Level of ID: Mild/Moderate/ Severe Or Profound, PIQ, Type of residence</td>
</tr>
<tr>
<td>Dementia or cognitive impairment</td>
<td>Q.79 Has dementia, organic brain syndrome or senility = YES</td>
</tr>
<tr>
<td>Behavioural issues / Challenging behaviour</td>
<td>Aggregate item: Does the person display challenging behaviour? = Yes if any of the following challenging behaviours are reported: Q.76 Scream=Yes OR Q.76 Throw things=Yes OR Q.76 Hit out=Yes OR Q.76 Self injure=Yes OR Q.76 Other=Yes</td>
</tr>
<tr>
<td>Emotional issues</td>
<td>Q.69 Has emotional, nervous or psychiatric condition = Yes</td>
</tr>
<tr>
<td>Physicial disability</td>
<td>Aggregate Item: Modified Barthel's Index of Activities of Daily Living (Burke, 2016)</td>
</tr>
<tr>
<td>Cerebral Palsy / Stroke</td>
<td>PIQ: Have you been told that you have any of the following: Q.45 Cerebral Palsy = Yes Q.34 Stroke = Yes</td>
</tr>
<tr>
<td>Down Syndrome</td>
<td>Q. What is the cause of intellectual disability? Down Syndrome = Yes Other / Unknown = No</td>
</tr>
<tr>
<td>Visual impairment</td>
<td>PH1. Is your eyesight (using glasses or contact lenses if you use them)...? (Recoded): Excellent to good= Excellent to good vision Fair/Poor/Blind = Fair to no eyesight</td>
</tr>
<tr>
<td>Medications</td>
<td>Aggregate item based on number of medications listed. Q.144 List the medications you currently take. 1-4: No Polypharmacy 5-9 Polypharmacy 10+Excessive polypharmacy</td>
</tr>
<tr>
<td>Anatomical issues</td>
<td>No item available</td>
</tr>
<tr>
<td>Ameliorating factors</td>
<td>Q.FL50 Does anyone ever help you with eating? (Recoded): Yes = Yes; No / Not asked = No</td>
</tr>
<tr>
<td>Provision of adapted equipment</td>
<td>Q.FL48 Do you ever use special utensils when you eat? (Recoded): Yes = Yes; No / Not asked = No</td>
</tr>
<tr>
<td>Modification of food texture</td>
<td>Q.PH49 What type of diet are you following? Answer option: Soft/liquidised foods Box ticked = Yes Not ticked / Not asked = No</td>
</tr>
<tr>
<td>Postural correction</td>
<td>No item available</td>
</tr>
</tbody>
</table>
Barthel's Index scored 0-100: 0-60: Severe to total dependence; 61-100: Moderate dependence to independence (Shah et al., 1989). Aggregate item, coded as per Burke (Burke, 2016).

6.3 Results

6.3.1 Sample description

Table 6.2 summarises the demographic profile of all participants included in this study. The most participants were between 50 and 64 years of age and almost half had a moderate ID (Table 6.2). Dentate status was recorded for 692 participants.

6.3.2 Dentate status: bivariate analyses

Of the 692 participants, 506 had some teeth. Of these dentate participants, 111 (21.9%) reported that they had all their teeth. Of the 395 (78.1%) who were partially edentulous, only 70 (17.7%) had dentures. Using natural counts, Table 6.2 demonstrates that difficulty eating was associated with dentate status ($p < 0.001$).

Table 6.2 Difficulty eating and dentate status

<table>
<thead>
<tr>
<th></th>
<th>No difficulty</th>
<th>Difficulty</th>
</tr>
</thead>
<tbody>
<tr>
<td>I have all my own natural teeth - none missing</td>
<td>75 (67.6%)</td>
<td>36 (32.4%)</td>
</tr>
<tr>
<td>I have my own teeth but some missing - I have no dentures</td>
<td>165 (50.9%)</td>
<td>159 (49.1%)</td>
</tr>
<tr>
<td>I have dentures as well as some of my own teeth</td>
<td>53 (75.7%)</td>
<td>17 (24.3%)</td>
</tr>
<tr>
<td>I wear full dentures</td>
<td>45 (80.4%)</td>
<td>11 (19.6%)</td>
</tr>
<tr>
<td>I have no teeth or dentures</td>
<td>29 (24.8%)</td>
<td>88 (75.2%)</td>
</tr>
<tr>
<td>I have dentures but don't wear them</td>
<td>4 (33.3%)</td>
<td>8 (66.7%)</td>
</tr>
</tbody>
</table>

Association significant at the .001 level of probability using Chi Square

Further analyses analysed the data across three groups: 506 participants had some teeth (Group 1). Fifty seven participants had no teeth and reported wearing complete dentures (Group 2) and 129 had no teeth or dentures (Group 3). As may be seen in Table 6.3, there was no statistically significant difference in dentate status according to age, gender, level of ID, or type of residence. Bivariate analyses did demonstrate some statistically significant associations with dentate status: Group 3 reported dementia, visual impairment and excessive polypharmacy more frequently than in the other groups.
Functionally, Group 3 were more likely to frequently report low levels of activity, difficulty eating and dietary modification (Table 6.3).
Table 6.3 Characteristics of the sample population, according to dentate status (Group 1 Participants reporting at least one tooth present; Group 2 Participants without teeth who report wearing dentures; Group 3 Participants without teeth or dentures.) (%=Valid %)

<table>
<thead>
<tr>
<th></th>
<th>Total</th>
<th>Group 1</th>
<th>Group 2</th>
<th>Group 3</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Gender</strong> (n=692)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>304</td>
<td>43.9%</td>
<td>226</td>
<td>44.7%</td>
</tr>
<tr>
<td>Female</td>
<td>388</td>
<td>56.1%</td>
<td>280</td>
<td>55.3%</td>
</tr>
<tr>
<td><strong>Age</strong> (n=646)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>44-49</td>
<td>185</td>
<td>28.6%</td>
<td>146</td>
<td>30.6%</td>
</tr>
<tr>
<td>50-64</td>
<td>322</td>
<td>49.8%</td>
<td>224</td>
<td>47.0%</td>
</tr>
<tr>
<td>65+</td>
<td>139</td>
<td>21.5%</td>
<td>107</td>
<td>22.4%</td>
</tr>
<tr>
<td><strong>Level of ID</strong> (n=596)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mild</td>
<td>143</td>
<td>24.0%</td>
<td>100</td>
<td>22.8%</td>
</tr>
<tr>
<td>Moderate</td>
<td>277</td>
<td>46.5%</td>
<td>199</td>
<td>45.4%</td>
</tr>
<tr>
<td>Severe\Profound</td>
<td>176</td>
<td>29.5%</td>
<td>139</td>
<td>31.7%</td>
</tr>
<tr>
<td><strong>Type of residence</strong> (n=645)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Independent/Family</td>
<td>105</td>
<td>16.3%</td>
<td>77</td>
<td>16.2%</td>
</tr>
<tr>
<td>Community group home</td>
<td>285</td>
<td>44.2%</td>
<td>217</td>
<td>45.6%</td>
</tr>
<tr>
<td>Residential Care</td>
<td>255</td>
<td>39.5%</td>
<td>182</td>
<td>38.2%</td>
</tr>
<tr>
<td><strong>Has dementia, organic brain syndrome or senility</strong> <strong>(n=653)</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>37</td>
<td>5.7%</td>
<td>22</td>
<td>4.6%</td>
</tr>
<tr>
<td>No</td>
<td>616</td>
<td>94.3%</td>
<td>459</td>
<td>95.4%</td>
</tr>
<tr>
<td><strong>Has emotional, nervous or psychiatric condition</strong> (n=666)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>339</td>
<td>50.9%</td>
<td>244</td>
<td>50.1%</td>
</tr>
<tr>
<td></td>
<td>No</td>
<td>49.1%</td>
<td>243</td>
<td>49.9%</td>
</tr>
<tr>
<td>--------------------------------</td>
<td>---------------------------</td>
<td>-------</td>
<td>-----</td>
<td>-------</td>
</tr>
<tr>
<td>Has challenging behaviour (n=674)</td>
<td>Yes</td>
<td>357</td>
<td>53.0%</td>
<td>265</td>
</tr>
<tr>
<td></td>
<td>No</td>
<td>317</td>
<td>47.0%</td>
<td>227</td>
</tr>
<tr>
<td>Has a visual impairment*** (n=660)</td>
<td>Excellent to good vision</td>
<td>535</td>
<td>81.1%</td>
<td>403</td>
</tr>
<tr>
<td></td>
<td>Fair to no eyesight</td>
<td>125</td>
<td>18.9%</td>
<td>82</td>
</tr>
<tr>
<td>Down Syndrome (n=595)</td>
<td>Yes</td>
<td>136</td>
<td>22.9%</td>
<td>99</td>
</tr>
<tr>
<td></td>
<td>No</td>
<td>459</td>
<td>77.1%</td>
<td>338</td>
</tr>
<tr>
<td>Polypharmacy*** (n=667)</td>
<td>No polypharmacy</td>
<td>253</td>
<td>37.9%</td>
<td>214</td>
</tr>
<tr>
<td></td>
<td>Polypharmacy</td>
<td>256</td>
<td>38.4%</td>
<td>181</td>
</tr>
<tr>
<td></td>
<td>Excessive polypharmacy b</td>
<td>158</td>
<td>23.7%</td>
<td>95</td>
</tr>
<tr>
<td>Dependency*** (n=691)</td>
<td>Total or Severe</td>
<td>193</td>
<td>27.9%</td>
<td>115</td>
</tr>
<tr>
<td></td>
<td>None to Moderate</td>
<td>498</td>
<td>72.1%</td>
<td>391</td>
</tr>
<tr>
<td>Activity level** (n=687)</td>
<td>Low</td>
<td>506</td>
<td>73.7%</td>
<td>355</td>
</tr>
<tr>
<td></td>
<td>Moderate to high</td>
<td>181</td>
<td>26.3%</td>
<td>148</td>
</tr>
<tr>
<td>Does anyone ever help you with eating??*** (n=689)</td>
<td>Yes</td>
<td>169</td>
<td>24.5%</td>
<td>106</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>------------------------</td>
<td>-----</td>
<td>-------</td>
<td>-------</td>
<td>-----</td>
</tr>
<tr>
<td></td>
<td>No</td>
<td>520</td>
<td>75.5%</td>
<td>398</td>
</tr>
<tr>
<td>Do you ever use special utensils when you eat? (n=690)</td>
<td>Yes</td>
<td>83</td>
<td>12.0%</td>
<td>56</td>
</tr>
<tr>
<td></td>
<td>No</td>
<td>607</td>
<td>88.0%</td>
<td>449</td>
</tr>
<tr>
<td>Soft/liquidised diet*** (n=686)</td>
<td>Yes</td>
<td>94</td>
<td>13.7%</td>
<td>42</td>
</tr>
<tr>
<td></td>
<td>No</td>
<td>592</td>
<td>86.3%</td>
<td>459</td>
</tr>
<tr>
<td>Difficulty eating *** (n=690)</td>
<td>No difficulty</td>
<td>371</td>
<td>53.8%</td>
<td>293</td>
</tr>
<tr>
<td></td>
<td>Difficulty</td>
<td>319</td>
<td>46.2%</td>
<td>212</td>
</tr>
</tbody>
</table>

* Modified Barthel's Activities of Daily Living Index (Burke, 2016); b Polypharmacy is defined as 5–9 medicines, Excessive Polypharmacy is defined as 10+ medications (O'Dwyer et al., 2016) * p<0.05; **p<0.01; ***p<0.001
6.3.3 Regression

Despite showing bivariate association with the DV, the variable *Stroke* (Unadjusted OR 4.4; 95% CI 1.2-15.7) was removed because cells with zero responses led to unreliable statistics. The two items *Does anyone ever help you with eating?* (Yes=169, 53.1% of people reporting difficulty eating) and *Do you ever use special utensils when you eat?* (Yes=83, 26% of people with difficulty eating) were also removed from the model because only people reporting difficulty eating (e.g. one response option of the DV only) were asked these questions. Therefore these two items presented complete separation of the outcome variable and were removed from the regression. All GVIF were low, below 2, meaning that no independent variables were removed for reasons of multicollinearity (Tabachnick and Fidell, 2013). Using no difficulty eating as the reference category, the full model demonstrated an AIC of 455.52. Following a number of reiterations, three further variables were removed from the final model to produce the model with the lowest AIC. As may be seen in Table 6.4, the final, reduced model presents all included independent variables, stratified by difficulty eating alongside unadjusted and adjusted associations. This model included 406 cases with an AIC of 451.62. The ROC Curve for this model is presented in Figure 6.1. The accuracy of this model, as measured by the area under the curve, was good at .823, indicating a model that is good at discriminating those with from those without difficulty eating.
Table 6.4: Multiple logistic regression exploring the predictive value of the independent variables on difficulty eating.

<table>
<thead>
<tr>
<th></th>
<th>No difficulty</th>
<th>Difficulty</th>
<th>Crude OR</th>
<th>95% CI</th>
<th>P-value</th>
<th>Adjusted OR</th>
<th>95% CI</th>
<th>P-value</th>
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<td><strong>Gender</strong></td>
<td></td>
<td></td>
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</tr>
<tr>
<td>Male</td>
<td>90</td>
<td>44.30%</td>
<td>87</td>
<td>42.90%</td>
<td>1</td>
<td>87</td>
<td>42.90%</td>
<td>0.81</td>
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<tr>
<td>Female</td>
<td>113</td>
<td>55.70%</td>
<td>116</td>
<td>57.10%</td>
<td>1.06</td>
<td>(0.72-1.57)</td>
<td>0.764</td>
<td>0.81</td>
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<tr>
<td><strong>Age</strong></td>
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<td></td>
<td></td>
<td></td>
<td></td>
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</tr>
<tr>
<td>44-49</td>
<td>66</td>
<td>32.50%</td>
<td>48</td>
<td>23.60%</td>
<td>1</td>
<td>48</td>
<td>23.60%</td>
<td>1.06</td>
</tr>
<tr>
<td>50-64</td>
<td>92</td>
<td>45.30%</td>
<td>107</td>
<td>52.70%</td>
<td>1.6</td>
<td>(1.01-2.55)</td>
<td>0.048*</td>
<td>1.5</td>
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<tr>
<td>65+</td>
<td>45</td>
<td>22.20%</td>
<td>48</td>
<td>23.60%</td>
<td>1.47</td>
<td>(0.84-2.55)</td>
<td>0.173</td>
<td>1.34</td>
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<td><strong>Level of ID</strong></td>
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<td></td>
<td></td>
<td></td>
<td></td>
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<td></td>
<td></td>
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<tr>
<td>Mild</td>
<td>51</td>
<td>25.10%</td>
<td>46</td>
<td>22.70%</td>
<td>1</td>
<td>46</td>
<td>22.70%</td>
<td>1</td>
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<tr>
<td>Moderate</td>
<td>101</td>
<td>49.80%</td>
<td>93</td>
<td>45.80%</td>
<td>1.02</td>
<td>(0.62-1.67)</td>
<td>0.93</td>
<td>0.86</td>
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<tr>
<td>Severe\Profound</td>
<td>51</td>
<td>25.10%</td>
<td>64</td>
<td>31.50%</td>
<td>1.39</td>
<td>(0.81-2.40)</td>
<td>0.233</td>
<td>0.95</td>
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<tr>
<td><strong>Residence</strong></td>
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<td></td>
<td></td>
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<tr>
<td>Independent/Family</td>
<td>33</td>
<td>16.30%</td>
<td>22</td>
<td>10.80%</td>
<td>1</td>
<td>22</td>
<td>10.80%</td>
<td>1</td>
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<td>Community group home</td>
<td>94</td>
<td>46.30%</td>
<td>87</td>
<td>42.90%</td>
<td>1.25</td>
<td>(0.76-2.60)</td>
<td>0.29</td>
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<td>Residential Care</td>
<td>76</td>
<td>37.40%</td>
<td>94</td>
<td>46.30%</td>
<td>1.85</td>
<td>(1.01-3.48)</td>
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<tr>
<td><strong>Dementia, organic brain syndrome or senility</strong></td>
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<td></td>
<td></td>
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</tr>
<tr>
<td>No</td>
<td>200</td>
<td>98.50%</td>
<td>182</td>
<td>89.70%</td>
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<td>182</td>
<td>89.70%</td>
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<tr>
<td>Yes</td>
<td>3</td>
<td>1.50%</td>
<td>21</td>
<td>10.30%</td>
<td>7.65</td>
<td>(2.58-32.77)</td>
<td>0.001**</td>
<td>3.36</td>
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<tr>
<td><strong>Emotional, nervous or psychiatric condition</strong></td>
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<td></td>
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</table>

162
<p>| | | | | | | | | | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
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<th></th>
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<td>58.60%</td>
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<td>84</td>
<td>41.40%</td>
<td>121</td>
<td>59.60%</td>
<td>2.09</td>
<td>(1.41-3.11)</td>
<td>0.009**</td>
<td>1.99</td>
<td>(1.19-3.38)</td>
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<td>Challenging behaviour</td>
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<td>Yes</td>
<td>88</td>
<td>43.30%</td>
<td>130</td>
<td>64.00%</td>
<td>2.33</td>
<td>(1.56-3.48)</td>
<td>3.34e-05 ***</td>
<td>1.95</td>
<td>(1.16-3.39)</td>
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<td>Down Syndrome</td>
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<tr>
<td>No</td>
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<td>79.80%</td>
<td>157</td>
<td>77.30%</td>
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<td>Yes</td>
<td>41</td>
<td>20.20%</td>
<td>46</td>
<td>22.70%</td>
<td>1.15</td>
<td>(0.72-1.86)</td>
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<td>(0.93-3.36)</td>
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<td>Modified Barthel's ADL Index</td>
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<tr>
<td>Total or Severe</td>
<td>19</td>
<td>0.094</td>
<td>101</td>
<td>0.498</td>
<td>1</td>
<td></td>
<td></td>
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</tr>
<tr>
<td>None to Moderate</td>
<td>184</td>
<td>0.906</td>
<td>102</td>
<td>0.502</td>
<td>0.1</td>
<td>(0.06-0.18)</td>
<td>5.22e-16 ***</td>
<td>0.14</td>
<td>(0.07-0.25)</td>
</tr>
<tr>
<td>Soft/liquidised foods</td>
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<td></td>
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<td></td>
</tr>
<tr>
<td>No</td>
<td>195</td>
<td>96.10%</td>
<td>152</td>
<td>74.90%</td>
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<td></td>
<td></td>
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<tr>
<td>Yes</td>
<td>8</td>
<td>3.90%</td>
<td>51</td>
<td>25.10%</td>
<td>8.18</td>
<td>(3.96-19.10)</td>
<td>1.06e-07 ***</td>
<td>2.44</td>
<td>(1.04-6.26)</td>
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<td>Dentate status</td>
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<td></td>
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</tr>
<tr>
<td>Group 1</td>
<td>162</td>
<td>79.80%</td>
<td>141</td>
<td>69.50%</td>
<td>1</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Group 2</td>
<td>23</td>
<td>11.30%</td>
<td>5</td>
<td>2.50%</td>
<td>0.25</td>
<td>(0.08-0.62)</td>
<td>0.00619 **</td>
<td>0.21</td>
<td>(0.06-0.64)</td>
</tr>
<tr>
<td>Group 3</td>
<td>18</td>
<td>8.90%</td>
<td>57</td>
<td>28.10%</td>
<td>3.64</td>
<td>(2.08-6.63)</td>
<td>1.11e-05 ***</td>
<td>2.01</td>
<td>(1.02-4.03)</td>
</tr>
</tbody>
</table>

406 included in analysis; OR=Odds Ratio. Group 1 = >1 Natural teeth, Group 2= No teeth, wearing dentures, Group 3 = No teeth, not wearing dentures.
6.4 Discussion

According to this study, under half of the nationally representative sample in this study of older adults with ID reported difficulty eating. This is higher than in other reports where about a third of people with ID are significantly affected (Matson and Kuhn, 2001, Palmer et al., 1975), but is within the range for reports for children and adults with severe disability (Munk and Repp, 1994, Gal et al., 2011). While any deficit in structure and/or function can lead to difficulties eating for people with ID (Gal et al., 2011), this study is the first to specifically examine the role of edentulism and its treatment, or not, on difficulty eating. Compared to those with teeth (Group 1), the odds of reporting difficulty eating was twice as high (OR=2.01, 95%CI=1.02-4.03) among people without teeth or dentures (Group 3). Conversely, the odds for edentulous participants who had dentures (Group 2) were five times as low (OR =0.21, 95%CI=0.06-0.64) than 164
those who had at least one tooth, controlling for covariates. Complete tooth loss is therefore predictive of difficulty eating only when untreated. Previously, Ball et al. did not find any association between poor dentition/lack of teeth and need for mealtime support in a sample of people with ID, perhaps this is because they did not consider whether edentulism was functionally restored or not (Ball et al., 2012).

The odds ratios seen in this study suggest that those with complete dentures have far lower odds of having difficulty eating than those with natural teeth. Conventional complete dentures offer significantly lower masticatory efficiency than natural dentitions (Schimmel et al., 2015) and this probably holds true for the population in this study. To explain this anomaly, it is important to consider that few (21.9%) of those reporting some teeth (Group 1) actually had an intact dentition. As well, any remaining teeth may be severely compromised by dental disease and thus less functionally proficient. Therefore, the findings in this study do not suggest that complete dentures are “functionally better” than an intact or functional natural dentition.

Two reasonable and feasible approaches may eliminate the risk of difficulty eating arising from unrestored edentulism. The first is to provide the benefits of functioning prostheses to edentulous older adults with ID and the second is to prevent edentulism. (Mac Giolla Phadraig et al., 2016). It is important to note that complete dentures are not a panacea; this study does not necessarily recommend them as a first line treatment because they can themselves, for many reasons, lead to difficulty eating (McCord and Grant, 2000). Implant retained prostheses are considered the first line treatment for total edentulism and these are slowly becoming an accepted treatment modality among adults with disabilities (Feijoo et al., 2012, Cune et al., 2009, Durham et al., 2006). Longer term, avoiding edentulism is a challenge because cumulative loss of teeth is extensive in this population, as they experience prevalent and extensive periodontal disease, and the treatment of dental decay is usually by extraction rather than filling (Crowley et al., 2005, Gabre et al., 1999, Gabre et al., 2001,
Anders and Davis, 2010). A paradigm shift towards preventive dental care for this population would reduce the risk of oral disability, difficulty eating and its sequelae.

Because difficulty eating, drinking and swallowing impacts on health and quality of life, annual assessment is recommended for people with intellectual disabilities (Perez et al., 2015). Assessment should consider individual reasons for not eating (Munk and Repp, 1994) and start by ruling out possible physical and medical causes (Sturmey). Difficulty eating is likely to become more common among the population with ID as they survive longer into older age (Lazenby, 2008) with few or no teeth (Mac Giolla Phadraig et al., 2015c), unless preventive strategies are put into place rapidly. This article highlights that if in the assessment of feeding problems edentulism is found to be a contributory factor, it is important that dentists skilled in the treatment of adults with ID be engaged. There is potential for people who have lost their teeth to have function restored if this option is offered in a meaningful way (Mac Giolla Phadraig et al., 2016). Best results are seen when denture processing is combined with nutritional counseling (Bradbury et al., 2006). Therefore, multi-disciplinary management teams should include a dentist to rule out structural and functional impairment leading to difficulty eating (Perez et al., 2015).

6.4.1 Strengths and weaknesses

A major strength of this study is the representative random national sample of this hard to reach population, who experience an unusually high rate of unrestored edentulism. Another methodological strength comes from the multiple regression approach which investigated the relationship between the dependent variable, Difficulty eating, and one explanatory variable, Dentate status, with the effects of possible confounds such as level of disability, comorbid conditions, challenging behaviour and dependency statistically eliminated, while also mediating the impact of softened diet. While a number of candidate variables were omitted in the final model, an accurate measure of the relationship between dentate status and difficulty eating emerged, which offered an accurate explanation of the data. A major limitation was that the design did not produce
evidence of causality. In that regard, unrestored edentulism can now be seen as a risk factor, rather than cause of difficulty eating.

6.5 Conclusions

Recent research has revealed a tendency for older adults with ID to not seek denture treatment when they lose their teeth. This study demonstrated that this group was at twice the risk from difficulty eating than those who have natural teeth. Total tooth loss without denture wear should be seen as a critical structural impairment that has a functional impact on eating, for older adults with ID emphasizing the importance of both prevention of tooth loss and the appropriate management of edentulism in preventing and managing difficulty eating among older adults with ID.
Chapter 7 Dental attendance among older adults with intellectual disabilities in Ireland

The contents of this chapter are based on this publication:
Summary of Chapter 7

**Purpose** This chapter is the first of three chapters, which look at the delivery of dental services to older adults with ID in Ireland. Its purpose is to investigate dental attendance patterns and reasons for non-attendance among older adults with intellectual disabilities (ID) in Ireland.

**Methods** A cross-sectional survey of quantitative data and text analysis of qualitative data, drawn from a nationally representative sample of 753 people with ID over 40 years of age in Ireland. Participants were considered as regular or irregular dental attenders for analysis of quantitative data. Text analysis grouped open-ended responses for analysis.

**Results** There were slightly more females. Mean age was 54.1 years (SD=8.8). Almost half had moderate ID. A majority (86.5%) of respondents attended dental services within the last two years. Age and type of residence were associated with frequency of attendance ($p<0.01$), as were dentate status and reported oral problems ($p<0.001$). Text analysis revealed a lack of perceived need as a reason for not attending regularly.

**Conclusions** Older people with ID in Ireland report a very high level of regular dental attendance. Irregular attenders did not attend because they saw no need. There is a need to further study the importance of regular dental attendance for this population.
7.1 Introduction

7.1.1 Overview
In the preceding chapters, we focused on edentulism, oral disability and functional impact of these poor oral health outcomes. In this chapter we take a fresh perspective and start to understand how older adults with intellectual disabilities use dental services in Ireland. This chapter is the first of three chapters, which look at the delivery of dental services to older adults with ID in Ireland. This chapter aims to understand how frequently older adults with ID attend dental services and the reasons why some don’t attend.

7.1.2 Background
The British Society of Disability and Oral Health and people with intellectual disabilities agree that dental visits are important for people with intellectual disabilities, advising “visit your dentist at least twice a year” or up to a maximum suggested interval of once yearly, dependent on individual needs (British Society for Disability and Oral Health/Faculty of Dental Surgery of Royal College of Surgeons of England, 2012). In Ireland, standards suggest a minimum interval of once yearly for those with intellectual disabilities (ID) living in residential care, or more frequently where indicated (Health Information & Quality Authority (HIQA), 2009b) although there is no standard for dental recall outside of residential care. Dental recall interval is actually contingent on individual risk assessment, with those at higher risk of oral disease being advised to attend more frequently than those at lower risk. There is however, little consensus on the preferred interval between dental visits (Davenport et al., 2003). In the UK, two yearly review is the maximum interval recommended for all people regardless of dentate status, though for many a more regular recall interval is preferred (National Collaborating Centre for Acute Care (UK), 2004).

While there is little agreement regarding what counts as regular attendance for people with ID in the literature, what is clear is that dental attendance among people with ID seems to vary across and within generations. Younger people have been found to regularly attend dental services from just 3% to over 50% of the time (Oredugba and Akindayomi, 2008, Oredugba, 2006, Nunn and Murray, 1990). In middle age, most research indicates regular attendance is more common than not, although exact comparison is difficult due to differing definitions and intervals presented (Gabre et al.,
The relationship between ageing and frequency of dental attendance for people with ID is unknown. Among the population without ID, dental attendance is known to be slightly lower among older people than those of middle age in Ireland (Whelton et al., 2007), and in the UK, recent data suggests that those aged 85 years and older are least likely to try to make dental appointments in the NHS, the main provider of dental care for this group (Morris et al., 2011).

The impact of dental attendance pattern on oral health seems to increase with age. That is, irregular attendees have increasingly worse dental health outcomes as they age, as compared to regular attendees (Murray, 1996). This is important as the population with intellectual disabilities is now increasingly ageing (Kelly and Kelly, 2011) and infrequent dental attendance has also been associated with dental disease among this group (Pradhan et al., 2009b). The current study investigated dental attendance patterns among older adults with intellectual disabilities in Ireland to increase knowledge in this area.

There are many recognised reasons for not attending dental services which include dental anxiety, costs of dental treatment, lack of access to dental services together with the individual’s perception of need (Cohen, 1987). These data are routinely captured in Adult Dental Health Surveys in Ireland and the UK (Whelton et al., 2007, Todd and Lader, 1991, Hill et al., 2013). The current study also assessed reasons for non-attendance, where suitable.

7.1.3 Research question

This study asks the following two research questions: Do older people with Intellectual Disability attend dental services regularly? and Why do some older people with ID not attend regularly?

7.2 Methods

7.2.1 Design

This is a mixed methods study using cross-sectional quantitative and qualitative data drawn from the first wave of the Intellectual Disability Supplement to the Irish Longitudinal Study on Ageing (IDS-TILDA). IDS-TILDA is a multi-wave longitudinal study of older adults with ID designed to explore their ageing profile, physical and behavioural health, health services needs, psychological health, social networks, living
situations and community participation. The methodology saw the input of both international scientific experts and people with intellectual disabilities in its design and implementation. Survey instruments and methods were tested in an extensive pilot study (McCarron et al., 2009). Ethical approval was gained from the Faculty of Health Sciences research ethics committee in Trinity College Dublin and all participating services.

7.2.2 Sample
A Nationally representative sample of 753 people with intellectual disability over 40 years of age was randomly selected from the National Intellectual Disability Database (Kelly and Kelly, 2011). Data for the 727 with valid responses regarding dental attendance patterns were included.

7.2.3 Data collection
Accessible invitation packs were sent to all invitees, through gatekeepers. These packs included consent forms; information leaflets and easy read formatted documents for invitees, their families and supporting staff. Concurrently, the research team provided information seminars. Eleven researchers who had extensive experience with people with ID collected data, following rigorous training. Part of this training involved familiarization with the data items, and the collection tools. Time was spent considering communication and consent issues. Data collectors also considered reflexivity specifically within the context of data collection and administration of the data instrument. Data collectors came from varied professional backgrounds including psychology, ID nursing, social work, general nursing, pharmacology and psychiatry. Their ages ranged from mid-twenties to over fifty, with a mix of males and females. Their experiences ranged from voluntary work, research and practice-based interactions. A two-stage data collection technique was used. The first stage involved a postal pre-interview questionnaire (PIQ), followed by face-to-face interviews.

7.2.4 Measures
Table 7.1 lists the dental health items considered in this article. Some respondents received support from proxy staff or family carers in answering questions where needed. Based on whether the participant had support in responding or not, respondents were categorised as respondent only, respondent and proxy or proxy only. Self reported dentate status and reported oral problems were noted. Background variables included information regarding gender, age, type of residence (independent/family or community group home or residential setting) and severity of intellectual disability (mild or moderate
or severe/profound). Severity of ID was validated using participant records where necessary. Participant time since last dental or dental hygienist attendance are presented for intervals of less than one year ago, one to two years ago, more than two years ago and never. For the purpose of analysis, respondents who had not attended dental services for more than two years were considered irregular attenders and those who had attended within two years were considered regular attenders, as per Richards and Aileen (Richards and Ameen, 2002). All irregular attenders were asked: Can you tell me the reasons why you haven’t seen a dentist or dental hygienist recently? As Figure 7.1 shows, some people who did not remember time since last visit also responded to this item and were therefore included in analysis. Text analysis grouped open-ended responses for analysis.

**Table 7.1 Items regarding dental health considered in this article**

<table>
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<tr>
<th>Closed Questions</th>
</tr>
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<tbody>
<tr>
<td>Which best describes the teeth you have?</td>
</tr>
<tr>
<td>When was the last time you visited a dentist or dental hygienist?</td>
</tr>
<tr>
<td>Do you have any obvious problems with teeth or gums? (E.g. painful or sensitive teeth, bleeding gums when you brush your teeth)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Open Ended Questions</th>
</tr>
</thead>
<tbody>
<tr>
<td>Can you tell me the reasons why you haven’t seen a dentist or dental hygienist recently *</td>
</tr>
</tbody>
</table>

All items from face to face interviews; *asked only when respondents reported no dental visit within the last 2 years; Closed questions produced quantitative data and open ended question produced qualitative data for text analysis.

**7.2.5 Analysis**

Quantitative data were entered into SPSS v.19 ® for analysis. Descriptive statistics were generated for demographic and oral health data for the sample as a whole as well as by regular / irregular attendance. Pearson’s Chi Square statistics were calculated to assess associations with independent variables. Open-ended items were transcribed verbatim and exported into PASW Text Analytics for Surveys 4.1® (IBM, 2010). This software uses natural language processing to transform qualitative data from survey text into terms for analysis, thus allowing extraction of core concepts, enabling linguistic analysis. Core terms were first extracted and grouped into categories and by concept. Then categories were refined further through an iterative process of joint manual/automated refinement (IBM Corporation, 2011). Text analysis exposed commonalities among core concepts and categories. Associations between categories were visualised using category web graphs, to help explain relationships.
Figure 7.1 Sampling and flow

Inclusion criteria: person on NIDD, over 40 years of age

Invitation to participate in study: 1,800 PINs randomly selected from NIDD

n = 753
RR = 46%
representing 8.9% of population

Dental attendance within last two years?

Yes = 629 (83.5%)
Unknown = 26 (3.5%)
No = 98 (13%)

Included
0
9
17*
90

Excluded
629
9
8**
9

107 (14.2% of sample ) responses included in TA

PIN =Personal Identification Number; NIDD=National Intellectual Disability Database; RR=Response rate; TA=Text Analysis; *17 responses from people whose last dental visit was unknown were included for text analysis as a reason for recent non attendance was provided in open ended response; ** eight respondants did not giva a response to the open ended item and were therefore not included
7.3 Results

7.3.1 Sample demographics
From a total of 753 participants, data were considered for the 727 with valid responses regarding dental attendance patterns (see Table 7.2). There were slightly more females than males. The mean age of participants was 54.1 years (SD 8.8, range 41 - 90 years) with almost half between fifty and sixty four years. Most participants (82.8%) lived in either community group homes or residential care with only 17.2% living independently or with family. Almost half of participants had moderate ID.

7.3.2 Frequency of dental visits
As may also be seen in Table 7.2, gender and level of disability were not associated with frequency of attendance but age and type of residence were. The proportion of respondents who reported irregular attendance increased with age also. Attendance pattern was also associated with type of residence ($p < 0.01$) with the proportion of regular attenders lowest among people living independently (78.4%), compared with those in residential settings (85.9%) and highest among those in community group homes (91.2%). Considering attendance within the last year (not shown in tables), a similar pattern emerged: 76/125 (60.8%) of people living independently reportedly attended the dentist in the last year, compared to 253/341 (74.2%) in residential settings and 197/261 (75.5%) in community group homes. Table 7.2 shows that 86.5% of respondents claimed to be regular attenders and 13.5% were irregular attenders. Table 7.3 shows these data presented by age and frequency of attendance.

7.3.3 Dentate status and attendance patterns
Table 7.4 demonstrates a strong association between claimed attendance patterns, reported dentate status and reported oral problems. Most (71.4%; n=70) irregular attenders were edentulous while only 17% (n=107) of regular attenders were reportedly edentulous. A minority (21.8%) of the sample reported obvious problems with teeth or gums, such as painful / sensitive teeth or bleeding gums when brushing. Participants reporting obvious problems with their teeth were more likely to report recent attendance than people who did not (Table 7.4).
<table>
<thead>
<tr>
<th>Parameter</th>
<th>Total</th>
<th>Irregular attender</th>
<th>Regular attender</th>
<th>p Value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Total</td>
<td>727 (100%)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Gender</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>330 (45.4%)</td>
<td>45 (13.6%)</td>
<td>285 (86.4%)</td>
<td>&gt;0.05</td>
</tr>
<tr>
<td>Female</td>
<td>397 (54.6%)</td>
<td>53 (13.4%)</td>
<td>344 (86.6%)</td>
<td></td>
</tr>
<tr>
<td>Age</td>
<td></td>
<td></td>
<td></td>
<td>&lt;0.01</td>
</tr>
<tr>
<td>40-49</td>
<td>268 (36.9%)</td>
<td>28 (10.4%)</td>
<td>240 (89.6%)</td>
<td></td>
</tr>
<tr>
<td>50-64</td>
<td>328 (45.2%)</td>
<td>40 (12.2%)</td>
<td>288 (87.8%)</td>
<td></td>
</tr>
<tr>
<td>65+</td>
<td>130 (17.9%)</td>
<td>30 (23.1%)</td>
<td>100 (76.9%)</td>
<td></td>
</tr>
<tr>
<td>Type of Residence</td>
<td></td>
<td></td>
<td></td>
<td>&lt;0.01</td>
</tr>
<tr>
<td>Independent/Family</td>
<td>125 (17.2%)</td>
<td>27 (21.6%)</td>
<td>98 (78.4%)</td>
<td></td>
</tr>
<tr>
<td>Community Group Home</td>
<td>261 (35.9%)</td>
<td>23 (8.8%)</td>
<td>238 (91.2%)</td>
<td></td>
</tr>
<tr>
<td>Residential</td>
<td>341 (46.9%)</td>
<td>48 (14.1%)</td>
<td>293 (85.9%)</td>
<td></td>
</tr>
<tr>
<td>Level of Intellectual Disability</td>
<td></td>
<td></td>
<td></td>
<td>&gt;0.05</td>
</tr>
<tr>
<td>Mild</td>
<td>158 (23.6%)</td>
<td>26 (16.5%)</td>
<td>132 (83.5%)</td>
<td></td>
</tr>
<tr>
<td>Moderate</td>
<td>315 (47.0%)</td>
<td>36 (11.4%)</td>
<td>279 (88.6%)</td>
<td></td>
</tr>
<tr>
<td>Severe/Profound</td>
<td>197 (29.4%)</td>
<td>24 (12.2%)</td>
<td>173 (87.6%)</td>
<td></td>
</tr>
</tbody>
</table>

p Value using Pearson’s $X^2$
Table 7.3. Dental attendance and Age

<table>
<thead>
<tr>
<th>Age</th>
<th>Never*</th>
<th>&gt; 2 years ago</th>
<th>1-2 years ago</th>
<th>&lt;1 year ago</th>
<th>p Value</th>
</tr>
</thead>
<tbody>
<tr>
<td>40-49</td>
<td>5</td>
<td>23 (8.6%)</td>
<td>31 (11.6%)</td>
<td>209 (78.0%)</td>
<td>&lt;0.01</td>
</tr>
<tr>
<td>50-64</td>
<td>5</td>
<td>35 (10.7%)</td>
<td>54 (16.5%)</td>
<td>234 (71.3%)</td>
<td></td>
</tr>
<tr>
<td>65+</td>
<td>3</td>
<td>27 (20.8%)</td>
<td>18 (13.8%)</td>
<td>82 (63.1%)</td>
<td></td>
</tr>
<tr>
<td>Total</td>
<td>13</td>
<td>85 (11.7%)</td>
<td>103 (14.2%)</td>
<td>525 (72.3%)</td>
<td></td>
</tr>
</tbody>
</table>

Responses to question: When was the last time you visited a dentist or dental hygienist?; p Value using Pearson's X²

Table 7.4 Dentate status and dental attendance

<table>
<thead>
<tr>
<th>Parameter</th>
<th>Total N (valid %)</th>
<th>Irregular attender</th>
<th>Regular attender</th>
<th>p Value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Total</td>
<td>726 (100%)</td>
<td>98 (13.5%)</td>
<td>628 (86.5%)</td>
<td></td>
</tr>
<tr>
<td>Dentate Status</td>
<td></td>
<td></td>
<td></td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>Dentate</td>
<td>549 (75.6%)</td>
<td>28 (5.1%)</td>
<td>521 (94.9%)</td>
<td></td>
</tr>
<tr>
<td>Edentate</td>
<td>177 (24.4%)</td>
<td>70 (39.5%)</td>
<td>107 (60.5%)</td>
<td></td>
</tr>
<tr>
<td>Do you have any obvious problems with teeth or gums?</td>
<td></td>
<td></td>
<td></td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>Yes</td>
<td>158 (21.8%)</td>
<td>8 (5.1%)</td>
<td>150 (94.9%)</td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>567 (78.2%)</td>
<td>89 (15.7%)</td>
<td>478 (84.3%)</td>
<td></td>
</tr>
</tbody>
</table>

*a* ex. 726 valid responses; *b* ex 749 valid responses; *p* Value using Pearson’s X²

7.3.4 Reasons for not attending dental services

Open-ended responses were received from 107 respondents (14.2% of the total sample), who reported not attending dental services in the last two years (See Figure 7.2) providing 153 items for categorisation in text analysis. Because categories are not mutually exclusive, some responses were considered under multiple categories. Table 7.5 summarises categories identified using text analysis. These can be considered under three major category groups: a) A lack of perceived need b) Ability and personal choice and c) Access. There was no association (*p > 0.05*) between who responded and whether data were included in text analysis.

Relationships between categories are visualised using the category web graph in Figure 2, which uses nodes and ties to illustrate commonalities among categories. Within the web
graph, each node represents a category. The size of the node represents the relative frequency of responses for each category. The thickness of the line between categories denotes the number of shared responses (ties) for each category (Mason, 2010b).

Table 7.5 Count of items relating to each category, following text analysis

<table>
<thead>
<tr>
<th>Category</th>
<th>Number of responses considered category (n)</th>
<th>% Total sample</th>
<th>% Responses included in text analysis</th>
</tr>
</thead>
<tbody>
<tr>
<td>Lack of perceived need</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Edentulism</td>
<td>48</td>
<td>6.4%</td>
<td>31.0%</td>
</tr>
<tr>
<td>Unnecessary</td>
<td>38</td>
<td>5.0%</td>
<td>24.5%</td>
</tr>
<tr>
<td>Lack of pain / problems</td>
<td>32</td>
<td>4.2%</td>
<td>20.6%</td>
</tr>
<tr>
<td>Ability and personal choice</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Preference</td>
<td>10</td>
<td>1.3%</td>
<td>7.7%</td>
</tr>
<tr>
<td>Cooperation / Ability</td>
<td>7</td>
<td>0.9%</td>
<td>4.5%</td>
</tr>
<tr>
<td>Access and availability</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Access to services</td>
<td>6</td>
<td>0.8%</td>
<td>3.9%</td>
</tr>
<tr>
<td>Excluded</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Reason not known</td>
<td>12</td>
<td>1.6%</td>
<td>7.7%</td>
</tr>
</tbody>
</table>

*Categories not mutually exclusive. A total of 153 items scored from sample of 107; Edentulism: respondent reported lack of teeth as reason for irregular attendance; Unnecessary: respondent reported a lack of necessity as reason for irregular attendance; Lack of pain / problems: respondent reported a lack of pain or problems as reason for irregular attendance; Preference: respondent reported a preference not to go to dentist or hygienist as reason for irregular attendance; Cooperation / Ability: respondent reported difficulty cooperating for or inability to undergo dental treatment with dentist or hygienist as reason for irregular attendance; Access to services: respondent reported barriers in access to dentist or hygienist as reason for irregular attendance.

Figure 7.2 Reasons for not attending dental services – concepts and relationships
7.3.4.1 A lack of perceived need

As Figure 7.2 illustrates, 48 items related to a lack of teeth (see also Table 7.5). As one respondent stated simply: “I have no teeth and I have no problems with my mouth.” A further 37 responses were grouped around the category: “unnecessary.” This group cited a lack of problems with gums, teeth and dentures as a common reason for non-attendance. One comprehensive response summarised this concept well: “No teeth, no signs of infection, soft diet and therefore no call to visit dentist.” Finally, thirty two responses related to a lack of problems / pain as the reason for not attending dental services.

7.3.4.2 Ability and personal preference

Seven responses related to the category of cooperation and ability (see Table 7.5) meaning that the respondent would not have the ability to attend for dental visits. For example, some respondents would simply not cooperate in the dental surgery. Only two responses referred to personal ability as a reason for not attending: one regarding the barrier of a person’s swallowing issues and one referencing physical mobility: “Mobility, very difficult to bring anywhere and doesn’t cooperate.”

Preference not to go to the dentist was reported in ten instances. Most of these responses conveyed a dislike / fear of the dentist. As one respondent put it: “I am terrified of a dentist – I had a terrible experience when I was a child. They tied my hands and forced me to open my mouth and took out four teeth.” Three responses reported simply choosing not to go: “no reason – just have not done it “.

7.3.4.3 Access and availability

Six responses identified access issues as the reason for irregular attendance with most reporting barriers arising from interactions between dental services and disability services: “Currently there is no dental service available within the (disability) service, however, when the (disability) service moves into the community … which is in operation at the moment … there will be a (dental) service available.” Others reported a relative lack of general anaesthetic facilities and recent changes to the delivery of dental services in Ireland as reasons: “Used to get her teeth cleaned under general anaesthetic annually. However, due to funding restrictions, this is no longer covered, so she hasn’t done this for three years. No services any more for adults – this is no longer covered after they are sixteen years old.”
7.4 Discussion

This study found that a very high proportion of older people with intellectual disability claimed to attend the dentist or dental hygienist regularly in Ireland, with 86.5% claiming attendance within the last two years. This includes 94.9% of dentate and 60.5% of edentulous participants. This is far higher than reported in the general population in Ireland, where 44% of dentate and 2.3% of edentulous adults over 65 years, attended within the last two years (Whelton et al., 2007) but similar to more recent data from the UK, where 74% - 84% of dentate adults over 45 years old reported attendance within the last two years (Morris et al., 2011). When considering contact within the last year, 72.3% of the sample as a whole and 63.1% of those over 65 years old attended dental services within the last year, which is broadly similar to the rate of dental attendance found among some adult populations with ID (Cumella et al., 2000, Hall et al., 2011, Stanfield et al., 2003) but again far greater than older adults in Ireland (National Council on Ageing and Older People, 2004). It is unclear why the current sample received more regular contact with dental services than the general population in Ireland.

Residential setting was found to be important. In the current study, three quarters of those in community group homes and residential centres reported dental attendance within the last year. This compares to just 60.8% of people living independently. Within residential centres in Ireland, National Quality Standards apply, meaning that “medical, dental and other health needs” (should be) “assessed at least annually” (Health Information & Quality Authority (HIQA), 2009b). These services are often provided by publicly funded dental service in Ireland (Crowley et al., 2005, PA Consulting Group, 2010) where it is customary for dentists to visit selected residential services on an annual basis, while people outside of residential services are not so easily targeted within this system. Other researchers have also found more regular attendance among people with ID when residing in more controlled residential settings (Stanfield et al., 2003, Pradhan et al., 2009a, Tiller et al., 2001).

Irregular attendance was associated with increased age, rising from 10% of 40-49 year olds to 23% of those 65+ year olds. A similar, though greater, increase with age is noted in the general population from 43% of 35 – 44 year olds to 56% of 65+ year olds not attending within two years (Whelton et al., 2007). Based on this trend of poorer attendance with age, the proportion of irregular attenders is likely to grow as the
population with ID ages. International surveys have also found high prevalence of precancerous lesions among people with ID (Crowley et al., 2005, Scott et al., 1998) and the incidence of mouth cancer is known to increase with age, where early detection dramatically improves survival rates (The National Cancer Registry Ireland, 1994-2009). This group are also shown to have greater prosthodontic treatment need (Mac Giolla Phadraig et al., 2015c).

Text analysis findings overwhelmingly supports a lack of perceived need as the main reported reason for not attending dental services regularly. A lack of teeth was seen as the main reason for this. After a lack of teeth, the next most common reason encountered was simply that attendance was considered unnecessary, followed by a lack of pain. As Figure 7.2 shows, these three categories were conceptually related. This supports the assumption that lack of perceived need is the primary driver for non-contact with dental services amongst older people with ID, a phenomenon reported in the older population, generally in Ireland (Woods et al., 2009, Whelton et al., 2007).

There was a low frequency of reported dental problems in this sample compared to the general public (Nuttall et al., 2001). Given that research found people with ID may underestimate their own level of treatment need (Cumella et al., 2000), this gives rise to some concern as people who may benefit from treatment (such as by receiving complete dentures to restore function) may not see a need and therefore not seek out contact with dental services.

Conventionally, research in ID focuses on disabling contextual factors encountered in the effort to access services, to explain dental non-attendance. Reported barriers include long waiting lists, lack of availability of general anaesthetic and sedation services, poor cooperation levels, fear, lack of perceived need, poor staffing levels (as well as attitudes, beliefs and prejudices of staff), and access difficulties (Crowley et al., 2005, Gordon et al., 1998, Taylor-Dillon et al., 2003). Rather surprisingly, only lack of perceived need featured strongly in this study, where many people with ID reported on their own behalf. The prevalent focus on environmental contextual barriers to care may under-represent choice as the main reason for non-attendance among a minority of older people with ID. A shift in focus from barriers to care and toward enabling salutogenic health decisions may enable this population to make informed choices in the future.
Dental outcomes for people with ID in Ireland, in line with the rest of the world, are poorer than for the general population (Elliot et al., 2005, Glassman and Miller, 2003). For example, they tend to have more extractions and untreated decay, increased prevalence of periodontal disease and a tendency for no replacement of missing teeth once lost, even when they are left with no teeth at all (Crowley et al., 2005, Mac Giolla Phadraig et al., 2015c). It is then at first, rather surprising to find that this group are in regular contact with dental services. Firstly, it may suggest that there is a negative oral health impact associated with regular attendance. Perhaps surprisingly, it is difficult to say that regular dental attendance improves oral health as research has identified often contrary positive (Scully, 1995, McGrath and Bedi, 2001, Todd and Lader, 1991) and negative (Sheiham et al., 1985, Sheiham, 2000) associations with various health, functional and psychosocial measures, which may, in part, be due to possible confounding factors (Kay, 1999). However, there is some research suggesting that regular contact can lead to favourable outcomes for specific groups with ID (Cichon, 2011, Freedman et al., 2011). Alternatively, this may then suggest a failure to access preventive and restorative care appropriate to their needs, despite regular interaction with dental services. Further investigation into the effect of regular dental attendance for people with ID is warranted.

7.4.1 Methodological issues
The major limitation of this study was that group allocation (Regular/Irregular attendance) was based on self reported dental attendance patterns. Previous research has found a tendency to overstate frequency or dental attendance (Nuttall and Davies, 1991, Eddie, 1984). This may introduce misallocation bias in the current study. The current design did not let us see why people attended dental services either and this may have given rise to more useful data. Additionally, this study relied on self-reported dentate status. This approach may be unreliable, but has been used in previous surveys considering dentate status of older adults (National Council on Ageing and Older People, 2004, Whelan and Savva, 2013, Mac Giolla Phadraig et al., 2015c).

Commonly agreed criteria for what constitutes regular and irregular dental attendance are needed. There is little consensus on this subject, making it difficult to make meaningful comparison within and between populations. Some authors use a two year interval as a delineation and others use one year (Richards and Ameen, 2002, McGrath and Bedi,
Irish and UK guidance are similarly at odds (National Collaborating Centre for Acute Care (UK), 2004, Whelan and Savva, 2013, Oral health Services Research Centre UCC and Foundation, 1999). Given this variation, two yearly attendance was selected to delineate irregular and regular attendance in this study as this represents an absolute minimum accepted standard, which 13.5% of the current sample are not meeting.

7.5 Conclusions

This study demonstrated that most older people with ID in Ireland reported regular dental attendance and those who did not tended to be older, lived independently and had no teeth. When asked why they did not have recent contact with dental services most explained that they saw no need, either due to a lack of teeth or pain or perceived need. These reasons were conceptually related. Regular dental visits may be beneficial for people with ID, though this is not clearcut. There is a need to study the impact of regular dental attendance on people with ID.
Chapter 8 Behavioural supports and dental care for older adults with Intellectual Disabilities: A mixed methods study.
Summary of Chapter 8

**Purpose**
This is the second of three chapters exploring dental service use among adults with ID in Ireland. This study investigates how frequently sedation, general anaesthesia and non-pharmacological supports are reportedly used with older adults with Intellectual Disabilities (ID) when accessing dental care, what these observations mean to expert dentists and which factors predict pharmacological support use.

**Methods**
Using sequential explanatory design, the initial quantitative phase measured frequency of use of pharmacological and non-pharmacological behaviour supports used by people with ID in Ireland and identified predictors of measured frequency of support using multiple logistic regression, with the effect of other independent variables statistically eliminated. This model offered the best fit of the data, based on Akaike’s information criterion (AIC). The predictive value of the overall model was tested using a ROC Curve and Area Under the Curve Statistic. To further explain the frequency data, a small sample of expert dentists highlighted the influence that poor access has on appropriate care.

**Results**
Using sequential explanatory design, the initial quantitative phase identified predictors of measured frequency of support using multiple logistic regression from a nationally representative survey. Most older adults with ID reported the use of non-pharmacological support to receive dental care: 1% reported use of inhalation sedation; 2% Intravenous (IV) sedation; 8% general anaesthesia (GA) and 14% oral sedation for dental care. Compared to those who were not, participants reporting challenging behaviour (OR = 2.3, 95%CI = 1.43-3.20), significant difficulty speaking (OR = 3.5, 95%CI = 2.19-5.57) and obvious oral problems (OR = 2.53, 95% (1.56-4.10) had greater odds of reporting treatment with GA or sedation rather than non-pharmacological supports. To further explain the frequency data, a small sample of expert dentists highlighted the influence that poor access has on appropriate care. Expert dentists, felt that these figures represented the unavailability of sedation and GA and inappropriate treatment.

**Conclusions**
The mixed methods design adopted in this study advanced both assessment and understanding of the frequency of sedation and GA, as reported by older adults with ID who access dental care in Ireland.
8.1 Introduction

Despite reported frequent access to dental services (Mac Giolla Phadraig et al., 2014a), older adults with intellectual disabilities (ID) in Ireland have poor outcomes that result in untreated oral disease or when treated, tooth loss rather than restoration (Anders and Davis, 2010, Mac Giolla Phadraig et al., 2015c). This brings into question the nature of these frequent interactions. Research has suggested that dental services, as currently delivered in Ireland, may not appropriately meet the individual needs of people with disabilities (Mac Giolla Phadraig et al., 2014c, Owens, 2011). People with ID face challenges in maintaining oral health and receiving dental care, which are compounded by the challenges that arise from ageing (British Society for Disability and Oral Health/Faculty of Dental Surgery of Royal College of Surgeons of England, 2012, Owens, 2011). For example, the inability to cooperate with treatment has been reported to lead to a greater need for behaviour management techniques, conscious sedation and general anesthesia, than for the general population (British Society for Disability and Oral Health/Faculty of Dental Surgery of Royal College of Surgeons of England, 2012).

Dental care must be provided in a manner, which is least restrictive of rights, freedom of action and autonomy (British Society for Disability and Oral Health/Faculty of Dental Surgery of Royal College of Surgeons of England, 2012, Department of Justice and Equality, 2015). This also empowers people with ID by increasing opportunities for learning that promote autonomy and independence. This means that non-pharmacological supports are preferable over more restrictive, pharmacological approaches (Lyons, 2009, Health Information & Quality Authority (HIQA), 2016), which can be seen as chemical restraints (Kupietzky, 2004). Non-pharmacological approaches may include behavioural, physical, psychological, social or preventive strategies (Glassman et al., 2009).

A better understanding of how supports are selected and applied, for those who do access dental care, should reduce reliance on pharmacological supports. However despite literature offering guidance (Becker et al., 2009, Boyle et al., 2000, Nathan, 2001) and evidence (Collado et al., 2008, Faulks et al., 2007) to dentists regarding specific pharmacological behaviour supports, there is very little primary research on the factors that actually influence the selection of pharmacological and non-pharmacological adjuncts among adults with ID (Prabhu et al., 2008, AlKindi and Nunn, 2016). There are
many parameters to consider, when selecting adjuncts for dental treatment in this population, such as the extent and urgency of treatment need, cost, likelihood of successful outcome, social circumstances, availability of treatment modalities, risks to the patient, communication needs and level of fear (Glassman et al., 2009, Coulthard et al., 2011). There is a need to understand the impact of such factors on the use of supports, so as to improve decision-making and application of related techniques. Therefore this Chapter aims, in the first instance, to explore factors predictive of pharmacological support use.

It is not known what proportion of older people with ID receiving mainstream dental services requires GA or sedation for dental treatment. Service data from specialist services indicate a high referral rate for secondary care, GA and sedation for people with disabilities in Ireland (AlKindi and Nunn, 2016, Kelly and Nunn, Holland and O’Mullane, 1986). However referred populations may not be representative (Cumella et al., 2000). From policy, clinical, service and workforce planning perspectives, it is essential to understand how often and by whom services such as IV sedation and general anaesthesia are used and needed.

8.2 Methods

8.2.1 Mixed Methods Design

This study aimed to analyse the supports that older adults with ID reportedly used, when accessing dental care in Ireland. Taking a pragmatic approach to research design, mixed methods were employed (Doyle et al., 2009). The pragmatic approach is informed by the belief that the practicalities of research are such that it may not be exclusively driven by theory or data (Morgan, 2007). Mixed methods research allows for the intentional collection of both quantitative and qualitative data, combining the strengths of each to answer research questions (Creswell et al., 2010). Prioritizing the analysis of data collected as part of the quantitative phase, we tested the predictive value of variables that we believed influence the type of pharmacological and non-pharmacological supports used by adults with ID in Ireland. Supports were quantified by the frequency of their reported use. These data raised questions, which directly informed the selection of participants and agenda setting for a further, qualitative phase. In a sequential explanatory (e.g. QUAN-qual) design (Creswell and Plano Clark, 2007), qualitative data then linked the frequency data specifically to care delivery, from the perspective of expert
dentists who provide these services. Figure 8.1 illustrates the mixed methods design and participant flow.

**Figure 8.1 Participant flow and study overview**

![Participant flow and study overview diagram]

### 8.2.2 Ethics statement
This study complies with the ethical standards and laws applicable in Ireland. The quantitative arm of this study received ethical approval from the Faculty of Health Sciences Research Ethics Committee in Trinity College Dublin and all 138 participating Intellectual Disability service providers across Ireland. The qualitative phase received a separate ethical approval from the Research Ethics Committee of the School of Dental Science, Trinity College Dublin.

### 8.2.3 The quantitative phase

#### 8.2.3.1 Population and sample
The sampling approach used in this study was sequential and primarily driven by the QUAN phase, which used data from the *Intellectual Disability Supplement to The Irish Longitudinal Study on Ageing* (IDS-TILDA). This is a national, longitudinal study exploring
the experience and impact of ageing among older adults with ID in Ireland (McCarron et al., 2011). The original Wave 1 sample was drawn randomly from a population, aged over 40 years registered on the National Intellectual Disability Database (NIDD) (Kelly and Kelly, 2011). All participants in Wave 1 (N=719) were invited into Wave 2. The overall response rate to Wave 2 was 94% (n=708). Inclusion criteria for this phase included: 1) Participants in Wave 1 of IDS-TILDA and, 2) written consent to participate and/or family/guardian written agreement, where required. This sample was largely comparable to both the Wave 1 sample and the NIDD database, from which the sampling frame was derived (Kelly and Kelly, 2011, McCarron et al., 2014).

### 8.2.3.2 Data collection

Data for this phase were obtained in two stages: Firstly a postal pre-interview questionnaire was completed by both self-report and review of participant records where needed. Secondly, a face-to-face, computer-aided personal interview (CAPI) was completed by trained data collectors. Proxies, who knew the participants well, supported some individuals in answering questions, where they could not respond independently. Respondent type was recorded as self-report only (n=142), self-report and proxy (n=318) or proxy only (n=331).

### Quantitative variables

**Dependent Variable**  
A multiple logistic regression model was developed to test whether variables that are reportedly relevant to the selection of adjuncts, actually predict support use. For the purposes of regression analysis, the dependent variable (DV), *Behaviour Support* was an aggregated variable measuring the reported use of pharmacological and non-pharmacological supports when attending for dental visits as self-reported or reported by proxy during the CAPI. This item consisted of two categories: The category *Pharmacological* behaviour support included participants with positive responses to use of Inhalational sedation (IS), Oral sedation (Oral), Intravenous sedation (IV) or General anaesthesia (GA). The category *Non-pharmacological* behaviour support included participants who reported use of items such as Verbal reassurance, don't use any of these and Other (which included a range of responses from local anaesthetic only, complete refusal to receive dental care, “does not need dental care” etc.). Because multiple responses to this item were accepted (total responses = 815), only the most restrictive form of adjunct reported for each individual participant was recorded, thereby
creating exclusive categories. Non-pharmacological, behavioural supports are considered the least restrictive support (Lyons, 2009). This is followed by nitrous oxide/oxygen inhalation sedation, which carries a large margin of safety and has minimal sedative effect. Next in the hierarchy is oral sedation, and lastly general anaesthesia, considered as the completely restrictive approach (Kupietzky, 2004).

**Covariates**

Candidate variables were initially identified through a systematic search strategy. This search demonstrated that most literature used expert judgement, rather than empirical data, to identify parameters that are reportedly important to the selection of supports. Table 8.1 lists these variables as mapped against the IDS-TILDA data items, which acted as IVs in this analysis. The independent variables entered into the full model included gender, age, level of ID (as non-modifiable risk indicators), type of residence, problems with teeth, self reported health, ASA classification, health condition which may indicate pharmacological support, reported organic brain syndrome, dementia, senility, emotional, nervous or psychiatric condition; difficulty sitting for length of time; challenging behaviour; difficulty speaking; and visual or auditory sensory impairment as independent variables. Fear of dentists was excluded because missing data was unacceptably high for this item (89%).
### Table 8.1 Candidate variables for regression model

<table>
<thead>
<tr>
<th>Predictive parameters</th>
<th>IDS-TILDA Factor, transformation and scoring</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Non-modifiable demographics</strong></td>
<td></td>
</tr>
<tr>
<td>PIQ: Gender</td>
<td></td>
</tr>
<tr>
<td>PIQ: Age Range</td>
<td></td>
</tr>
<tr>
<td>PIQ: Level of ID: Mild / Moderate / Severe or Profound</td>
<td></td>
</tr>
<tr>
<td><strong>Social status, environment and support available for the patient</strong> (Glassman et al., 2009, British Society for Disability and Oral Health/Faculty of Dental Surgery of Royal College of Surgeons of England, 2012).</td>
<td></td>
</tr>
<tr>
<td>PiQ: Residential setting</td>
<td></td>
</tr>
<tr>
<td><strong>Patients who have extensive dental needs that would require extended dental treatment over a prolonged period of time</strong> (Prabhu et al., 2008) AND urgency of care required (Glassman et al., 2009).</td>
<td></td>
</tr>
<tr>
<td>Q.PH41 Do you have any obvious problems with teeth or gums?</td>
<td></td>
</tr>
<tr>
<td>• Yes / No</td>
<td></td>
</tr>
<tr>
<td><strong>The patient’s health history and current medical and physical status</strong> (Glassman et al., 2009, AlKindi and Nunn, 2016b, Prabhu et al., 2008, British Society for Disability and Oral Health/Faculty of Dental Surgery of Royal College of Surgeons of England, 2012).</td>
<td></td>
</tr>
<tr>
<td>PH1. Would you say your health is... (Recoded):</td>
<td></td>
</tr>
<tr>
<td>• Excellent, Very Good Or Good = Excellent to Good</td>
<td></td>
</tr>
<tr>
<td>• Fair Or Poor= Fair to Poor</td>
<td></td>
</tr>
<tr>
<td><strong>ASA Classification</strong> (Glassman et al., 2009, Coulthard et al., 2011).</td>
<td></td>
</tr>
<tr>
<td>Aggregate item: ASA Classification based on logic:</td>
<td></td>
</tr>
<tr>
<td>• Q.PH6 Do you have any long-term health conditions:</td>
<td></td>
</tr>
<tr>
<td>• If No = ASA 1, if Yes go to Q.PH8 Do these conditions limit your activities in any way?</td>
<td></td>
</tr>
<tr>
<td>• If No=ASA 2</td>
<td></td>
</tr>
<tr>
<td>• If Yes= ASA 3</td>
<td></td>
</tr>
<tr>
<td><strong>Individuals with complex medical problems who require intra- and peri-operative monitoring or with complex medical problems (e.g., severe hypertension and cardiac or respiratory disease) whose physiologic state will be more safely controlled in a sedated or anesthetised state (Glassman et al., 2009) or that may be exacerbated by dental treatment (Coulthard et al., 2011).</strong></td>
<td></td>
</tr>
<tr>
<td>Aggregate item: Health condition indicating pharmacological supports = Yes if any of the following were scored:</td>
<td></td>
</tr>
<tr>
<td>• Q.9 Has had high blood pressure=Yes (n=121) OR</td>
<td></td>
</tr>
<tr>
<td>• Q.11 Has had angina =Yes (n=3) OR</td>
<td></td>
</tr>
<tr>
<td>• Q.14 Has had Heart attack (n=7)=Yes OR</td>
<td></td>
</tr>
<tr>
<td>• Q.22 Has had congestive heart failure=Yes (n=12) OR</td>
<td></td>
</tr>
<tr>
<td>• OR Q.45 Has Asthma (n=38) = Yes OR</td>
<td></td>
</tr>
<tr>
<td>• Q.81 Has Epilepsy (223) = Yes</td>
<td></td>
</tr>
<tr>
<td><strong>Individuals with cognitive impairment or emotional conditions who have difficulty understanding what is expected in dental treatment</strong> (Glassman et al., 2009); Memory problem/dementia OR psychiatric illness/fear/emotional condition (Lyons, 2009).</td>
<td></td>
</tr>
<tr>
<td>Aggregate item: Reported organic brain syndrome, dementia, senility, emotional, nervous or psychiatric condition</td>
<td></td>
</tr>
<tr>
<td>• Q.79: Has dementia, organic brain syndrome or senility=Yes OR</td>
<td></td>
</tr>
<tr>
<td>• Q.69: Has emotional, nervous or psychiatric condition=Yes</td>
<td></td>
</tr>
<tr>
<td><strong>Patients whose fear about receiving dental treatment prevents them from receiving the needed treatment</strong> (Glassman et al., 2009).</td>
<td></td>
</tr>
<tr>
<td>Q.PH4005 Fear of going to the dentist *</td>
<td></td>
</tr>
<tr>
<td>• Yes / No</td>
<td></td>
</tr>
<tr>
<td><strong>Patients who are unable remain still enough to have dental procedures performed</strong> (Glassman et al., 2009); or voluntary or involuntary movement affecting ability to receive treatment (Lyons, 2009).</td>
<td></td>
</tr>
<tr>
<td>Q.FL5 Please indicate the level of difficulty, if any, you have with sitting for about two hours (Recoded)</td>
<td></td>
</tr>
<tr>
<td>• Recoded into No difficulty or Some difficulty due to small numbers.</td>
<td></td>
</tr>
<tr>
<td>Aggregate item: Does the person display challenging behaviour? = Yes if any of the following challenging behaviours are reported:</td>
<td></td>
</tr>
<tr>
<td>• Q.76 Scream=YES OR</td>
<td></td>
</tr>
<tr>
<td>• Q.76 Throw things=YES OR</td>
<td></td>
</tr>
</tbody>
</table>
• Q.76 Hit out=Yes OR
• Q.76 Self injure=Yes OR
• Q.76 Other=Yes

Communication impairment (AlKindi and Nunn, 2016b) or cognitive or physical impairments that complicate basic communication (Lyons, 2009).

Q.PH31 Do you have any difficulty speaking or making yourself understood when speaking?
• Recoded: Much Difficulty And Cannot Do At All Coalesced.

Sensory impairment affecting ability to receive treatment. b
Aggregate item: Aggregate Item: Visual or auditory sensory impairment
• Q. PH25 Is your hearing (with or without a hearing aid)…
• Q. PH14 Is your eyesight (using glasses or contact lenses if you use them)
• No Visual/auditory sensory impairment if both items: Excellent/Good
• Visual/auditory sensory impairment if either: Fair/Poor/Blind Or Deaf

8.2.3.3 Statistical methods
Quantitative data were analysed in SPSS v.20 and RStudio v.1.0.44, with frequencies and proportions reported. Once independent variables were selected and respondents with missing data removed, a total of 545 participants were included for multiple logistic regression in the full model. All candidate IVs in this full model were tested for multicollinearity using General Variation Inflation Factor (GVIF) (Fox and Weisberg, 2011). From this model, information criterion was used to select model parameters. Akaike’s information criterion (AIC) considers both error and the principle of parsimony. AIC penalises a model for too many parameters. The model with the lowest AIC, while controlling for age, gender and level of ID, was considered to be the optimal model and therefore selected in this analysis. The discriminatory value of the final model was then observed using the receiver operating characteristic curve (ROC curve) and the Area Under the Curve (AUC) was calculated.

8.2.4 The qualitative phase
8.2.4.1 Sample
Typically in sequential mixed methods sampling within QUAN-qual studies, a subsample of the original sample is purposively selected for the qualitative phase (Teddlie and Yu, 2007). Whilst dental research has successfully included people with ID and those who support them in exactly this way (McKelvey et al., 2014), the authors here were concerned that participants/proxies may not have had the rationales for choice of techniques shared with them, and may not therefore have been in a position to give
meaningful insight into the techniques used. For these reasons, we instead selected expert dentists with extensive experience of supporting adults with ID to receive dental care within an Irish context. Social media allowed targeted notification of the research project, by a gatekeeper to potential participants through the Irish Society for Disability and Oral Health and Project SMILE Ireland. Study documentation, and inclusion criteria, specified that only dentists with experience of working with adults with ID were sought for a focus group study. The gatekeeper was offered as a first port of call to clarify any queries in relation to the project to avoid pressure on potential participants and snowballing was applied. Eight dentists responded and seven were deemed to meet inclusion criteria (one was excluded as he worked in the UK). All seven potential participants were invited to attend an online focus group: One could not attend. Six dentists participated, all of whom had extensive experience / training in treating people with disabilities. Three were trained to the level of a postgraduate diploma in Special Care Dentistry (SCD); one held a diploma in sedation and two were trained as specialists in SCD. One ran a private practice for patients with disabilities and all the others worked as specialists or senior dental surgeons, with responsibilities for populations with disabilities, in public dental services. All were members of the Irish Society for Disability and Oral Health. Geographically, participants came from across Ireland, from a mix of rural and urban areas.

8.2.4.2 Data collection

In this study, data were essentially integrated in a process termed connecting data (Creswell et al., 2010), i.e. the analysis of results from the initial phase dictated the data collected in the second phase of research. The frequency of behavioural support use data (Table 8.2) was summarised in charts and presented to the focus group for discussion. This discussion produced data for further analysis. Following the initial focus group, two further focus groups and two interviews, involving the same participants from the initial focus group, ensued, using a semi-structured interview schedule.

An open schedule approach was used for the first focus group. Data from this initial event were analysed inductively, supporting the development of a semi-structured schedule for data collection in the subsequent group meetings/interviews. Figure 8.1 summarises participant flow. Focus groups and interviews were undertaken online using video and audio enabled programmes (FUZE ®). Transcripts were generated using audio-only recordings.
8.2.4.3 Data analysis

This researcher reviewed alternative qualitative analytic frameworks, such as framework, discourse and phenomenological analysis, and decided to apply Using Thematic Content Analysis (Burnard et al., 2008), as it met the aims of the research question best. Open coding was undertaken by CMGP and subsections were checked with CG, with JN acting as arbiter. Using a constant comparative method, the data were then recoded and a final coding framework developed. From a practical perspective, this process started by transcribing the data into Word. The researcher then read the resultant data line by line noting possible codes, across a subsection of the transcript. This initial open coding was discussed with CG, to ensure that the method adhered to that of Burnard. Given a lack of a priori theory, multiple codes were recordable and no set framework was applied. Following this debriefing CM continued to open code the rest of the transcript. As the coding progressed repeated and common themes were identified, which allowed the initial formation of final codes and categories. The format and relationship of these codes and categories merged and shifted until the final codes were developed and clustered conceptually into subcategories and then categories allowing data to be separated for interpretation. Microsoft Word and Excel enabled data coding, clustering and analysis. Member checking was carried out with two participants, thereby giving participants a chance to react to both the data and the final narrative. Peer debriefing was also undertaken to avoid lone researcher bias (Long and Johnson, 2000).

8.3 Results

8.3.1 Quantitative phase

8.3.1.1 Sample demographics

This study included the 708 people with ID, participating in the second wave of the IDS-TILDA cohort study. This represented 94% retention of subjects from Wave 1. Valid responses were received from 673 participants (95%) regarding behavioural support for dental care. There were more females than males and almost half lived in community group homes and had moderate ID. The characteristics of this sample are reported in Table 8.2.
8.3.1.2 Frequency of behavioural support use

Table 8.2 also reports the distribution of pharmacological and non-pharmacological supports. Non-pharmacological supports only, were reported by 72.1% (n=485) of the sample and pharmacological supports were reported by 27.9% (n=188). GA was the most restrictive support received by 7.7% (n=58) while sedation was reported as the most restrictive support used by 17.3% (n=130) of respondents. Oral sedation was the most frequently reported sedative route and it was the most restrictive route for 83.1% of those using any sedation, followed by IV sedation (12.3%) and then inhalational sedation (4.6%).

<table>
<thead>
<tr>
<th>Table 8.2 Sample demographics and reported use of behavioural supports.</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Age range</strong></td>
</tr>
<tr>
<td>44-49</td>
</tr>
<tr>
<td>50-64</td>
</tr>
<tr>
<td>65+</td>
</tr>
<tr>
<td><strong>Gender</strong></td>
</tr>
<tr>
<td>Male</td>
</tr>
<tr>
<td>Female</td>
</tr>
<tr>
<td><strong>Type of residence</strong></td>
</tr>
<tr>
<td>Independent / Family</td>
</tr>
<tr>
<td>Community group home</td>
</tr>
<tr>
<td>Residential Care</td>
</tr>
<tr>
<td><strong>Level of ID</strong></td>
</tr>
<tr>
<td>Mild</td>
</tr>
<tr>
<td>Moderate</td>
</tr>
<tr>
<td>Severe\Profound</td>
</tr>
<tr>
<td><strong>Support</strong></td>
</tr>
<tr>
<td>Pharmacological</td>
</tr>
<tr>
<td>IS</td>
</tr>
<tr>
<td>Oral</td>
</tr>
<tr>
<td>IV</td>
</tr>
<tr>
<td>GA</td>
</tr>
<tr>
<td>Non-pharmacological</td>
</tr>
<tr>
<td>Verbal reassurance</td>
</tr>
<tr>
<td>None</td>
</tr>
<tr>
<td>Other</td>
</tr>
</tbody>
</table>

IS=Inhalational Sedation; Oral= Oral sedation; IV=Intravenous sedation; GA= General Anaesthesia; Behavioural guidance = Verbal reassurance (eg. Someone with you to tell you that you will be ok); none = don’t use any of these.

8.3.1.3 Regression Analysis

Within the Regression model, GVIF was found to be below 2 for all variables, meaning that there was no significant multicollinearity observed within the full model, which demonstrated an AIC of 608.66. The final model, which found to be most parsimonious (AIC=599.13), while controlling for age, gender and level of ID is reported in Table 8.3. This table also displays the sample stratified by behavioural support alongside unadjusted
and adjusted associations. Non-pharmacological support was used as the reference category. Unadjusted association for dropped variables were as follows: type of residence (Community: OR=1.00, 95%CI=0.58-1.77, Residential: OR=0.91, 95%CI=0.52 - 1.62); self reported health (OR=0.74, 95%CI=0.45 – 1.24); ASA classification (ASA2 (OR=1.06, 95%CI= 0.65 – 1.75), ASA3 (OR=1.55, 95%CI= 0.97-2.01); health condition which may indicate pharmacological support (OR=1.15, 95%CI=0.78 – 1.67); reported organic brain syndrome, dementia, senility, emotional, nervous or psychiatric condition (OR=1.62, 95%CI= 1.11 - 2.40); difficulty sitting for length of time(OR=1.56, 95%CI=0.96 – 2.51); and visual or auditory sensory impairment (OR=1.21, 95%CI=0.78 – 1.87). Figure 8.2 demonstrates acceptable predictive power: Area Under the Curve (AUC)=.701.
Table 8.3 Regression model with IVs stratified according to behavioural support and adjusted / unadjusted association.

<table>
<thead>
<tr>
<th></th>
<th>Non-pharmacological</th>
<th>Pharmacological</th>
<th>Unadjusted OR</th>
<th>95% CI</th>
<th>P-value</th>
<th>Adjusted OR</th>
<th>95% CI</th>
<th>P-value</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Gender</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>176</td>
<td>65</td>
<td>27.00%</td>
<td>1</td>
<td>Reference</td>
<td>1</td>
<td>Reference</td>
<td>1.14</td>
</tr>
<tr>
<td>Female</td>
<td>222</td>
<td>82</td>
<td>27.00%</td>
<td>1.00</td>
<td>(0.68-1.47)</td>
<td>0.99</td>
<td>1.14</td>
<td>(0.76-1.74)</td>
</tr>
<tr>
<td><strong>Age</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>44-49</td>
<td>114</td>
<td>41</td>
<td>26.50%</td>
<td>1</td>
<td>Reference</td>
<td>1</td>
<td>Reference</td>
<td>1</td>
</tr>
<tr>
<td>50-64</td>
<td>195</td>
<td>76</td>
<td>28.00%</td>
<td>1.02</td>
<td>(0.70-1.70)</td>
<td>0.72</td>
<td>1.04</td>
<td>(0.65-1.69)</td>
</tr>
<tr>
<td>65+</td>
<td>89</td>
<td>30</td>
<td>25.20%</td>
<td>0.94</td>
<td>(0.54-1.61)</td>
<td>0.816</td>
<td>0.85</td>
<td>(0.47-1.52)</td>
</tr>
<tr>
<td><strong>Level of ID</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mild</td>
<td>100</td>
<td>34</td>
<td>25.40%</td>
<td>1</td>
<td>Reference</td>
<td>1</td>
<td>Reference</td>
<td>1</td>
</tr>
<tr>
<td>Moderate</td>
<td>183</td>
<td>68</td>
<td>27.10%</td>
<td>1.09</td>
<td>(0.68-1.78)</td>
<td>0.72</td>
<td>1.03</td>
<td>(0.62-1.73)</td>
</tr>
<tr>
<td>Severe\Profound</td>
<td>115</td>
<td>45</td>
<td>28.10%</td>
<td>1.15</td>
<td>(0.69-1.94)</td>
<td>0.60</td>
<td>0.94</td>
<td>(0.54-1.64)</td>
</tr>
<tr>
<td><strong>Obvious problems with teeth or gums</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>423</td>
<td>131</td>
<td>23.60%</td>
<td>1</td>
<td>Reference</td>
<td>1</td>
<td>Reference</td>
<td>2.53</td>
</tr>
<tr>
<td>Yes</td>
<td>61</td>
<td>57</td>
<td>48.30%</td>
<td>2.93</td>
<td>(1.86-4.63)</td>
<td>&lt;0.001</td>
<td>1.56</td>
<td>(1.56-4.10)</td>
</tr>
<tr>
<td><strong>Challenging behaviour</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>196</td>
<td>46</td>
<td>19.0%</td>
<td>1</td>
<td>Reference</td>
<td>1</td>
<td>Reference</td>
<td>1</td>
</tr>
<tr>
<td>Yes</td>
<td>202</td>
<td>101</td>
<td>33.3%</td>
<td>2.13</td>
<td>(1.43-3.20)</td>
<td>&lt;0.001</td>
<td>1.91</td>
<td>(1.26-2.94)</td>
</tr>
<tr>
<td><strong>Difficulty speaking</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>No difficulty</td>
<td>168</td>
<td>32</td>
<td>16.0%</td>
<td>1</td>
<td>Reference</td>
<td>1</td>
<td>Reference</td>
<td>1</td>
</tr>
<tr>
<td>Some difficulty</td>
<td>98</td>
<td>28</td>
<td>22.2%</td>
<td>1.50</td>
<td>(0.85-2.64)</td>
<td>0.16</td>
<td>1.52</td>
<td>(0.84-2.72)</td>
</tr>
<tr>
<td>Much difficulty / cannot do at all</td>
<td>132</td>
<td>87</td>
<td>39.7%</td>
<td>3.46</td>
<td>(2.19-5.57)</td>
<td>&lt;0.001</td>
<td>2.96</td>
<td>(1.84-4.84)</td>
</tr>
</tbody>
</table>

Non-pharmacological support n= 398 (73%), pharmacological support n= 147 (27%); Reference category = non-pharmacological supports; OR=Odds Ratio; 95%CI= 95% Confidence Interval; Statistically significant responses in bold.
8.3.2 Qualitative Phase

Members of the focus group reviewed and discussed the frequency data arising from the QUAN phase on pharmacological and non-pharmacological support use as individual adjuncts described above (see Table 8.2). Two relevant categories emerged: Subtlety of communicative guidance, which explained the frequently reported responses “verbal reassurance” or “no support” identified in the QUAN phase and the impact of availability on care, which explained the results from the dentists’ perspective. Figure 8.3 summarises these categories. The categories were based on experts’ interpretation of the data described below. Quotes, which support interpretation, are in italics.
8.3.2.1 Subtlety of communicative strategies

Dentists reported that communicative strategies was purposefully applied so that it is not noticed by patients: “(when) you are using… behavioural support techniques… the goal for the patient, is to make them seem like it is… an open communication.” and that those expert in its application are in fact “… working through a sequence… of behavioural supports, but… from a patient’s perspective… you think that that’s her personality” [Expert 1]. This expert went on to say that what is reported as “verbal reassurance” may involve nuanced application of psychological and behavioural theory: “Verbal reassurance may be what it looks like… from a lay man’s perspective, because a lot of the techniques that we use: the tell-show-do, the reinforcement… the step-by-step approach uses verbal reassurance and could be interpreted as that, ya know, but it’s a bit more complicated.” [Expert 1]. By contrast, some respondents felt that these data may also reflect that many dentists fail to provide appropriate non-pharmacological support: “I just don’t know if the dentist uses anything in a lot of those responses.” [Expert 2].
8.3.2.2 The impact of availability on care

Lack of availability of sedation and GA  Focus group members felt that the frequent use of communicative supports may also suggest poor availability of pharmacological supports and that restricted access to GA and sedation, had led to inappropriate reliance on non-pharmacological approaches only: “*a high percentage of behaviour management is purely because the clinician does not have anything else to offer and if they did have, for example, pharmacological to offer, would that be a much lower percentage being treated with behaviour management only?*”. In their experience “*access to sedation isn’t readily available*”. They questioned the appropriateness of care when dentists relied on non-pharmacological supports alone: “*Is this because the clinician has been providing (non-pharmacological supports) and this has been beneficial, or this is all the clinician is (able to) provide?*”

Inappropriate care  The data also suggested inappropriate care to members of the focus group, who repeatedly questioned the quality of care when non-pharmacological supports alone were used: “*Coming back to that pie chart… if the majority… get their treatment carried out with behavioural approaches only, how successful is the treatment with those behavioural approaches?*” To this group of expert dentists, the heavy reliance on non-pharmacological supports meant that dental disease might not be treated adequately: “*It makes me wonder what is actually being done with behaviour management*”. The expert group of dentists felt that reliance on inadequate skills led at times to supervised neglect: “*How many times have we had people come in for assessment and they have said "we go to our dentist all the time, he really likes him, gets on really well with him, sits on the chair, he likes him because he plays music and he gets to look at some trains or whatever" and then we look in and they need 20 fillings?*”

The members of the focus group felt that this may lead to compromised outcomes for patients: “*I have no doubt it means a compromise in some patient’s view points*. However, an alternative explanation was that older adults with ID do not require behavioural support because they have higher rates of edentulism and therefore require less intervention. One focus group member responded that she felt that dentists may ignore the management of gum disease and the often difficult process of scaling teeth, obviating a need for pharmacological support: “*It’s probably more likely that (dentists) have ignored perio (dentin).*”
8.4 Discussion

8.4.1 Methodological issues

Before considering these results relative to the existing literature, a number of methodological issues arise. Firstly, adopting mixed methods allowed us to integrate data by connecting results of QUAN and QUAL phases. This enhances the readers’ interpretation of these data by explaining what these observed frequencies represented to the dentists who work in this highly specialised field. By using a *weaving narrative* (Fetters et al., 2013), this article revealed a nuanced interpretation that seemingly positive frequencies (i.e. most of this population receive dental care without restriction of rights and body) may actually represent service inadequacies. Neither method would have achieved this alone. However there are issues that the design adopted raises. For example, explanatory, sequential design often leads to what is termed “The Representativeness/Saturation Trade-Off” when balancing resources between developing representative QUAN and purposive QUAL samples (Teddlie and Yu, 2007).

The Quan phase of this study is based on a representative sample of a difficult-to-access population, enabled by utilisation of the unique National Intellectual Disability Database in Ireland (Kelly and Kelly, 2011). This is a major strength. The QUAL phase of this study involved only a small number of focus group participants, but these were information-rich cases from a restricted population. To illustrate, the sample included two of three available “specialists in Special Care Dentistry” in Ireland, and three “Senior Dental Surgeons Special Needs” from a population of less than thirty. This group was revisited on up to three occasions, in order to enrich the data and ensure robust analysis. By the end of this process, no new categories arose, suggesting data saturation *within the sample*, but it is likely that a larger sample may have led to richer inference of the QUAN data.

Using online media to deliver the focus group and interview data collection enabled the involvement of an information-rich group from a geographically diverse, restricted population. It also facilitated iterative data collection. However, at times, the focus group discussions did feel somewhat stultified, with more facilitator involvement than would have been hoped for. Nevertheless, the software used allowed real-time sharing of
quantitative data visuals and the group did engage with each other through these. Transcription was at times difficult due to “line drops” from time to time. In all, the multimedia aspect was crucial to this project and the advantages outweighed the disadvantages.

Large, multi-disciplinary datasets such as used here often involve trade-off between the richness of data and the number of items included. This in turn may impact on response rates and, importantly for this population, burden. This trade-off affected our regression model because many items we would have liked to include were addressed using proxy measures. For example, proxy items were used for an assessment of the extent of treatment need and adjunct availability was not assessed at all. Fear of dentists responses were also not included due the small number of respondents affecting the power of the model and the number of independent variables that could be included (Tabachnick and Fidell, 2013). Nevertheless, the regression did produce data that offered the reader an initial understanding of these phenomena.

Participants in the focus groups self-reported their use of behavioural adjuncts allowing for comparisons with reported general population use (Dionne et al., 1998, Chanpong et al., 2005). It is acknowledged that if participants incorrectly categorised this may introduce misallocation bias. Given that both “no support” and “verbal reassurance” groups were collapsed for analysis, this issue was largely negated in analyses comparing pharmacological and non-pharmacological supports.

Lastly, the data do not provide information on behavioural support use over time (number of treatment visits) or across types of treatment or whether treatment was successful or not. This study represents initial research in this field and IDS-TILDA Wave 3 data collection has been modified to permit further sequential consideration of these issues.

8.4.2 Main findings
Between three and five per cent of the general American and older British populations either self-report the use of pharmacological adjuncts such as GA or sedation (Dionne et al., 1998) or may, at some stage, seek pharmacological supports, such as sedation to 202
receive dental care (Pretty et al., 2011). In this mixed methods study, sedation or GA were reportedly used by almost three out of every ten older people with ID in Ireland: up to ten times higher than these nearest, albeit imperfect, comparisons in the UK and USA. However, these data are in fact lower than the estimated 50% of adults with ID, who are said to need pharmacological support in Northern Ireland (Gray, 2005) and approximates expected rates for populations with ID in the Republic of Ireland. The expected rate comes from research by Crowley et al. who used a manageability index to estimate that between 20% to 40% of adults with ID, in residential care in Ireland, would require the adjuncts of GA or sedation in order to complete invasive dental care (Crowley et al., 2005). Similarly, Holland and O’Mullane found that 33% of their younger Irish sample with disabilities required secondary care, many of whom were judged to require GA as an adjunct (Holland and O’Mullane, 1986).

It is difficult to compare the rates here to international norms, because reported rates range dramatically from 0.5% to 50% of defined populations (Ananthanarayan et al., 1998, Feldberg and Merrick, 2014, Gray, 2005), suggesting that cultural, structural and epidemiological factors may account for such variation. For example, the widespread deployment of physical restraint in Israel, in the form of the routine availability of a papoose board has led to significant reduction in the use of GA when delivering care to people with disabilities over recent decades (Feldberg and Merrick, 2014).

In the general population, international research suggests that the level of interest in sedation or GA as adjuncts to dental treatment (between 8% and 12% of the population) far outstrips the level reportedly used (Chanpong et al., 2005, Dionne et al., 1998, Quteish Taani, 2001). With this in mind, it is important to note that these data report use of rather than need for various supports.

The qualitative data go further and suggest that the frequent use of non-pharmacological support seen in the QUAN phase reflects that access to sedation or GA is limited, a view supported by others (Irish Society of Disability and Oral Health, 2012, Quinn et al., 2006, Smith et al., 2010). The availability or lack of availability of such options affects the decision of how best to support patients with disabilities (Glassman et al., 2009).
Therefore, as the group suggested, dentists relying on non-pharmacological supports alone, may do so, inappropriately leading to poor or no treatment for older adults with ID. This potentially represents failure in the dentist’s duty of care and can increase inequality, manifested in poorer oral health and oral health outcomes for people with ID in Ireland (Whelton et al., 2007, Crowley et al., 2005, Gabre et al., 1999, Mac Giolla Phadraig et al., 2015c). The mixed methods approach applied here suggests that, given the prominent role of communicative support and the impact that a lack of available pharmacological supports is seen to have, it is imperative that dentists are enabled to support adults safely and appropriately with both pharmacological and non-pharmacological supports. Research is needed to understand how this can best be achieved.

### 8.4.3 Routes of sedation

Focusing on the quantitative phase, oral sedation was the most commonly used delivery route for supportive adjuncts: used for one in eight of this population and seven times more frequently than was IV sedation. Reported frequency of use, as seen in the current study, reflects availability in general practice in Ireland, where 70% of dentists offer no sedation, 21% oral and 6% intravenous sedation (only 3% offer inhalation sedation) (Fisher et al., 2011). In the public dental services, special care senior dentists who are responsible for much of the dental care provided to people with ID were more likely to provide dental treatment under GA (Quinn et al., 2006). Despite the ease of administration of oral sedation, acceptability to patients (Fisher et al., 2011), avoidance of expensive equipment / hospital facilities, there are a number of significant limitations to the use of oral sedation, compared to IV and IS routes. These include a propensity for drug-drug interactions, variable and unreliable bioavailability, and variable onset and duration of action (Broderick et al., 2014). These issues are compounded by the unsafe practice of frequent administration of these drugs off site, at the patient's home, before they attend for a dental appointment. Oral sedation also circumvents the need for IV access (something that dentists may not be generally confident to undertake), which is the crucial key to titration and delivery of a reversal agent, should over-sedation arise. For these reasons, recent guidelines state that “oral sedation must only be… carried out by practitioners who are already competent in intravenous sedation.” (The Intercollegiate Advisory Committee on Sedation in Dentistry, 2015). There is evidence to suggest that 204
oral sedation, as reported here, might fall short of these standards. For example, Fisher et al. (2011), found that half of the dentists in Ireland, who claimed to provide conscious sedation, only provided oral sedation, suggesting that they are not competent in intravenous sedation, as contemporary standards dictate. Quinn, in a survey of senior public dental surgeons, found that oral sedation only was provided by half of the public dentists contacted and that training in its use was limited (Quinn et al., 2006). Placing these findings in context, this suggests a need for the Dental Council of Ireland to adopt the standards of those recently accepted elsewhere (The Intercollegiate Advisory Committee on Sedation in Dentistry, 2015) to ensure the safety of all patients, but particularly older adults with ID, a cohort who experience comparatively enhanced anatomical and functional limitations of older age, multiple co-morbidities and polypharmacy, all of which may impact on their capacity to undergo sedation safely (McCarron et al., 2013, O'Dwyer et al., 2016). The findings also suggest a need for training in sedation, specifically in its use with older people with ID.

8.4.4 Features predictive of sedation or GA use.
The regression model developed here predicted support use correctly about 70% of the time. It is not surprising that it did not do so more often, considering that many dental specific aspects such as complexity of treatment and length of time to treat were not measured here. Focusing on this model, very few of the variables from the literature actually predicted whether behavioural support was pharmacological or non-pharmacological. Only reported challenging behaviour, dental problems and difficulty speaking were predictive of sedation or GA use. This differs from findings for the general public, for whom medical complexity, level of dental anxiety (not testable here) and treatment need, are considered to indicate the need for pharmacological support (Coulthard et al., 2011).

Initial associations suggested that participants reporting at least one organic brain syndrome, dementia, senility, emotional, nervous or psychiatric conditions (OR=1.62, 95%CI= 1.11 - 2.40) were at higher odds to use pharmacological supports than those with none. These associations were not sustained once adjustment was made for variables sharing covariance. The final model demonstrated that participants reporting oral problems, such as painful teeth or bleeding gums were three times more likely to
experience treatment with GA or sedation as adjuncts rather than non-pharmacological supports. This seems reasonable as this group are not only more likely to attend dental care, but are more likely to have teeth, and need treatment and are therefore more likely to require dental intervention (Mac Giolla Phadraig et al., 2014a). Those reporting challenging behaviour were at twice the odds to use sedation or GA rather than non-pharmacological support. In this study, participants who had no difficulty speaking were more likely to report using a non-pharmacological than a pharmacological support for dental care. Those with much difficulty or who could not speak at all were three times more likely to use sedation or GA than non-pharmacological adjuncts. Difficulty in communicating is seen to be strongly and independently predictive of the need for pharmacological support. What these results suggest is that there is perhaps a need to re-focus on dentists’ receptive communication skills, with a renewed focus on non-verbal and behavioural communication, in order to better understand the patients’ own message. There is also a need to reduce need for dental care and focus on non-pharmacological behaviour support as a means of avoiding restrictive chemical support use.

8.5 Recommendations

Mixed methods design allowed the identification of the need for improved dental services capable of delivering skilled communicative supports, adjuncts such as GA and sedation, in order to enable adults with ID to receive safe, effective and acceptable dentistry. This means that there is need for dental teams capable of providing these supports and working within appropriate care pathways to be developed. Such integrated models of care have previously been recommended for people with dental phobias (Newton, 2011) and can be recommended for this population. The above also indicates a need for education for the dental team in non-pharmacological as well as pharmacological approaches relevant to supporting behaviour during dental care of older adults with ID. A suite of appropriate training is therefore required. Lastly, improved clinical governance, particularly in the use of oral sedation in dentistry for adults with ID, is also needed.

This study highlighted the need to include items in Wave 3 of IDS-TILDA that focus on the quality of care and treatment provided when using behavioural supports. This study
also suggested a need to better understand the role of communication in behaviour support for older adults with ID. By deconstructing the communicative process, dentists can better support behaviour of older adults with ID, leading to improved care and reduced reliance on pharmacological supports. These questions would also benefit from further research by other independent research groups.

8.6 Conclusions
The adoption of mixed methods in this study facilitated both measurement and increased understanding of the frequency of sedation and GA used as adjuncts by older adults with ID, accessing dental care in Ireland. Expressive communication impairment, challenging behaviour and treatment need were predictive of the need for sedation or GA. Older adults with ID most frequently received support using non-pharmacological approaches. Very few availed of GA and most sedation was by the oral route. The findings highlight that there is a need for contemporary clinical governance of such practice in Ireland. Appropriate application of effective, non-pharmacological support may obviate recourse to pharmacological, sometimes ineffective, supports. The findings offer insights into enabling minimally restrictive dental care and reasonable accommodation, appropriate to individual need, increasing the likelihood of effective interventions and better oral health outcomes for all people with ID as they age.
Chapter 9 Exploring the development and application of communicative behaviour support by dentists working with adults with ID: A focus group study.
Summary of Chapter 9

**Purpose** A better understanding of how non-restrictive behaviour supports are applied with adults with intellectual disabilities to facilitate dental care may reduce reliance on restrictive practices such as holding, sedation and General Anesthesia. In this study we explore communicative support used by dentists who provide treatment for adults with ID in Ireland.

**Methods** A synchronous online focus group was undertaken with six dentists. All members were further contacted again in pairs or individually for further data collection. Data were analysed using thematic content analysis.

**Results** Four categories emerged from the data. The first related, pair of categories focused on the development of communicative supports and the dentists’ motivation for their use. The second category pair related to the selection and application of these strategies.

**Conclusions** Building on these categories, a co-regulating model of communication was presented as the means by which dentists iteratively apply and adapt support strategies and decision-making processes were explored. This exploration revealed rationalist and intuitive decision-making. Areas for further research were identified.
9.1 Introduction

In this chapter, focus shifts to how adults with ID are supported to receive dental care using communicative supports.

9.1.1 Communicative support

As demonstrated in Chapter 2, dentists often manage behaviour through communicative support to help children and adults accept oral care and to engender a positive relationship with oral healthcare. Support is needed because people can find it difficult to receive dental treatment, which can be demanding. It is through such communication that patients are supported to participate in non-restrictive dental care and learn to participate independently. Many specific examples of this communicative support including desensitization and modeling are available in Section 2.4.4. Communicative support is roughly synonymous with paediatric oriented communicative guidance, which includes pre-visit imagery, direct observation, tell-show-do, ask-tell-ask, voice control, nonverbal communication, positive reinforcement, distraction, memory restructuring, motivational interviewing and Teach Back (American Academy of Pediatric Dentistry, 2015). It should be noted that the term guidance in this context, is a specifically child oriented term and thus unsuitable for use with adults. The AAPD recognise that there is a need to develop the evidence base supporting the application of existing approaches and develop new ones. It is proposed that this will encourage a shift towards research- rather than culture-driven developments in the field (Law and Karp, 2014, Strange, 2014). Chapter 2 consolidates this need by demonstrating a need to understand what communicative support involves.

In the past, such pediatric-oriented skills have been adapted to enable the delivery of dental care for adults with disabilities, As seen in Chapter 2.4, many of the techniques recommended for use with adults with ID are actually extrapolated from paediatrics. However a reliance on pediatric support skills to support adults with disabilities is increasingly seen as unacceptable (Dougherty et al., 2001). The major limitation in adapting these recommendations for adults with intellectual disabilities (ID) is that they apply specifically to children, and do not consider factors specific to adults with ID. While adults with ID may share with children similar difficulties in accepting dental care,
the reasons for this and the way in which this difficulty may manifest are very different (Peltier, 2009, Lyons, 2009). Recognising these limitations, the Special Care Dentistry Association (SCDA) in the USA developed consensus statements on sedation, anesthesia, and alternative techniques for people with special needs (Glassman et al., 2009). The resulting guidelines do consider communication difficulties and issues surrounding physical, medical and behavioural abilities specific to people with ID but are largely adaptations of the paediatric approaches recommended for children by the AAPD (Lyons, 2009), with additional suggestions from the field of dental phobia (Peltier, 2009).

9.1.2 Need for further research

Despite these helpful documents, and as Chapter 2.4 demonstrates, there is a lack of understanding about how traditional child-oriented techniques like those listed above have been applied to adults with ID. Even though non-restrictive behaviour support techniques are commonly applied, dentists are often indiscriminate and unaware of the principles underlying their application (Kawia et al., 2015, Humza Bin Saeed et al., 2012). This emphasises the need to understand how dentists learn and apply communicative behaviour support strategies. We also know little of dentists’ and patients’ experiences of behaviour support (Grant et al., 2004, Alshammasi, 2014). Chapter 2.4 demonstrates that the evidence base for whatever strategies are applied is lacking. There is a paucity of research in the field of non-restrictive behaviour support strategies and their application in people with ID. This is likely to contribute to an over-reliance on restrictive approaches to behaviour support for this population (Newton, 2009). Therefore, research is needed to develop and refine effective, non-restrictive strategies for use with adults with ID.

This is an exploratory study of the communicative supports used by experts providing dental care to adults with ID in Ireland. This study will explore how dentists develop communicative support skills for use with adults with ID and how these techniques are applied. A better understanding of these concepts, and their application, should reduce reliance on restrictive supports, perhaps rendering them unnecessary and even unethical (Lyons, 2009, Newton, 2009, Sturmey, 2015).
9.1.3 Research question

How do dentists working with adults with ID develop their skills in communicative behaviour support, why do they do so and how do they select and apply the different strategies available to them?

9.2 Methods

9.2.1 Design and methodological orientation

We undertook an exploratory qualitative study using online, synchronous, focus groups and interviews sequentially. Data were analysed using qualitative Thematic Content Analysis, as described by Burnard et al. (Burnard et al., 2008). Ethical approval was granted from the School of Dental Science Ethics Committee, Trinity College Dublin.

9.2.2 Sample

Six expert dentists acted as informants. We sampled from expert dentists who have extensive experience and unique perspectives of supporting adults with ID to receive dental care within an Irish context to explore the study issues. This technique shares features of key informant sampling (Marshall, 1996). Social media was utilised to notify potential participants of the research project. Given the highly specific and limited population of interest, we targeted the Irish Society for Disability and Oral Health and Project SMILE Ireland social media sites. Due to the recognised difficulties associated with social media recruitment for online focus groups we encouraged snowballing once participants agreed to participate (Boydell et al., 2014). Inclusion criteria, published online, specified that dentists with experience of working with adults with ID were sought for a focus group study exploring non-restrictive behaviour support for adults with ID. A gatekeeper made participant information leaflets available to avoid pressure on potential participants. Eight dentists responded. All had extensive experience with this group however one was excluded as he worked in the UK meaning that seven were included. All were deemed suitable for data collection and were invited to attend an online focus group: One could not attend. A final group of six dentists participated, all of whom had extensive experience / training in treating people with disabilities. Three were trained to the level of a postgraduate diploma in Special Care Dentistry (SCD); one held a diploma in conscious sedation in dentistry and two were trained as specialists in SCD.
One ran a private practice for patients with disabilities and all others worked in public dental services. All were members of the Irish Society for Disability and Oral Health. Geographically, participants came from across Ireland, from a mix of rural and urban areas.

9.2.3 Data collection

Sequential, reconvened or repeated focus groups have been used on occasion to deepen the sharing of knowledge on health related topics. Repeating focus groups may, among other benefits, potentially improve reliability while eliciting “a more in-depth understanding of the array of perceptions, beliefs, attitudes, and experiences held by participants” (Jacklin et al., 2016). Serial interviews present a more established method understood to deliver similar advantages (Murray et al.). Data in this study came from sequential focus groups / interviews with the same group of participants. This approach was not selected a priori in this project, rather it was adopted to meet the shifting conditions of the real world research being conducted. Participants had originally planned to meet in a face-to-face focus group at an annual conference. However, the conference program over-ran meaning that most participants were unable to attend. Given the geographic dispersion of participants the researcher explored the utility of interviews, and synchronous or asynchronous online focus groups. A synchronous online focus group was selected because it offered the advantages of focus group methodology while addressing the difficulties in convening such a geographically dispersed information-rich group (Janghorban et al., 2014). Other research teams have decided to use online media to address similar difficulties (Deggs et al., 2010). At the initial level of data collection, the researcher found that an online focus group also presented barriers for the group. While participants were visible and audible to each other the absence of material non-verbal communication and real-life atmosphere meant that discussion was somewhat stunted at times. This meant that the facilitator’s role as “traffic cop” was more involved than would have been the case in face-to-face focus group sessions. This diminished the depth of understanding that researchers hope to find from intra-group dynamics. Following this focus group it was decided to return to participants to increase the depth and breadth of exploration of the research topic and give time for narrative accounts to fully unfold. Serially collecting data among the same
participants has previously been shown to carry such advantages (Jacklin et al., 2016, Murray et al.).

The dental experts in this study initially met as a focus group online to discuss behaviour support for adults with ID. An open schedule was used for this synchronous online focus group with a focus on aspects of communicative support rather than specifically defined “behaviour management techniques”. The focus group concentrated mainly on members’ own applications but did offer reflections of other dental professionals’, carers’ and families’ support skills too. Data from this initial event were analysed inductively. This led to the development of a semi-structured schedule for further data collection. Two further online groups of two and two individual interviews involving the same participants from the initial focus group ensued, using the semi-structured interview schedule. Figure 9.1 summarises participant flow. Focus groups and interviews were undertaken online using video and audio enabled programs (FUZE ®). Transcripts were generated using audio-only recordings.

Figure 9.1 Study Flow
9.2.4 Data analysis
Using Thematic Content Analysis (Burnard et al., 2008), open coding was undertaken by CMGP and subsections were checked with CG, with JN acting as arbiter. The data were then recoded and refined using the constant comparative method throughout coding leading to the development of the final coding framework. Codes were clustered conceptually into subcategories and categories and from there data were separated by category and subcategory for interpretation. Microsoft Word and Excel enabled data coding, clustering and analysis.

9.2.5 Rigour of analysis
Member checking was carried out with two participants (all were invited) thereby giving participants a chance to react to both the data and the final narrative, adding credibility to the analysis. Peer debriefing was also undertaken between CG and CMGP to avoid lone researcher bias and enhance rigour (Long and Johnson, 2000). Borrowing a lens from the critical paradigm (Creswell and Miller, 2000), the lead author declared his own prejudices that behaviour support skills were lacking among dentists in Ireland, at the start of this project. As a secondary care provider, he acknowledged often seeing primary care dentists refer adults with ID for sedation or general anesthesia when it was possible to deliver oral care to the individual with ID, if only the most basic of supports had been provided with skill, confidence and knowledge. As a teacher, he had supported dentists to develop skills in behaviour support. Despite their assertions that they were skilled in behaviour support for adults with ID, they often made poor selection and application of techniques. Lastly, he recognised that he was an advocate and activist for better dental services for people with disabilities in Ireland. The researcher utilised peer review by other team members to manage any potential impact of these positions and the reader is also encouraged to consider these views and their possible impact on the analyses that follow (Long and Johnson, 2000).

9.3 Results

9.3.1 Introduction: Framework, codes and categories
Figure 9.2 summarises the four data categories, their subcategories and codes. The first related pair of categories focused on the development of support skills and motivation
for their use. The second category pair related to the selection and application of strategies. An extended coding framework is presented in Appendix 3.

9.3.2 Skill development

Three subcategories were identified as components of skill development: aptitude, formal education and experiential learning. Together these aspects enabled dentists to develop individualised techniques over time.

**Aptitude**

Respondents reported personality traits that were inherent and fundamental to developing support skills. These included having an interest in people and an ability to build relationships: “It is something that is within us all… its something that you are born with: that you can communicate with people and relate to people” [Expert 4]. These traits seemed to support an aptitude within which their skills developed: “It’s a combination of your natural ability obviously and with years of experience that ability is allowed to change for the better or the worse...
depending on how well you adapt…” [Expert 2]. These traits, they argued, present variably across dentists and seem to impact on how well one can learn support skills “It’s an approach you can teach and it’s an approach you can learn but the level to which you can teach and learn it is very much based on your own ability and commitment to that particular cohort of patients” [Expert 2].

Education
One participant captured the feeling of the group regarding their undergraduate training in behaviour support for adults with disabilities as “…very much a case of poor training.” [Expert 2]. Members of the group felt that dentists in public dental services, where the majority of care for adults with ID is provided currently in Ireland, had inadequate training “In the HSE….there is probably little or no experience of training on behaviour management.” [Expert 2].” In the absence of specific training, it seemed that dentists extrapolated pediatric oriented skills learnt in their undergraduate pediatric training and then applied these to adults with ID: “I think that dentists think that they know about behaviour management but its often in relation to pediatric patients.” [Expert 1]. However, reliance on pediatric skills without adaptation, was seen as limiting: “There is subtle but important differences with adults with disabilities. A pediatric model from your training… needs to be restructured and re-emphasised with people with disabilities as they progress through the life span.” [Expert 1]. All experts had also received varying levels of post-qualification training in sedation or special care dentistry. One who had undergone specialist-training felt that this conferred an advantage: “training in this area for dentists is really poor outside of specialist training [Expert 1].”

Experiential learning
Observation: Participants felt that observation of dental teams, inside and outside of formal education, played an important role in how they developed their skills: “if you watched another clinician in operation you pick up a lot of (communicative nuances) without being specifically taught.” [Expert 3]. Members repeatedly reported that they also observed carers and family members: as examples of good and poor practice. Observation was also how one participant passed on her skills to peers: “I have often had people come to my clinics and just watch me in action. I think they find that very useful because they see themselves, rather than me try to tell them what I do.” [Expert 6]
**Trial and Error**: Outside of education, the group experienced what they described as a kind of on-the-job learning: “You learn. Just like any job, you learn on the job. You learn a lot from experience and mistakes.” [Expert 4]. They discussed a process of learning, from their successes and failures: “A lot of it you learn as you go along, basically, from doing the wrong things at times: to what works and what doesn't work.” [Expert 6]. Specifically, through trial and error members learnt how to attune to individuals with ID on their terms, to be patient, and to know when to “push” and when to withdraw.

**Experience**: The group felt that skills developed over time, as all facets of learning blend to nurture and mature practitioners’ individual styles: “With experience… you would still have a certain level of modification on what you have been trained in.” [Expert 2]. This maturation process was felt to be an important part of skills development: “some clinicians… will be better than others and that will depend on how well they modify… the process of their behaviour management.” [Expert 2]. Practitioners did express that they could benefit from on-going professional support or mentoring to enhance this maturation: “Training and experience is obviously key, however more… discussion and elaboration of modifications as you advance in your experience and training would be important…” [Expert 2].

### 9.3.3 Dentists’ motivation to develop and apply support skills

Two subcategories arose regarding motivation. Firstly, under the subcategory of success and failure, dentists applied communicative strategies to achieve successful outcomes. Secondly, communicative support was used in place of and alongside more restrictive approaches in order to complete treatment and instill positive attitudes.

**Success and failure**

Success, as it emerged in this study, was a fluctuating concept. At times it meant achieving health and comfort or a positive experience of treatment for the patient; for others it could mean completion of a procedure or, equally, the temporisation of a filling when completion was impossible. What success meant to the group depended on the patient’s age, treatment need, experience and importantly, the outcome of the proposed procedure. The will to succeed was described among these dentists as driven internally by a heightened responsibility to patients with disabilities and a strong sense of vocation. In contrast, failure to support people with disabilities, was viewed as disappointing and
You may feel like, maybe, more of the responsibility is on you… because they are so much more reliant on you for behavioural support.” [Expert 3]. The decision to accept failure of a certain behaviour support technique seemed to be difficult for dentists at times: “You know, sometimes you can be stubborn and keep going and going, sometimes it may just be a case of going OK!” [Expert 2]. The decision to stop a procedure was particularly difficult when patients had found treatment up to that point difficult, because stopping treatment effectively removed the “reward” for the patient of having the treatment completed. In instances, this was characterised as a tendency to push patients to the edge of their coping capacity as dentists felt they pass points of “no return” in treatment.

The group recognised the difficulty of balancing between completing essential treatment and accepting failure. As one participant illustrated: “I think from my perspective, sometimes you can be unready to fail, which sometimes means that you try and push patients beyond what they can cope with in order not to go to IV [sedation] or GA, whenever it may be better for the patient, if you went back and rethink the plan earlier.” [Expert 1]. The group reported that failure to complete treatment using non-pharmacological approaches is actually often accepted by patients, their carers and families, if they feel that the dentist has tried their best: “As long as you have involved them and tried everything then people are happy to move on and try something else once they realise its not going to work.” [Expert 3]. The group were not as accepting of failure as patients and their families, except when there was a back up option, such as ready access to another more experienced colleague or a service providing GA or IV sedation. When these adjuncts were available to the dentist, it seemed to ‘permit’ earlier acceptance of failure and delivery of acceptable treatment: “I am not inclined to keep muddling through if the treatment is difficult. If it is difficult for people to tolerate, you should be inclined to make it easier rather than muddling through and pushing people through what is too much for them, really.” [Expert 6].

Reducing reliance on restrictive supports

The group noted that communicative support strategies offered an alternative to restrictive supports such as general anesthesia and sedation. The group, nevertheless, acknowledged the benefit of restrictive approaches, which they had used selectively and sparingly “…I think it’s right and proper that you should only use pharmacological supports when you need them, but there is no good reason not to use them, if ya know a person needs them.” [Expert 6].
Upon further exploration with this group member, communicative skills were typically applied as an alternative to these more restrictive approaches: “You always avoid GA and sedation as far as you can… you use the least restrictive methodology of treatment.” [Expert 6]. Effective communicative support also enabled dentists to apply less restrictive adjuncts, obviating the need for more restrictive care: “…Good behavioural supports using milder forms of sedation, both inhalation sedation or a pre-med can actually obviate the need for heavier forms, be it of IV or GA… so it is very important.” [Expert 6]. When restrictive approaches were applied, communicative strategies maintained an important role in negotiating a positive, long-term experience of dentistry care. Communicative support was used with a number of aims. Firstly, to enhance pharmacological supports in a variety of combinations, such as before GA: “…I don’t think that there is any patient that you should go straight to sedation or GA and not have done some of the basic behavioural beforehand…”[Expert 5]. Others reported their utility after GA: “…you can work backwards from there and you can have a patient who requires a GA for start and then can get treatment with sedation and back from there towards (Inhalation sedation).” [Expert 6]. Thus, the group used non-restrictive approaches alongside and in lieu of pharmacological adjuncts in a variety of ways.

9.3.4 The selection and application of strategies.

Two categories were identified relating to selection and application of techniques and together represented a continuous, iterative communicative process of assessment, application, reassessment and adaptation.

Rational and intuitive decision making

Participants demonstrated highly individualised decision making processes when selecting support strategies. Each person relied on a varying balance of rational and intuitive processes (see Figure 9.2 later). “it can be… an organised process or a disorganised process, if that makes sense?” [Expert 2]. Drawing from a rational perspective, participants often referred to their initial assessment process, whereby they matched their approach to the patient by bringing together information from a broad range of sources: “So its knowledge and what you see personally in front of you, and what you are told: what they are like and you try and get the bigger picture of the whole thing, before you try anything.” [Expert 5]. Sources of information included previous experience with the patient, observing/considering carer interactions with the individual, assessment of ability, preferences, and discussion with
the patient and those who support them: “I think the most important thing… is to speak to the person, the patient, and see what they feel comfortable with.” [Expert 5]. Apart from diagnoses of people with specific behavioural profiles, such as Fragile X syndrome or Autism, respondents considered the patient’s diagnosis secondary to personalised information collected before and then during the encounter.

This structured process was juxtaposed by a selection process that was also naturalistic and subconscious: “You are reading the person from the vibes they are giving off.” [Expert 4]. These intuitive processes varied and were more prominent for some group members than others. “Ya know, it’s not something I consciously think. It is just something that you would instinctively and automatically fall into.” [Expert 6]. Upon further discussion, it appeared that many seemingly intuitive processes relied upon assessment of non-verbal messages, communicated by the patient: “When I’m assessing… the minute they walk through the door… I’m looking, aware of what’s going on, looking at the reactions of the carers, picking up little things, the movements, the way they… Just the whole demeanour… As I talk, just the reaction, the whole experience of coming into the surgery, I’m just looking all the time, picking up all the time and learning all the time.” [Expert 4]. Given the significance of non-verbal communication, intuition was most prominent in peri-operative assessment and reassessment, when the patient could be observed: “Then you are moving from that pre-assessment, where you are judging them based on information, you are getting to reading their body language, their sense of anxiety, you know, very physical signs, I suppose.” [Expert 2]. Experts explored the processes underlying this intuition, concluding that it may actually represent a more structured, transferable process than at first sight: “I would have thought that it happened naturally, but when I think about it, there probably is a certain amount of thought process that you are going through in your head and you’re ticking certain boxes, unknown to yourself… and making a decision.” [Expert 5]. It is important to note that while tool selection was reported as led by the dentist, patients communicated their preference either expressly or through their non-verbal or behavioural cues and thereby controlled the selection process to varying degrees: “you just knew, the way she was… automatically going towards him and not coming towards me… if that’s the person that she wants to go for, then let her.” [Expert 5].
Respondents noted that formal postgraduate education promoted rational rather than intuitive approaches to decision making “If you get the training, that will certainly organise your process accordingly, and if you get the experience and never have the training, you will probably carry on with a certain level of modification over time but not a thought out process: I think, probably, a subconscious modification.” [Expert 2]. It appeared that the rational approach, where strategies were purposefully selected and applied in an organised manner and assessed explicitly, offered a structure to the communicative support process and promoted reflective practice: “There is benefit to training ‘cause it often makes you more aware of the structured approach, where you are sort of able to evaluate better when you are doing it. Sometimes when you are just going on experience you are frantically trying to find different things, but not able to evaluate what worked and what didn’t work or why it worked for that individual.” [Expert 1].

**Adaptability**

During behaviour support, experts adapt by matching the strategies they used to the situation as it developed. “I adapt to the situation. The situation can change…and you change accordingly, you know… to suit the situation…” [Expert 4]. This adaptation occurs along with changing expectations from treatment. The group recognised this flexibility of approach as a fundamental skill: “I think that an important aspect… is that (it) is very dependent on flexibility and ability of the clinician… (to) be willing to change their attitudes towards behaviour mid-treatment.” [Expert 2]. Participants as experts then adapted by continuous assessment, explicit or implicit, attuning accordingly. The group reported a reflexive process whereby the strategies selected changed based on changes within and between patients: “I think that it is an on-going process… no two patients are the same they are all different and as you move through the treatment plan and move through the process you may change and adapt.” [Expert 4].

**9.3.5 Applying strategies**

Participants discussed how their strategies were applied. They focused on generic communicative strategies rather than behavioural or other recognised strategies.

**Attuning with people**

The group recognised the need to engage with people as a foundation for effective support, enabling connection, rapport, the application of behavioural interventions and
ultimately cooperation: “There has to be an initial level of communication built up with the person before you start any of those styles of tell-show-do, or any of that, ya know?” [Expert 2]” This connection was often made subtly, and in the context of a positive atmosphere, purposefully crafted to increase the likelihood of successful dental visits: “The aim is to make the patient happy; to take the threat out of the environment; to deliberately make the patient like you and like coming.” [Expert 6]. Within this context, this expert illustrated a process of synchronising their being, attention and engagement with their patients, rather than using specific behavioural strategies “You could call it behaviour management but it is just interacting with people and making them comfortable and actually like being there.” [Expert 6]. Other approaches to attuning included playing together and sharing fun “We are deliberately creating that atmosphere “the good craic atmosphere” for ourselves, as well as our patient.” [Expert 6].

**Adaptability**

Experts recognised the importance of being versatile in how they communicated with patients. Some applied different personae depending on the support needs of the patient: “I think that’s very important because who you are with the patient can change, not fundamentally, but you can make jokes with some patients and other patients will be more serious, ya know.” [Expert 1]. Experts repeatedly described ways of switching tack if the technique they applied was not working. This might involve the dentist changing their behaviour “Where you are using bargaining or... positive reinforcement: molly coddling and then you say: Right! This isn’t particularly working. It becomes a lot more directive and setting limits.” [Expert 1]. Other examples of adaptability involved the dentist substituting with a colleague, having assessed a lack of progress in supporting the patient. This substitute clinician (Swapping out) may be used specifically because they are the preferred clinician (one group described a patient who just preferred men) or to specifically attempt an alternative approach “You may fail on all grounds and it might not be just a case of changing the behavioural approach but changing the clinician.” [Expert 2].

**Having the right team**

Experts understood that having the right team in place to support the patient was vital and that managing this team can lead to success for the patient. Equally, having the wrong team was seen as limiting: “[If] you are given somebody... who has no intent... or no experience... that can mean that your clinic is a complete waste of time then” [Expert 5]. The
importance of their role in developing their team to more effectively support people with ID was clear. The team included specialist colleagues within their referral networks, the wider dental team and those who support the patient to come to the dentist “See the carer, that comes in and you are very successful, then you just request that, the next time that that patient comes in, that that carer comes in with them.” [Expert 5]. The skill and confidence of the team, and not just the expert, was seen as crucial “the two nurses we work with… are very confident and I have experienced in the past when other girls have come in, and they aren’t confident, it can change the dynamics in the room and it may not be as successful as it could have been, ya know?” [Expert 4].

9.4 Discussion
This exploratory study produced a broad and rich analysis exploring how, why and in which way do expert dentists apply their behavioural support strategies. The results of the focus group discussions explored dentists’ views on learning and applying these skills and acknowledged inadequacies in education, training and resources that would provide better outcomes for patients, families and carers. The study also illustrates the variety in how skills are applied and in which situations they are selected. The following discussion presents these issues in context and suggests areas of further research.

9.4.1 How behavioural supports are learnt
Each expert developed their skillset through an individualised interplay of three components. Firstly, participants referred to personality traits, which they felt set them apart from other dentists. Lyons maintains that the application of behavioural support techniques, without a strong psychological and behavioural understanding, is likely to be ineffective or even detrimental (Lyons, 2009). Yet, the group reported poor undergraduate training in adult, compared pediatric behaviour support approaches, with restricted access to postgraduate education and training. This means that many dentists rely heavily on adapting learning from pediatric dentistry, despite acceptance that ongoing reliance on pediatric skills to support adults with ID to receive dental care is not ideal (Dougherty et al., 2001). Given the prominent role of pediatrics in dental education and, specifically, the development of behaviour support in dentistry, it is not surprising that dentists rely on transfer of pediatric skills to develop their adult oriented strategies (Lyons, 2009). This study supports the belief that skills from pediatrics are not directly transferrable to providing care for adults with ID and that reliance on such skills is
limiting. This finding supports the assertion that behaviour support for adults with ID requires the acquisition and development of a set of skills, separate to those practiced in pediatrics (Newton, 2009).

Participants also referred to opportunities for learning informally, through trial and error as well as direct observation. Some respondents relied heavily on this form of learning. This was despite a number of participants reporting that this form of “on-the-job” learning was limiting. Nevertheless, learning was reportedly enhanced by experience, enabling experts to develop individualised techniques over time. The learning process described here maps closely to the concept of experiential learning, which considers learning as a transformative, creative process of adaptation where experience is transformed into knowledge, which in turn affects experience (Kolb, 1984). This study suggests that a lack of specific education, which is widespread, has led to over-reliance on self-taught skills, with adaptation of pediatric skills supplemented by on-the-job learning. By contrast, specialist education was reported to be transformative by those who received it. The group also reported a need for improved undergraduate education and professional mentoring. Previous research has recommended better education in behavioural management principles for dentists too, having found that dentists are more confident than knowledgeable regarding support techniques for adults with ID (Humza Bin Saeed et al., 2012). This is echoed by participants’ experiences.

9.4.2 Why support skills are used
This group of experts reported a drive to achieve successful outcomes for their patients due to a sense of vocation, a heightened responsibility towards patients with disabilities as well as a means of role fulfilment. In dentistry, behaviour support has two aims: to develop a positive relationship between the patient and dentistry; and to enable the establishment/maintenance of oral health (American Academy of Pediatric Dentistry, 2015). This may in some way explain why the concepts of success seen here fluctuated. The aims of behaviour support may at times conflict, meaning that sometimes health outcomes are compromised to secure better experience for patients and vice versa. The placement of a temporary filling, for example, where a permanent restoration is impossible due to difficulty in tolerating treatment serves as a case in point, discussed by this group. Conversely, this study also found that a drive for a successful outcome can
lead dentists to fail to accept failure with a particular support, when treatment challenges their patients’ coping capacity. A slowness to adapt when initial approaches fail is also reported among pediatric dentists (Alshammasi, 2014).

Positive outcomes ultimately influenced the acceptability of behaviour support techniques here, as has also been reported in a number of vignette studies (Newton and Sturmey, 2003, Jaafer et al., 2007). Ideally, a standardised method to reliably determine the need for adjuncts for patients would correct this problem. There have been attempts to achieve this (Prabhu et al., 2008). Research that targets both concepts of success, as well as identifying end points of treatment, may lead to further developments.

### 9.4.2.1 Pharmacological support

Many studies advocate the use of pharmacological support such as minimal (or conscious) sedation, either by oral, nasal, rectal or IV routes for people with ID (Becker et al., 2009, Boyle et al., 2000, Stillwell and Anderson, 2012). These studies suggest that pharmacological and non-pharmacological approaches are intimately related and are essentially complementary. The group of experts in this study recognised that communicative support skills can and do reduce reliance on pharmacological approaches. They supported Newton’s perspective that better, non-pharmacological behaviour guidance should reduce reliance on sedation and GA (Newton, 2009). This would be appreciated by dentists and patients’ parents, who prefer non-pharmacological approaches (de Castro et al., 2013, Quinn et al., 2006). Interestingly, the data here suggested that dentists come to accept a failure of communicative support more readily, when they have ready access to GA and IV sedation. The availability of supports such as GA or sedation may minimise the likelihood of over-stretching patients’ tolerance for treatment with non-pharmacological support alone.

### 9.4.3 How support strategies are selected and applied.

Three factors warrant discussion in seeking to understand the selection and application of strategies: decision-making, application and the communicative model they share.
9.4.3.1 Decision-making

Participants adopted an individualised iterative process when selecting communicative support strategies, by considering a wide range of data sources, which mirrors other areas of healthcare decision making (Aitken, 2003). Members of the group used both rationalist and intuitive decision making processes to select these approaches. Figure 9.3 maps these processes alongside each other, from assessment to application and reassessment and adaption. Among the group, it seems that both processes occurred simultaneously, to greater or lesser degrees, as pointed out in member check.

The rationalist approach assumes explicit analytical activity by the decision-maker. Here it involved pre-assessment of the patient based on information from carers, parents and the patients themselves. This analysis led to the selection of a communicative strategy that was then explicitly assessed e.g. by reading non-verbal and behavioural cues, before adapting approach purposefully. The rational approach espoused especially by those members with formal postgraduate training, seemed to give a sense of clearer outcomes from decision making. Broader research suggests that structured approaches like this are preferred for behaviour support selection (Alshammasi, 2014). Data and member checking supported this.

This is not to dismiss intuitive processes. This study shows that observation and experience intuitively informed the selection process too. In this way, dentists went along with the situation in an organic manner, without explicit selection or assessment of their strategies. Expert opinion recognises the importance of instinct and emotional skills in this regard, Raposa compels readers to “be guided by instinct and creativity, rather than by strict reasoning” (Raposa, 2009). Intuitive judgment is said to be based on experience. In fact, intuition is a recognised and accepted approach to decision making, which may reflect expertise in a field (Aitken, 2003), as a practitioner moves from novice to expert (Benner, 1984). In this instance, it seemed to be different. Rather, intuition was reportedly applied in the absence of training and knowledge necessary for decision making, possibly an outcome of poor undergraduate education.
On further reflection, the instinctive process used by this group of experts was based on structured steps such as assessment of patient related factors, awareness of non-verbal communication, applying previous learning to new situations and reflective practice. Perhaps these steps are largely ill-defined by those who use them “intuitively”. Theory supports this assumption. Intuition, it seems, is built on the use of a “sound, rational, relevant knowledge base in situations that, through experience, are so familiar that the person has learned how to recognise and act on appropriate patterns (Cert and Wilcockson, 1996)”. This is important because receptive communication skills, knowledge of support techniques, reflective practice etc. are learnable attributes. By recognising these steps, it is possible to consider apparently non-transferable traits, implied by intuition, as learnable skills.
Figure 9.3 Rational and intuitive decision-making in selecting support strategies
9.4.3.2 Applying skills

When supporting behaviour, experts focused on communicative rather than strictly behavioural strategies (see Table 2.9). They highlighted sharing attention and engagement with their patients to offer support. It is clear that these dentists actively promote alignment emotionally and behaviourally with their patients with ID. In this way dentists attune with their patients leading to more successful outcomes. Griffiths has previously identified attuning as a natural means of promoting cooperation and empathy between care provider and people with ID (Griffiths and Smith, 2016). In this sense, communication can be viewed as a broad transaction between dentists and patient, which allows each to “tune in” with each other (Roberts, 2005). This ties in with advice from Kemp (2005) who suggests a humanistic approach, that respects the dignity of the patient and Peltier who suggests showing a genuine interest in the patient with intellectual disability (Peltier, 2009).

Aligned somewhat with the concept of rapport, the importance of dentist interaction to increase patient’s acceptance of dental care has been previously reported among non-disabled populations (Gale et al., 1984). This group saw the value of connecting with their patients. They repeatedly referred to affinity-seeking behaviours, where they actively aimed to generate positive feelings towards themselves from their patients (Bell and Daly, 1984). Respondents also noted that they acted in their role as a behaviour guide contingently, with the option to adapt according to response. Response options included changing tack e.g. changing persona from supportive to directive or the use of alternative dentists e.g. “swapping out” or alternative adjuncts such as sedatives. Teamwork was also noted as an important aspect of care, reflecting the assertion, embodied within AAPD guidelines, that the wider clinical team act as an extension of the dentist in behaviour support and communication (American Academy of Pediatric Dentistry, 2015). Recent guidance for orthodontists for example, highlights the need for flexibility and teamwork to facilitate care for people with disabilities (Rada et al., 2015). The data collected from this group of experts confirmed that having the ‘wrong’ team can have an equally important (negative) impact on the outcome of dental care.
9.4.3.3 Co-regulating dynamic communication for supporting behaviour

The selection and application of support techniques involved the dentist iteratively assessing and applying a strategy, then reassessing and adapting this approach. Exploring this interaction, a process of cyclical communication between patient and dentist occurred, it should be noted, within a larger context involving carers, family and dental nurse. The description of how participant dentists selected and applied support techniques suggests a communicative model whereby the dentist and patient co-regulate, continuously by sending and receiving messages simultaneously, but with roles of receiver and sender of messages predominating alternately, depending on the specific function of communication (e.g. assessment/reassessment or strategy application/adaptation). To expand, when the dentist assesses the need for a communicative strategy, either intuitively or rationally, receptive communication skills predominate, for example by identifying patient preference and reading non-verbal and behavioural cues. The dentist’s expressive communication skills then come to predominate in applying their strategy (e.g. by attuning, seeking-affinity or applying formal approaches like Tell-Show-Do). In applying such techniques, the sender (dentist) receives feedback (using receptive communicative skills) from the patient (applying their expressive skills). As Figure 9.4 illustrates, the dentist and patient accordingly attune their communication, in a co-regulating manner, by assessing and applying communicative strategies, which are in turn reassessed and adapted.

This dynamic, ongoing interaction involves communicators interdependent in a circular and continuous process, and acting as both receiver and sender of messages using multiple indiscrete channels (verbal, non-verbal and behavioural cues). This reflects, in ways, a continuous processing model of communication (Fogel, 1993), whereby dentist and patient co-regulated as part of a continuous, dynamic process, rather than a simply transactional interaction (Barnlund, 1970). While concepts of reciprocation and iterative interaction in dentist-patient communication are numerous (British Society for Disability and Oral Health/Faculty of Dental Surgery of Royal College of Surgeons of England, 2012, Sondell and Soderfeldt, 1997), this model of dentist-patient communication as presented, simplifies the communicative behaviour support interaction so as to understand the need to be clear in how dentists express themselves holistically and to
“listen” objectively and subjectively to the wide range messages sent by patients with ID and adapt their communicative strategy accordingly.

Figure 9.4 Co-regulating dynamic communication for supporting behaviour of adults with ID.

![Diagram](image)

Note: While this illustration separates discreet steps in the process, dynamic communicative support involves cyclic and continuous sending and receiving of messages before, during and even after behaviour support. Communicative roles predominate depending on the specific step and communicative function.

Typically, when giving advice on communication with people with disabilities, there is a tendency to focus on how the dentist can improve their expressive communication rather than receptive skills. For example, Peltier very helpfully recommended communicating with an appropriately slow pace, careful selection of specific positive language and the avoidance of specific negative words, a calming tone of voice, and alignment of the entire office staff (Peltier, 2009). Furthermore, focus group members were concerned far more with non-verbal communication, possibly reflecting the frequency of communication impairments noted in this specific population. This study
adds to our understanding by highlighting the need to focus training on both expressive and receptive as well as verbal and non-verbal communicative skills.

9.4.5 Methodological issues

Focus Groups. Repeated focus group sessions can impact recruitment and retention of participants due to the time commitment required (Morgan et al., 2010). Therefore we facilitated participants by allowing interviews and smaller groups to ensure that all participants had the opportunity to expand the discourse. Synchronous focus groups often take the form of “chat-room” style (Boydell et al., 2014, Jacklin et al., 2016). In this study the group used video-conferencing software. The fact that the group met online did seem to initially stifle the flow of conversation, leading to regular facilitator involvement to re-direct or probe. However it also ensured, naturally, that there was no overlapping talk and gave “centre stage” to talking participants as their image enlarged while talking. Online focus group interviews necessitate access to high-speed Internet, familiarity with online communication, and digital literacy (Janghorban et al., 2014). This only created issues for one participant who cutout and rejoined the group a number of times necessitating repeated “catch ups”. As it happened, this offered opportunity for confirmation and real-time member checking but it did impact flow. The software also allowed real-time sharing of visual cues. Later, transcription was at times difficult due to “line drops” from time to time. In all, the online aspect was crucial to completion of this project and was justified as the advantages outweighed the disadvantages.

Sample Size and Saturation Issues. This study took a broad perspective, outlining a number of areas for further research and did not attempt to present a comprehensive picture of the phenomena it describes. This is in part because this study is exploratory in nature, focusing on what was salient to participants. The small sample also influenced potential for saturation but reflected that these dentists are a small, information rich, geographically dispersed population. As Mason suggests, there are aspects of this study, which supported the use of a smaller sample size (Mason, 2010a). Firstly, participants are a homogenous group of highly skilled experts. In one study of eight highly skilled practitioners’ clinical decision making, the authors suggested that expertise in the chosen topic can reduce the number of participants needed to produce rich data (Jette et al., 2010).
2003). Given the richness of data here, this study supports that assertion. Secondly, studies that use multiple, in-depth interviews with the same participant have less reliance on larger samples (Lee et al., 2002). We did not attempt to achieve saturation of themes or concepts in this study, nevertheless it can be assumed that a larger sample would have given a broader narrative.

Data Status and Group Member Issues.

Silverman encourages qualitative researchers to ask what is the status of their data (Silverman, 2006). By this Silverman, reminds the researcher, acting as the analytic tool, that data are constructed by interviewees, which may involve a mixture of both fact and fiction. Indeed there are many metaphors, which the data may carry from that of unifying cultural identity to offering a socially validating narrative. In this way, it is possible that participants, to some degree, presented a narrative that secured their shared perspective of expertise or validated their own training and positions. Nevertheless, member checking was useful because participants in confirming the overall analysis informed a discussion that followed on the relationship between rational and intuitive decision making by dentists. Given the limited access to education in Special Care Dentistry in Ireland, all participants had either undergraduate or postgraduate ties to [location details withheld] where the researcher is based and this may also have influenced the responses given by participants.

9.5 Conclusions

This study used an inductive approach to explore dentists’ learning and use of non-restrictive strategies to support adults with ID. They mostly discussed communicative strategies rather than others, such as behaviourist approaches (see Chapter 2). Firstly, the study found that undergraduate education did not enable dentists to support adults with ID; rather experiential learning helped develop skills. Expert dentists were found to make complex decisions to assess and reassess their support strategies iteratively by using intuitive and rational decision-making to apply and adapt their communicative strategies. In applying those skills, a highly adaptable, versatile co-regulatory communication process was described and is modeled here. Within this model, emphasis on receptive and expressive communication alternated, depending on stages within the process of
communicative support. This study also found that dentists applied communicative support as a means of reducing reliance on restrictive supports, such as GA. The decision to use communicative approaches was validated by what they judged to be a successful outcome. What this means exactly varied, and was highly context and outcome dependent. Taking the data as a whole, dentists learned and applied skills to ultimately achieve better patient experience, reduce reliance on pharmacological supports and improve outcomes, by applying knowledge, skills and experience they personally possessed and had the opportunity and motivation to utilise in the clinical setting. There is a need to value what are clearly highly specialised skills in communicative support. Investment needs to be made in training, both under- and post-graduate, and practice to promote appropriate behavioural support to reduce restrictive practices among adults with ID in Ireland.

9.5.1 Further Research

Firstly, there is a need to gain consensus on the taxonomy and classification of behaviour support strategies used by dentists to support adults with ID. Secondly, research should evaluate the effectiveness of recognised and novel behaviour support techniques in clinical practice. Research is then needed to explore how these strategies are applied: decision-making and application of communicative supports. Research into the teaching of support strategies focusing on both receptive and expressive communication skills is also needed, so as these skills can be taught at undergraduate and postgraduate levels for future generations of dentists supporting people with disabilities as Special Care Dentistry moves from art to science.
Chapter 10 Discussion
10.1 Introduction

This study had two objectives. Firstly, to understand the prevalence, sequelae and impact of edentulism, and secondly, to understand the frequency of dental attendance and use of behavioural supports among older adults with intellectual disabilities. This chapter brings together the main findings of both objectives, which we discover are actually closely related. These objectives are reviewed, in brief, before demonstrating how, together, they meet the aim of the study. We then discuss some issues that this research raises, before considering some strengths and limitations. This chapter then concludes by making recommendations for policy, practice and research.

10.2 Overview

The first objective of this study was to understand the prevalence, sequelae and impact of edentulism among older adults with intellectual disabilities in Ireland. Collectively, Chapters 4-6 demonstrated that edentulism is unacceptably high among people with ID. Further, these chapters show that when total tooth loss occurs, oral disability ensues rather than restoration of function. Lastly, it is apparent that this unmet treatment need translates into higher risk of difficulty eating and its tangible, social and medical consequences for adults with ID.

The second objective of this study was to understand the frequency of dental attendance and use of behavioural supports among older adults with intellectual disabilities in Ireland. Collectively, Chapters 7-9 demonstrate that service use was frequent, with limited use of sedation and general anaesthesia. The non-pharmacological supports applied to reduce or enhance such restrictive interventions, are, at best, patchy. Together, a picture of poor outcomes from oral disease alongside frequent use of inappropriate dental services emerges.

10.3 Edentulism and complete denture wear

The reported prevalence of edentulism among older adults with ID was 34% compared to 15% of the general population. This is a striking disparity. Once they become edentulous, about two thirds of adults with ID do not wear dentures. That is equivalent to 237
to twelve times that of the general population (Mac Giolla Phadraig et al., 2016). The reason for this, reportedly, was that adults with ID did not want dentures, although the data hint at a disempowered group who may not receive the support, or the opportunity to make such decisions. This is impactful on this population, because edentulism is a risk factor for difficulty eating among adults with ID, when edentulism is not rehabilitated. In fact, complete denture wear predicts a reduction in difficulty eating, even relative to those who have teeth, who mostly presented with unrestored partial edentulism. For the groups with suboptimal oral health, the literature reviewed in Chapter 2.3 and Chapter 6.1 suggests that eating difficulties can impact health, nutrition and psychosocial well being, in turn increasing risk of disease. Research is needed to explore the relationship between difficulty eating and dentate status further, because these findings suggest that oral disease and its management further disable people with ID, (Figure 10.1) .

**Figure 10.1: Disabling impact of oral disease among people with ID**

Oral disease, mediated by non-conservative and non-preventive management, manifests as tooth loss and ultimately edentulism. Unrestored edentulism is a risk factor for difficulty eating. This much is shown in the current study. The literature suggests that this may impact health, nutrition and social circumstance. Further research is needed to explore whether this leads to further oral disablement, in a cyclic fashion.

**10.3.1 The tip of the Iceberg**

Edentulism is the ultimate consequence of the late and inappropriate management of oral disease, representing a failure of prevention and conservative treatment. In this study we have adopted edentulism, as many researchers do, as a marker of oral disease burden (Weintraub and Burt, 1985, Hobdell et al., 2003, Müller et al., 2007). But, to observe oral disease and outcomes of treatment by counting edentulous individuals is like firemen counting fires by seeking burnt-out ashes, while ignoring the flames. Nevertheless, edentulism is adopted as an outcome variable here for a number of reasons. Firstly,
because it is an important and disabling condition in and of itself (Walls et al., 2000, Sheiham et al., 2002, Polzer et al., 2010, Emami et al., 2013, Kassebaum et al., 2014, Felton, 2015), secondly, it offers a focus for reporting both oral disability and health gain at population level (Vos et al., Hobdell et al., 2003). In addition, it is frequently (National Council on Ageing and Older People, 2004, Mac Giolla Phadraig et al., 2015c, Whelan and Savva, 2013, Tyrovolas et al., 2016) and validly (Douglass et al., 1991) recorded through self-report and this worked within the limitations of IDS-TILDA methods. However, complete tooth loss is merely the tip of the iceberg; oral disease occurs prior to edentulism and oral function declines, as teeth are lost. Therefore, not being completely edentulous does not translate to having a functioning, disease-free dentition. In fact, some studies find that about 25% of “dentate” people are actually edentulous on either the maxillary or mandibular arches (Müller et al., 2007). This brings with it all the functional and restorative challenges of edentulism, without being identified categorically as such, for research purposes.

A more valid measure is therefore needed. The literature uses a range of tooth counts, in addition to edentulism, as thresholds of oral function and markers of oral disease outcomes. For example, the WHO set a defined aim of the retention of more than 20 natural teeth (rather than a complete dentition), the so-called 'shortened dental arch' as a goal for oral health in 1992. Research supports this number (when it includes all front teeth) as a “functionally intact” dentition (Gottfredsen and Walls, 2007), which plays an important role in consuming a healthy diet rich in fruits and vegetables, a satisfactory nutritional status, and an acceptable BMI (Marcenes et al., 2003). When such a shortened dental arch includes anterior and premolar teeth, in general, it is felt to fulfill the requirements of a functional dentition including aesthetics, oral comfort and mastication (Kanno and Carlsson, 2006). Other researchers have considered tooth loss severe if less than ten teeth are retained (Kassebaum et al., 2014). Both 10 and 20 teeth act as functional watersheds, highlighting the point that edentulism is merely the tip of the iceberg. That is, there is likely to be a large body of poor oral function and health “below the surface”. Svatun’s study is a case in point. Focusing on edentulism alone, only 13% of 35-44 year olds in their random sample were edentulous, however only 32% of their representative sample had more than twenty teeth (Svatun and Heloe, 1975). The design
of the first two waves of IDS-TILDA, did not include measures of dental treatment need, function and disease, but they are nevertheless needed. Future research is therefore needed to explore the oral health, disease, function and treatment need of this population at a more sensitive level, to establish what “lies beneath” the rather blunt measure of edentulism.

10.4 Dental attendance and pharmacological support

This study found that the overwhelming majority of people with ID reported seeing a dental care provider regularly (Chapter 7). Indeed, the majority of participants living in residential care, particularly, met the minimum standards (current at the time of data collection) laid out by the Health Information & Quality Authority (HIQA), which advised that adults with ID in residential care should be reviewed annually. Importantly, these standards have since been streamlined with other relevant guidance (Health Information & Quality Authority (HIQA), 2009a, Health Information & Quality Authority (HIQA), 2013, Health Information & Quality Authority (HIQA), 2016b) and no longer specify frequency of dental visits. Given the driving role of HIQA on disability services practice in Ireland, the impetus for accessing oral care services may therefore wane as focus shifts elsewhere. Future waves of IDS-TILDA will offer an opportunity to measure the impact of this and other policy innovations (HSE), 2011, Money et al., 2012). Recommendations for frequency of recall are made later in this chapter.

10.4.1 Appropriate services

When access to oral health services for adults with ID is considered, based on frequency of use, as it often is (Naseem et al., 2016), older adults with ID, would seem to present little cause for concern. However, as Owens and others point out, it is the appropriateness of care that is of paramount importance to this population (Owens, 2011, Mac Giolla Phadraig et al., 2014c, Mac Giolla Phadraig et al., 2015a). Therefore, frequent service use is not synonymous with suitable services. In fact, the appropriateness of services was brought into question by this study. For example, Chapters 8 and 9 paint a picture of infrequent use of pharmacological supports, other than oral sedation, which itself is most likely inappropriately prescribed (Dentistry, 2015, Scottish Dental Clinical Effectiveness Programme (SDCEP), 2017). Expert dentists felt that the use of sedation and GA observed in Chapter 8 underestimates the need and demand for these adjuncts,
suggesting that their provision is insufficient, which may promote inappropriate dental care. Access to a service that offers a range of supports is therefore recommended later in this chapter. Research offers further guidance in this regard (Mac Giolla Phadraig et al., 2014c).

Limited access to pharmacological supports increases the extent to which dentists rely on their communicative support skills to meet the support needs of adults with ID. The literature reviewed in Chapter 2 illustrates that this support could take a wide range of forms, much of which is not evidence based. Chapter 9 demonstrates that little of what is applied was learned formally.

10.5 Overall aim

This study set out to explore two seemingly distantly related phenomena: oral disease burden and oral health service use among adults with ID. However, they are more closely linked than they first may seem. In fact, edentulism acts as an accumulative marker of both: it is both the terminal outcome of oral diseases over the lifetime and an indicator of their management. As such edentulism acts as a barometer of both the experience and the outcomes of oral disease and its management.

10.5.1 Square pegs and round holes

While it would seem reasonable to assume that a group with high disease burden are outside of the reach of care, this research demonstrates that these poor outcomes are present alongside frequent use of dental services (Mac Giolla Phadraig et al., 2014a). Crucially, this study demonstrates that poor outcomes are present despite frequent use of dental services (Mac Giolla Phadraig et al., 2014a). This study therefore suggests that, even when applying as blunt an indicator as edentulism, regular access to dental services, as they are provided in Ireland, has not translated into the prevention or conservative treatment of oral disease. Rather, regular attendance occurred alongside severe tooth loss. Further, once all teeth were lost, people with ID were not rehabilitated. The demonstrable benefit from dental services is therefore unclear. Further research is needed to explore oral care delivery in greater detail. This is discussed later but suffice to say, honest debate regarding the purpose and benefits of dental services for people with ID in Ireland is overdue.
When considering the study as a whole, the data suggest that, for older adults with ID, oral health service use is high but outcomes are poor. Efforts to maintain oral health fail many. However, before expounding a conclusion further, the study’s strengths and limitations should be considered so as the reader can consider the validity of the results and conclusions, which they lead this author to.

10.6 Limitations

Whilst this study focuses on the two major causes of tooth loss: periodontal disease and caries, it is important to note that there are other biological (including tissue surface loss from grinding and acid erosion and soft tissue lesions) as well as functional (such as oral pain, drooling and self injury) oral conditions that impact on people with ID. Trauma to the dental and paradontal tissues from falls and epilepsy is also often seen in this population. These are outside of the focus of this study but at this point, their impact on people with ID as they age is recognised. Equally there are many other facets to health service use outside of frequency of care and support use, which this study did not address. This means that my research focus leaves much in the shadows. Nevertheless, it acts as a baseline and impetus for further research.

10.6.1 Internal validity of outcome measures

Many items in this study are self-reported, including dental attendance and dentate status. This is not ideal as respondents may misallocate themselves in their responses. Taking edentulism as an example, this could be as edentulous, when they have teeth Conceptually at least, this state (edentulism) is easily understood and attributable, but the validity of this item is unknown, as used here. Reasons for misattribution may include the use of proxies who supported many participants’ responses. That said, for this reason the protocol did ensure that participants were well known to proxy respondents. Responses were also at risk of misattribution and social desirability bias.

Nevertheless, a number of large epidemiological series use self-report generated edentulism data, particularly as a baseline measure (Vos et al., U.S. Department of Health and Health Education and Welfare, 1960, National Council on Ageing and Older People, 2004, Kassebaum et al., 2014) before further waves of clinical data collection. Examples
include the IMS 1979 Irish oral health data (from IMS, Department of Health and Children, 1981, cited in Whelton et al. (Whelton et al., 2007)) and the 1957-58 data set from the USA (U.S. Department of Health and Health Education and Welfare, 1960), which acts as a baseline against which later NHANES clinical datasets were compared (Whelton et al., 2007, Slade et al., 2014). The data reported in this thesis will have the same role. Indeed with the absence of recent oral health surveys in Ireland due to cost and possibly declining prominence, the value of these data may in fact increase over time. For example, these data report the first published results for almost twenty years, for dentate status for nationally representative samples with or without ID in Ireland.

10.6.2 External validity and other bias

The representative nature of the sampling in the quantitative phases of this study suggest strong external validity. However, there are some points to consider when considering the generalizability of these findings. In this chapter we report that edentulism occurs despite regular access to dental care. However, edentulism is irreversible. Therefore observed tooth loss may indicate historical rather than current disease burden and treatment trends. In other words, we do not know if tooth loss is recent or historical. Nevertheless, this study found continued disparity in edentulism among the youngest old. This would suggest on-going, or at least recent, trends rather than simply evidence of historic disease and treatment trends. Future waves of IDS-TILDA will offer more reliable evidence as incidence data emerge and historic comparisons are generated. Similarly, one could look at the data in this study and say that the service use data from Wave 1 (collected in 2010/2011) are no longer relevant to current services. However, Special Care services, shown to be disjointed at that time (Elliot et al., 2005, PA Consulting Group, 2010), are unlikely to have improved dramatically since, given the continued lack of policy innovation in this field, moratorium on recruitment within the Health Service and restriction of state supported schemes (Primary Care Reimbursement Service, 27th April 2010, Primary Care Reimbursement Service, 14th October 2010). Nevertheless, the author acknowledges that the cumulative and irreversible nature of edentulism does not allow one to say with certainty that the outcomes observed are related to current service delivery. Further research is planned for Waves 3 and 4 to explore current trends in greater detail and to draw conclusions with greater confidence.
10.6.2 Discerning effect from background trends

When considering the authors’ conclusion that poor outcomes have occurred despite frequent access to services, it should be acknowledged that some authors (such as Aubrey Sheiham and Liz Kay) hold that 'regular' dental check ups may lead to overtreatment and poorer dentate status for those who attend regularly. However, this argument is generally contained to the general population, who are at far lower risk of disease and its treatment. People with ID may not receive preventive treatment when they attend dentists (Scott et al., 1998, Pradhan et al., 2009b). Nevertheless, a number of high quality longitudinal studies suggest that, when frequent support with appropriate dental care is made available to adults with ID, tooth loss can be minimised. (Gabre et al., 2002, Gabre et al., 2001, Gabre, 2000, Gabre and Gahnberg, 1994). Supportive therapy for periodontal disease may also be effective at maintaining the dentition among adults with ID (Cichon, 2011). Therefore, there is potential to deliver demonstrable benefit to adults with ID if they are given access to appropriate dental care.

10.7 Strengths

Serial nature Researchers have explored serial study-sets to establish that edentulism is in rapid decline among the general population in Western society (Mojon et al., 2004, Müller et al., 2007, Slade et al., 2014). The existing literature makes it impossible to tell if this is the case within the population with ID for a number of reasons. Firstly, it is important to note that many data sets have purposefully excluded people with ID to simplify recruitment issues and facilitate ethical processes. Secondly, the trend within ID research over time has been away from studying institutionalised populations towards epidemiological studies of healthy young adults with ID, making historical comparison difficult. Representing a shift towards nationally representative samples, and by returning to the same sample serially, IDS-TILDA offers, for the first time, an opportunity to monitor edentulism (first by counting prevalence and soon by incidence) longitudinally and representatively, rather than by comparing sequential, distinct, cross-sectional samples.

Involvement Dental studies tend to not involve people with ID to any great degree (Whelan et al., 2010). This study, with an underpinning ethos of promoting
inclusion and participation, included people with ID at many stages to generate national prevalence data. By including people with ID in this research from its inception, this study has taken a key role in setting standards for research in this field. Perhaps most fundamentally, people with ID, who are often excluded from epidemiological research, were given the option to participate in research that will lead to improvements in their lives. They were also involved in selecting and piloting items for answering and then given the opportunity to report their experiences based on what was important to them. Despite the difficulties of research involving people with ID, the potential health benefits of research like this far outweigh the recruitment barriers experienced. The inclusive nature of this study is a definite strength and efforts will continue to maintain this element of the study in future waves of IDS-TILDA.
10.8 Recommendations

This section considers recommendations for policy, practice and research based on the outcomes from this study, acknowledging gaps in knowledge, where they exist. These recommendations (summarised in Figure 10.2) are aimed at a diverse readership because it is for all to advocate for, and enable, better outcomes and improved services.

10.8.1 Policy

1. Targeted, responsive and cohesive policy is needed to prioritise and plan for the oral health of people with ID over the life course.

The outcomes observed in this study have developed for many years within an inconsistent and fragmented service delivery model, which has evolved within an aged policy context (see Chapter 1). Fundamentally, this study demonstrates the need for policy innovation that prioritises oral health for people with ID over a lifetime. In the short term, there is a clear need to prioritise older people with ID in both oral health policies for older people and policy for people with disabilities. In the longer term, a life course approach is required to ensure preventable dental diseases are avoided by early interventions at all ages.

1.1 People with ID should be recognised as a subpopulation among both older adults and people with disabilities requiring targeted Oral Health Policy

Successful ageing for older adults with ID will be assured through policy protection. To meet the goals set out in Healthy Ireland (Ireland, 2013), policy should prioritise people with ID. To date, policy development has focused on older adults in general (Department of Health, 2015). This research suggests that it is vital that older adults with ID are salient among this group. Research has shown that there is a gradient of need within the ageing population, meaning that there are subgroups within this seemingly homogenous group, who should be targeted by policy to ensure equity and reduce overall levels of disease (Pretty, 2014). The subpopulation with ID should be prioritised, as one such group, given the disabling cycle observed in this thesis.
**Figure 10.2 Summary of recommendations**

<table>
<thead>
<tr>
<th>Policy</th>
<th>Practice</th>
<th>Research</th>
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<tr>
<td><strong>Targeted, responsive and cohesive policy is needed to prioritise and plan for the oral health of people with ID over the life course.</strong></td>
<td><strong>Ensure lifelong function for adults with ID by promoting personal and professional preventive and conservative oral care.</strong></td>
<td><strong>Research is needed to empower people with ID to maintain their health and function throughout life</strong></td>
</tr>
<tr>
<td>1.1 People with ID should be recognised as a subpopulation among both older adults and people with disabilities requiring targeted Oral Health Policy</td>
<td>2.1 Caries should be managed through risk assessment, prevention and minimally invasive care throughout life for people with ID.</td>
<td>3.1 There is a need for detailed study of the use of oral care services by people with ID.</td>
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<tr>
<td>1.2 Oral Health Policy should be developed based on a National Oral Health Needs Assessment using good data.</td>
<td>2.2 Periodontal disease should be prevented for people with ID throughout life through effective personal and professional care.</td>
<td>3.2 Basic and applied research is needed to explore non-pharmacological behaviour supports: their use, selection, application, teaching and effectiveness.</td>
</tr>
<tr>
<td>1.3 Policy should be aligned to ensure cohesive care for adults with ID across disability and dental contexts.</td>
<td>2.3 People with ID should be supported holistically to maintain a functional dentition throughout life.</td>
<td>3.3 Research is needed into the oral health and dental treatment of people with ID.</td>
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<td></td>
<td>2.4 Adults with ID should be empowered by ensuring control, choice and support in how they receive appropriate dental care.</td>
<td>3.4 Future waves of IDs TILDA should include oral assessment measuring oral status, disease, treatment need and function that is valid, reliable, feasible and minimises burden on participants.</td>
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The accumulative and irreversible nature of tooth loss means that lifelong measures to promote oral health are needed, to prevent negative outcomes in older age. ID specific oral health policy is therefore needed to promote oral health of people with ID across the lifespan. Such a policy will naturally encompass the broader population with disabilities, a group rumoured to be the focus of future policy development in Ireland. Given the clear focus on older adults in general in policy development thus far, policy makers should avoid accidentally developing a two-tier policy context, whereby older adults in general are prioritised and people with disabilities are effectively seen as a bolt-on, rather than an integral part of the whole. This, in a way, has been the prevailing model up to this point, where Special Care Services have been provided alongside the school based public dental service. Readers should be aware that this service runs with no key performance indicators that focus on Special Care Dentistry.

Population growth, improved neonatal medicine and longer life combine to increase the number of people living with ID. At the same time, dental services that have traditionally provided care for adults with ID, will come under increasing pressure from the growing population without ID in Ireland, especially those who go on to acquire multiple disabilities of older age. Together, these phenomena mean that the ratio of skilled dental providers to service users will decrease unless capacity increases. It is therefore reasonable to plan for increased numbers of dental care providers for these groups.

1.2 Oral Health Policy should be developed based on a National Oral Health Needs Assessment using good data.

Within the context of Healthy Ireland (Ireland, 2013), this study suggests that policy can meet its aims to increase the proportion of people who are healthy at all stages of life and to reduce health inequalities by providing appropriate services that offer a range of supports to adults with ID. To achieve this, policy makers must balance the reality of demographic trends and changing treatment need with service capacity. A series of sequential national oral health needs
assessments (OHNA) that consider demographics, skills mix, training needs, care pathways and assets when planning services should inform this process transparently and inclusively. Successful models of how such processes can successfully feed into how national dental services for people with ID are re-organised, communicated, planned, delivered and evaluated, are available (Greening and Jones, 2015). This thesis and ongoing data from IDS-TILDA will be invaluable for this process. Future waves of this study offer great potential to generate this knowledge in a timely manner for policy makers, ideally, alongside better health informatics based on data collected as part of daily practice.

This study shows that oral service use by adults with ID drops with age, probably due to increasing edentulism. In contrast and despite this decline in overall serviced use, the use of GA/sedation remains constant. The proportion accessing appropriate care is likely to drop further as people with ID shift towards community-based living and service-links, as observed in one case study (Stanfield et al., 2003). Community dwelling adults with ID have different oral health, service use and needs than those in congregated settings (Kendall, 1991, Gabre, 2000, Tiller et al., 2001, Mac Giolla Phadraig et al., 2014b). There is a need to monitor service use closely for this population, and in more detail than presented in this thesis, as this shift occurs so that services can be responsive to demographic shift. Future waves will explore service use in greater detail (See Appendix 2).

There is a need to reconsider how people choose their service providers. The integration of choice into a cohesive care pathway is challenging but important (Mac Giolla Phadraig et al., 2015a). Funding models will also need to be updated. In line with Value for Money (Money et al., 2012), appropriate person-centred incentives should be made available to dental care professionals, rather than institution level funding of dental care. This can be ensured by giving each individual with ID purchase power, so as they become consumers of dental services rather than service users.

It is evident from the data gathered as part of this thesis that training is needed to address many of the issues raised. Firstly, training should be made available at
undergraduate and professional levels to improve the requisite behaviour support, communication and clinical skills. This requires changes in curriculum and financing. Further, to develop leadership in this field, there is a need to ensure training of specialist dentists (Elliot et al., 2005). The reality is that these specialists are best placed within the public dental service and hospitals to support dentists with suitable skills and qualifications to offer a spectrum of care (Gallagher and Fiske, 2007). Career pathways should be established to attract and retain high quality talent in this field. Gaps analyses should focus on availability of facilities for sedation and GA and include a measure of dentists, and dental practices, suitably skilled in behaviour support (though this may be difficult to measure).

1.3 Policy should be aligned to ensure cohesive care for adults with ID across both disability and dental contexts.

Disability and dental policies should complement each other. Dental services have evolved symbiotically alongside but separate from disability services over the years. As evidenced by the many ID institutions that had a dental surgery on site and, more recently, by public dentists often registering and recalling patients through ID residential/day services. However, disability services in Ireland are changing dramatically due to the policies and standards, listed in Chapter 1, that speak to changes in day service use, residential arrangements and financial independence. These policies help to shape an independent future for adults with ID, in part, by promoting service provision in the community and financial independence. Logically, this will lead to changes in patterns of dental service use. This holds many benefits and is potentially emancipatory, but this shift of service model should be built on sound principles and care must be taken to ensure that dentists do not simply discharge people with ID ad hoc to general dental practices in the name of emancipation. We face a period of transition and transitions need to be managed.

Standards drive care in the disability sector (Health Information & Quality Authority (HIQA), 2013, Health Information & Quality Authority (HIQA), 2009a, Department of Justice Equality and Law Reform, 2005). Those standards
and related policies should recommend that oral health assessment be undertaken at an appropriate interval, determined with the person with ID. Further, dental data should be collected as a core measure of health and healthcare need and utilisation in personal plans, where appropriate.

What is clear from the preceding is that dental services, and the policies that shape them must change to improve outcomes for adults with ID in Ireland. This study suggests a need to integrate choice and a range of supports into new models of dental care delivery with improved prevention, conservation, and function as outcomes. The intention to address the health burden and disparities observed in this study should be consolidated within policy. This will require a commitment for change, from those who drive oral health policy in Ireland.

10.8.2 Practice
The outcomes observed can be attributed in part to failures of the strategies employed when preventing and managing oral disease as well as to poor access to services that largely operate ineffectually. Recommendations for change are given in this section for how oral disease is managed for those with ID in Ireland. The underlying principle of this section was captured long ago by Shapira and colleagues who stated that “Greater emphasis needs to be placed upon the importance of maintaining the natural dentition in populations [with ID] for as long as possible” (Shapira et al., 1998). In this section, we look at this problem and consider a responsive reorientation of health services and personal empowerment

2. Ensure lifelong function for adults with ID by promoting personal and professional preventive and conservative oral care.

This study identified that poor outcomes of oral disease burden and service use, are more common among older adults with ID. Therefore preventive, conservative and prosthodontic services will increasingly be required for this population to ensure equity. The two diseases of most importance in this regard are caries and periodontal disease.
2.1 Caries should be managed through risk assessment, prevention and minimally invasive care throughout life for people with ID.


Minimally invasive care Minimally invasive dentistry should be practiced when managing caries, if reasonable (Hayes et al., 2014a, Hayes et al., 2014b, Frencken et al., 2012, Banerjee, 2013, Molina et al., 2014). This approach involves “contemporary ultraconservative operative management of cavitated lesions requiring surgical intervention”. This focuses on the biological approach to caries management, recognizing the need for chemomechanical and conventional instrumentation to remove caries-infected dentine if needed, to improve infectious, restorative and biological outcomes (Banerjee, 2013, Hayes et al., 2014a, Hayes et al., 2014b)

Atraumatic Restorative Technique (ART) is a minimally invasive care approach in preventing and halting progression of dental caries. This technique is proving
especially effective and acceptable among people with disabilities compared to conventional restorations (Molina et al., 2014), as well as older people (Hayes et al., 2014a, Hayes et al., 2014b) although prejudices among dentists reduce its application (Molina et al., 2013). The approach consists of two components: sealing caries-prone pits and fissures and restoring cavitated dentine lesions with sealant-restorations (Frencken et al., 2012). ART restorations involve the removal of soft, completely demineralised carious tooth tissues with hand instruments, followed by restoration with Glass Ionomer Cement.

The indications for Stainless Steel Crowns (SSCs) should be extended to adults with ID (Randall, 2002), particularly with grossly carious permanent molars. Their application as single stage full coverage restorations is most attractive, especially when GA is required as an adjunct for care. However, research is needed to establish the long-term benefits of such approaches with this group. In addition, applying SSCs using the Hall Technique causes less pain, at least in children (Innes et al., 2015) For children, this technique involves no tooth preparation, reducing the aversive nature of dental restoration placement, For adults, where the occlusion is established and often compromised due to tooth migration, the Hall technique would require modification to obtain occlusal space for SSCs. Despite this drawback, this approach still offers many advantages for adults with ID.

When the vitality of the pulp is compromised or questionable, the tooth should be conserved by adopting conventional root canal therapy or vital pulp therapy (VPT) rather than extraction, where sufficient tooth structure exists. Vital pulp therapy may offer a cheaper and technically simpler conservative option for the retention of teeth that would have been previously extracted. Research is increasingly supporting this option among the general population (Ghoddusi et al., 2014).

Broad adoption of effective preventive and conservative caries management techniques will reduce tooth loss, thereby extending the functional life of the dentition. Minimally invasive alternatives to conventional caries management strategies (Hayes et al., 2014a, Hayes et al., 2014b, Mata and Allen, 2015) should
also reduce the averseness, length, cost and complexity of dental care and rehabilitation. These approaches may reduce the need for GA circumventing the often drastic treatment planning associated with it (McGeown and Nunn, 2015). These approaches offer viable alternatives to the traditionally destructive “Drill and Fill” approach, which brings teeth further down the restorative cascade and incrementally nearer extraction.

2.2 Periodontal disease should be prevented for people with ID throughout life through effective personal and professional care.

The key to successful prevention and treatment of periodontal diseases is maintaining low periodontal inflammation levels life-long. This is achieved through effective personal oral hygiene and professional preventive care (Scottish Dental Clinical Effectiveness Programme, 2014, Periodontology, 2016).

Steps to secure regular, effective personal care start in childhood. Families should be engaged and supported early to prioritise oral health, establish salutogenic practices and avoid sensitisation to oral procedures (Stapleton, 2015). Dental professionals should support people with ID and their families lifelong, to this end. While most children develop self care skills in their early school years, children and even older adults with ID often continue to rely on others to brush their teeth (Mac Giolla Phadraig et al., 2014b). Therefore, people with ID and those who care for them should be enabled to brush teeth effectively through skills building, motivation and support. At a population level at least, research has failed to show that this is achievable (Mac Giolla Phadraig et al., 2015b, Waldron et al., 2016). There is a need for radical innovation in how home care programmes are developed for this increasingly diverse community (Mac Giolla Phadraig et al., 2014b, Waldron et al., 2016). Interventions must be based on sound theory (Michie et al., 2011), inclusively developed and evaluated(Watt et al., 2006). This is a fundamental step in changing the outcomes witnessed in this study.

Assessment and management To secure regular, effective clinical care, periodontal screening should be provided regularly for all people with ID, unless
there is a defensible reason not to. Indices such as CPITN, Periodontal Screening Record or Basic Periodontal Examination should be used to indicate an appropriate periodontal management protocol (Ainamo et al., 1982). Dental professionals should then provide appropriate therapy, which may include oral hygiene advice, scaling, root surface debridement and surgery (Scottish Dental Clinical Effectiveness Programme, 2014, Periodontology, 2016). Periodontal tissues should be screened or fully assessed within eight weeks after treatment or at each dental review. Supportive periodontal therapy should be provided at intervals up to three monthly, for those who show signs of periodontitis (Periodontology, 2016).

While most of the steps outlined above are, in the author’s experience, within the basic skillset of dentists, they seldom apply such processes with adults with ID, despite the high rates of periodontitis seen in this population. Perhaps this is because assessment and treatment of the periodontium involves invasive instrumentation below and into the gingival tissues, which is anxiety and pain-provoking. Treatment often challenges patients’ coping skills and dentists’ support skills. Perhaps the failure to manage periodontitis (See Chapter 2), is in part due to the chronic nature of the disease. Unlike caries, the impact of not controlling periodontal care is distant. Conceptually, this separates the (in)action from the outcome (tooth loss). At the same time the costs (opportunity cost, coping capacity, difficulty in carrying out treatment, financial cost in private care) are immediate and recurring. This may dis-incentivise dentists from diagnosing and managing periodontal disease among adults with ID. Therefore, incentives are needed to motivate all involved in the prevention, detection and management of periodontitis. Financial incentives have been shown to promote conservative treatments in the Irish dental system (Woods et al., 2010) and should be considered to promote the maintenance, rather than extraction of periodontally involved teeth. That is, unless a sound rationale for removal is demonstrated.

2.4 People with ID should be supported holistically to maintain a functional dentition throughout life
An holistic approach should inform equitable care planning for rehabilitating function for people with ID, when they lose teeth. This study suggests that this may reduce difficulty eating. For people with ID, if teeth, anterior to the premolars, are lost, replacement should be offered as standard, if that is their wish. For partially dentate adults with ID, a shortened dental arch including all anterior teeth offers demonstrable benefit (Guiney et al 2011). To achieve this, the full range of removable and fixed prostheses should be considered on an individual basis.

When all teeth are lost, complete dentures are often offered to replace function for adults with ID. The results of this study suggest that for many, this is inadequate. For many years, for the general population, dentists have come to recognise that two-implant supported overdentures offer many advantages, including enhanced chewing efficiency and should therefore be considered the first line option for restoring the edentulous mandible (Feine et al., 2002, Thomason et al., 2009). Implant dentistry is not commonplace among adults with ID as evidenced by the handful of case studies reporting implant-supported prostheses for this group (Griess et al., 1998, Lopez-Jimenez et al., 2003, Oczakir et al., 2005, Durham et al., 2006, Feijoo et al., 2012, Ekfeldt et al., 2013, Romero-Perez et al., 2014). Implant supported overdentures on the mandible should be offered to edentulous people with ID unless there is a valid reason not to. Extrapolating from the literature referring to other older, frail dependent populations, Müller suggests that one should consider anatomical and physiological challenges along with the difficulties of processing for people with cognitive impairment. In addition, he urges consideration of the holistic needs of dependent, edentulous adults, who rely on others and present access and legal complexities (Müller, 2014). He also pointedly suggests delivering these prostheses early, to ensure that the perceived benefits outweigh the fear of surgery among people, who may have become accustomed to life without implants. Offering such treatments may not necessarily lead to uptake. Lessons can be learned in the roll-out of such options from the work of Brahm and colleagues in Sweden, where few people accepted offers of implant-retained prostheses (Brahm et al., 2009). People with ID, as we see in Chapter 5, should have information provided in an acceptable manner.
2.5 People with ID will be empowered through control, choice and support in how they receive appropriate dental care.

The challenge for the dental profession, and those who support them, is to make dental care attractive to older people with ID, by providing quality care. Suggestions for enhancing quality and appropriateness of dental services include increasing options across services so that people can choose services that meet their needs and expectations (Mac Giolla Phadraig et al., 2015a, Mac Giolla Phadraig et al., 2014c). Fundamentally, services must offer appropriate care that is acceptable to people with disabilities rather than, simply, what can be delivered.

A basic component of acceptable care is choice. People with ID have a right to choice, and their ability to exercise this right is likely to increase with the changes in their social settings and funding models that current policies promote ((HSE), 2012, Money et al., 2012). This includes the right to choose whether they attend the dentists or not, or whether they wish to wear dentures or not. New legislation in assisted decision making offers guidance in how choices can be supported depending on the capacity of the person involved in the decision (Department of Justice and Equality, 2015). This study suggests that when people with ID had choice, they were more likely to choose not to go to the dentists, especially when they had no teeth or saw no benefit from attendance. These seem like sensible choices but may carry risks. By way of guidance, this thesis suggests that frequency of dental service use should be based on choice, where this choice is informed by need. This approach aims to balance the needs and preferences of people with ID so as they are not neglected and, equally, that any positive discriminatory practice does not lead to over-burdened individuals and needless stretching of support capacity. This reflects NICE guidance, which suggests dental attendance on a frequency agreed with the patient, informed by professional risk assessment (National Institute for Health and Clinical Excellence, 2004). This contradicts advice given by the BSDH, which suggests that people with ID should have a dental review at least six-monthly (British Society for Disability and Oral Health/Faculty of Dental Surgery of Royal College of Surgeons of England, 2012). The reality, seen in the results of this
study, is that for many older people with ID, there is no need to see them that frequently, because it is too late. Their teeth are lost and they are not getting dentures.

Patients and their carers should be informed meaningfully regarding their options for care. While this study, in Chapter 5, focuses on the use of dentures, it is reasonable to assume poor communication of options across other treatments. This means that dentists should ensure that the full range of treatment options are meaningfully offered to patients with ID. This may require use of augmentative and alternative communication (Hollingsworth and Kalambouka, 2015).

On a related note, carers should be involved in decisions, where appropriate. This is because research shows that most dental appointments by people with ID, were made by, and attended in the company of, carers (Stanfield, Stanfield et al. 2003)(Cumella et al., 2000). These same carers report a perceived lack of need as the main reason for non-attendance by people with ID, in the UK at least (Cumella et al., 2000, Stanfield et al., 2003), meaning that it is important to consider their perceptions.

Dentists should apply evidence-based behaviour supports to enable care in a minimally restrictive manner that promotes independence and maximises learning of skills (Kemp, 2005), while ensuring successful treatment and minimising the aversive effect on future oral care (Lyons, 2009). There is also a need to make these and other supports accessible to adults with ID. This is considered further below.

The above will require specific expansion of current dental training in Ireland. Based on the findings of this study, dental teams require tiered training proportionate with the level of complexity of their role within a service that caters for older people with disabilities in a hub and spoke framework, as recommended by the Hanley Report. At a basic level, all dentists should have basic training regarding disability awareness, inclusive practice, communication skills, behaviour support to augment their general dental skills. This needs to be
implemented for all dental students with retrofitting for practicing general
dentists in tandem with training for the wider dental team. For dental
professionals who are likely to see more people with ID, particularly those with
mild to moderate disabilities, extended training at postgraduate level is needed.
This should include extensive training in basic communication and
communication-based support. This group also need to focus on minimally
invasive dental care and management of periodontal disease. Within the
imagined hub of the Hanley model a core group of Dental Specialists and
consultants are needed to orchestrate service delivery and support their network
of dental care providers and patients through advanced skills in Special Care
Dentistry. Such training is available in Trinity College Dublin. This training,
based on the findings of this research project should further focus on minimally
invasive dentistry, biological treatment of caries and pulpitis and implant
supported two implant over dentures.

10.8.3 Research

3. Research is needed to empower people with ID to maintain their health and function
throughout life

3.1 There is a need for detailed study of the use of oral care services by people with ID
This study focused on just two aspects of dental care: frequency of attendance
and use of supports. Nevertheless what actually happens at these visits and what
benefits arise from them are essentially unknown. Where research has explored
this, under 60% of adults with ID who attended the dentist for check ups
received scaling or cleaning (Scott et al., 1998, Pradhan et al., 2009b). This thesis
highlights the need to fully understand the role of dental attendance in
preventing or contributing to tooth loss among this population. The quality of
any treatment provided is also unknown. Chapter 2 demonstrates that there are
no reliable data on the service use profile of adults with ID in Ireland. Therefore
research is needed to inform policy. To achieve this, IDS-TILDA will expand its
dental items in Wave 3 to include (See Appendix 2):

1. Assessment of which dental services people with ID use in Ireland
2. Identify which treatments are provided when adults with ID attend the dentists and how they were perceived.

3. Assess items relating to oral health related quality of life to explore the impact of oral health and service use.

3.2 Basic and applied research is needed to explore non-pharmacological behaviour supports: their use, selection, application, teaching and effectiveness.

In Chapter 9, a need for a better understanding of which interventions work where, when and for whom, is evident. To begin with, there is a need to standardise the terminology and classification of behaviour support techniques. Chapter 2 clearly shows that available evidence is scarce and limited by non-standardised terminology, study design, small samples and variable outcome measures. There is a need for research that uses standardised terminology, strong designs, adequate samples and validated outcome measures. Clinicians and researchers in this field should offer guidance based on evidence but this is lacking, leading many to offer advice based on experience or preference. Consensus is needed. Research should also aim to establish the role of communication, behaviour and oral problems on the need for supports and their value in predicting need for supports. The experiences of dentists, recorded in chapter 9, suggest a need for research into the use and knowledge of behavioural supports among dentists in Ireland. Further research into how supports are selected, applied and taught is also needed.
3.3 Research is needed into the oral health and dental treatment of people with ID

Edentulism should be assessed longitudinally to monitor prevalence and establish incidence, specifically for people with ID. Similarly, evidence is needed to measure the effectiveness and acceptability of strategies recommended here for the management of caries and periodontal disease. There is also a need to explore the functional impact of tooth loss and replacement among this group. This should include measures of quality of life, masticatory function, food selection and preparation, nutritional status, specific feeding difficulties such as food packing, choking, and medical sequelae such as pneumonia and constipation. Further, experimental research is needed to explore the causative effect of denture wear on nutritional outcomes (McKenna et al 2012).

3.4 Future waves of IDS-TILDA should include an oral assessment measuring oral status, disease, treatment need and function that is valid, reliable, feasible and minimises burden on participants.

Fundamentally, the main limitations of this study revolve around how oral health was assessed: edentulism was used as a proxy for oral disease burden, and this was self-reported. For the results of this study to develop the science in this area, data are needed that measure oral health at a less granular level, and that are clinically valid. In addition, the focus should broaden to include not only disease but also clinical measures of normative treatment need and function. To this end, a novel index has been developed by this research team and colleagues from Trinity College Dublin to measure the oral status, disease, treatment need and function of this population, specifically in a longitudinal setting, with multiple non-dental assessors. A concurrent study, led by Dr Nurul Ishak, is exploring the validity and reliability of this index with a view to inclusion as part of a health fair in Wave 4 of IDS-TILDA.

10.9 Conclusions

This thesis suggests the need for dramatic change in how oral diseases are managed and services are delivered among adults with ID in Ireland. In this study we found that edentulism was common among older adults with ID meaning that the oral disease burden experienced by older adults in Ireland was disproportionately greater among those with ID. In this thesis, total tooth loss
led to increased risk of functional impairment, evident in increased risk of
difficulty eating among adults with ID, who seldom wore prostheses. Edentulism
also represents a measure of cumulative treatment over a lifetime and thus a
partial assessment of dental services.

This study suggests that, oral health service use is high but outcomes are poor,
for older adults with ID. From this perspective, the model of care experienced
by adults with ID in Ireland over their lifetime, which involved regular
attendance with inappropriate support, is therefore not conducive to health or
function. Therefore, this study suggests a need for a new model of care,
incorporating choice of appropriate services and focusing on prevention and
conservative treatment, with appropriate support. People with ID, for whom the
impact of such burden is amplified, should therefore be prioritised, at a policy
level, for targeted services to reduce such disparity.

While this study does not describe how services are delivered to, and experienced
by, older people with ID in Ireland, it demonstrates a need for further research
to understand what, where, how and by whom dental care is delivered to adults
with ID in Ireland. This study demonstrates the need for ongoing monitoring of
oral health service use in future waves of IDS-TILDA to measure the impact of
policy response. This study also demonstrates that there is a need to further
explore oral health and treatment need in finer detail, using clinical data captured
by validated instruments. These data should measure the levels of disease,
treatment need and oral health related function of this cohort. This study
demonstrates the importance of ongoing research of this kind, to promote oral
health within disability policy.

The methods applied here give a unique perspective on oral disease burden and
illuminate the need for innovative care focused on keeping teeth in place for as
long as possible. Efforts to achieve this must offer choice of appropriate services
and treatment with suitable support and communication. This will require
commitment from key players.

End.
Chapter 11 References


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12 Appendices
Appendix 1.

<table>
<thead>
<tr>
<th>Section/topic</th>
<th>#</th>
<th>Checklist item</th>
<th>Page #</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>TITLE</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Title</td>
<td>1</td>
<td>Identify the report as a systematic review, meta-analysis, or both.</td>
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<tr>
<td><strong>ABSTRACT</strong></td>
<td></td>
<td></td>
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</tr>
<tr>
<td>Structured summary</td>
<td>2</td>
<td>Provide a structured summary including, as applicable: background; objectives; data sources; study eligibility criteria, participants, and interventions; study appraisal and synthesis methods; results; limitations; conclusions and implications of key findings; systematic review registration number.</td>
<td>66-68</td>
</tr>
<tr>
<td><strong>INTRODUCTION</strong></td>
<td></td>
<td></td>
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</tr>
<tr>
<td>Rationale</td>
<td>3</td>
<td>Describe the rationale for the review in the context of what is already known.</td>
<td>66</td>
</tr>
<tr>
<td>Objectives</td>
<td>4</td>
<td>Provide an explicit statement of questions being addressed with reference to participants, interventions, comparisons, outcomes, and study design (PICOS).</td>
<td>Protocol</td>
</tr>
<tr>
<td><strong>METHODS</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Protocol and registration</td>
<td>5</td>
<td>Indicate if a review protocol exists, if and where it can be accessed (e.g., Web address), and, if available, provide registration information including registration number.</td>
<td>66</td>
</tr>
<tr>
<td>Eligibility criteria</td>
<td>6</td>
<td>Specify study characteristics (e.g., PICOS, length of follow-up) and report characteristics (e.g., years considered, language, publication status) used as criteria for eligibility, giving rationale.</td>
<td>67</td>
</tr>
<tr>
<td>Information sources</td>
<td>7</td>
<td>Describe all information sources (e.g., databases with dates of coverage, contact with study authors to identify additional studies) in the search and date last searched.</td>
<td>66-67</td>
</tr>
<tr>
<td>Search</td>
<td>8</td>
<td>Present full electronic search strategy for at least one database, including any limits used, such that it could be repeated.</td>
<td>66-67</td>
</tr>
</tbody>
</table>
Study selection 9 State the process for selecting studies (i.e., screening, eligibility, included in systematic review, and, if applicable, included in the meta-analysis).

Data collection 10 Describe method of data extraction from reports (e.g., piloted forms, independently, in duplicate) and any processes for obtaining and confirming data from investigators.

Data items 11 List and define all variables for which data were sought (e.g., PICOS, funding sources) and any assumptions and simplifications made.

Risk of bias in individual studies 12 Describe methods used for assessing risk of bias of individual studies (including specification of whether this was done at the study or outcome level), and how this information is to be used in any data synthesis.

Summary measures 13 State the principal summary measures (e.g., risk ratio, difference in means).

Synthesis of results 14 Describe the methods of handling data and combining results of studies, if done, including measures of consistency (e.g., I^2) for each meta-analysis.

<table>
<thead>
<tr>
<th>Section/topic</th>
<th>#</th>
<th>Checklist item</th>
<th>Page #</th>
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</thead>
<tbody>
<tr>
<td>Risk of bias across studies</td>
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<td>Specify any assessment of risk of bias that may affect the cumulative evidence (e.g. publication bias, selective reporting within studies)</td>
<td>protocol</td>
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<tr>
<td>Additional analyses</td>
<td>16</td>
<td>Describe methods of additional analyses (e.g., sensitivity or subgroup analyses, meta-regression), if done, indicating which were pre-specified.</td>
<td>protocol</td>
</tr>
<tr>
<td>RESULTS</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Study selection</td>
<td>17</td>
<td>Give numbers of studies screened, assessed for eligibility, and included in the review, with reasons for exclusions at each stage, ideally with a flow diagram.</td>
<td>70</td>
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<tr>
<td>Study characteristics</td>
<td>18</td>
<td>For each study, present characteristics for which data were extracted (e.g., study size, PICOS, follow-up period) and provide citations.</td>
<td>71-81</td>
</tr>
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<td>Risk of bias within studies</td>
<td>19</td>
<td>Present data on risk of bias of each study and, if available, any outcome level assessment (see item 12).</td>
<td>82-88</td>
</tr>
<tr>
<td>Results of individual studies</td>
<td>20</td>
<td>For all outcomes considered (benefits or harms), present, for each study: (a) simple summary data for each intervention group (b) effect estimates and confidence intervals, ideally with a forest plot.</td>
<td>82-88*</td>
</tr>
<tr>
<td>Synthesis of results</td>
<td>21</td>
<td>Present results of each meta-analysis done, including confidence intervals and measures of consistency.</td>
<td>NA</td>
</tr>
<tr>
<td>Section</td>
<td>Item</td>
<td>Content</td>
<td>Page</td>
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<tr>
<td>Risk of bias across studies</td>
<td>22</td>
<td>Present results of any assessment of risk of bias across studies (see Item 15).</td>
<td>82-88</td>
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<tr>
<td>Additional analysis</td>
<td>23</td>
<td>Give results of additional analyses, if done (e.g., sensitivity or subgroup analyses, meta-regression [see Item 16]).</td>
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</tr>
<tr>
<td>DISCUSSION</td>
<td>24</td>
<td>Summarize the main findings including the strength of evidence for each main outcome; consider their relevance to key groups (e.g., healthcare providers, users, and policy makers).</td>
<td>88-101</td>
</tr>
<tr>
<td>Summary of evidence</td>
<td>25</td>
<td>Discuss limitations at study and outcome level (e.g., risk of bias), and at review-level (e.g., incomplete retrieval of identified research, reporting bias).</td>
<td>101-103</td>
</tr>
<tr>
<td>Limitations</td>
<td>26</td>
<td>Provide a general interpretation of the results in the context of other evidence, and implications for future research.</td>
<td>103-104</td>
</tr>
<tr>
<td>Conclusions</td>
<td>27</td>
<td>Describe sources of funding for the systematic review and other support (e.g., supply of data); role of funders for systematic review</td>
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<td>FUNDING</td>
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<td>Funding</td>
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<td>Describe sources of funding for the systematic review and other support (e.g., supply of data); role of funders for systematic review</td>
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<tr>
<td></td>
<td></td>
<td><em>Meta-analysis not undertaken (Moher et al., 2009)</em></td>
<td></td>
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### Appendix 2

#### Table S3a Wave 1 Computer Assisted Personal Interviews Oral Health Items

<table>
<thead>
<tr>
<th>Oral Health</th>
<th>Item, instructions to data collector and response categories</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>INTRO:</strong> I would now like to ask you some questions about your oral health.</td>
<td></td>
</tr>
<tr>
<td><strong>IWER:</strong> Which best describes the teeth you have?</td>
<td></td>
</tr>
<tr>
<td><strong>IWER:</strong> READ OUT AND CODE THE ONE THAT APPLIES</td>
<td></td>
</tr>
<tr>
<td>I have all my own natural teeth – none missing</td>
<td>(Go to PH 38)</td>
</tr>
<tr>
<td>I have my own teeth, no dentures – but some missing</td>
<td>(Go to PH 38)</td>
</tr>
<tr>
<td>I have dentures as well as some of my own teeth</td>
<td>(Go to PH 38)</td>
</tr>
<tr>
<td>I have no teeth but wear full dentures</td>
<td>(Go to PH 38)</td>
</tr>
<tr>
<td>I have no teeth but don’t wear/use dentures</td>
<td>(Go to PH 38)</td>
</tr>
<tr>
<td>I have dentures but don’t wear them</td>
<td>(Go to PH 36)</td>
</tr>
<tr>
<td><strong>Unclear response</strong></td>
<td>97 (Go to PH 35)</td>
</tr>
<tr>
<td><strong>Don’t know</strong></td>
<td>98 (Go to PH 35)</td>
</tr>
<tr>
<td><strong>Refused to answer</strong></td>
<td>99 (Go to PH 35)</td>
</tr>
</tbody>
</table>

| **PICR:** I would now like to ask you some questions about your oral health. |
| **IWER:** SHOW CARD PH12. |
| **IWER:** How often do you brush your teeth or dentures/have them brushed OR how often do you clean your mouth/have it cleaned for you? |
| **IWER:** READ OUT AND CODE THE ONE THAT APPLIES |
| Once or more a day | (Go to PH 40) |
| 2 to 6 times per week | (Go to PH 40) |
| Once per week | (Go to PH 40) |
| Less than once per week | Go to PH 40 |
| Never | Go to PH 40 |
| **Unclear response** | Go to PH 40 |
| **Don’t know** | Go to PH 40 |
| **Refused to answer** | Go to PH 40 |
### PH39
(Adapted from SLAN)

**IWER**: SHOW CARD PH13.

**IWER**: When was the last time you visited a dentist or dental hygienist?

**IWER**: READ OUT AND CODE THE ONE THAT APPLIES

<table>
<thead>
<tr>
<th>Option</th>
<th>Code</th>
<th>(Go to PH 40)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Less than a year ago</td>
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<td></td>
</tr>
<tr>
<td>1-2 years ago</td>
<td>2</td>
<td></td>
</tr>
<tr>
<td>More than two years</td>
<td>3</td>
<td></td>
</tr>
<tr>
<td>Never</td>
<td>4</td>
<td></td>
</tr>
<tr>
<td>Unclear response</td>
<td>97</td>
<td></td>
</tr>
<tr>
<td>Don’t know</td>
<td>98</td>
<td></td>
</tr>
<tr>
<td>Refused to answer</td>
<td>99</td>
<td></td>
</tr>
</tbody>
</table>

### PH41
(Adapted from OK Health Check)

**IWER**: SHOW CARD YN1.

**IWER**: Do you have any obvious problem with teeth or gums? (e.g. painful or sensitive teeth, bleeding gums when you brush your teeth)

**IWER**: PROBE IF NECESSARY - 'WOULD YOU SAY YES OR NO?'

<table>
<thead>
<tr>
<th>Option</th>
<th>Code</th>
</tr>
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<tbody>
<tr>
<td>Yes</td>
<td>1</td>
</tr>
<tr>
<td>No</td>
<td>5</td>
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<tr>
<td>Unclear response</td>
<td>97</td>
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<tr>
<td>Don’t know</td>
<td>98</td>
</tr>
<tr>
<td>Refused to answer</td>
<td>99</td>
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</table>

### PH43
Any Other Information (Oral Health):
Table S3b Wave 2 Computer Assisted Personal Interviews Oral Health Items

<table>
<thead>
<tr>
<th>Oral Health</th>
<th>Item, instructions to data collector and response categories</th>
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<tbody>
<tr>
<td>PH34</td>
<td>INTRO: I would now like to ask you some questions about your oral health.</td>
</tr>
<tr>
<td></td>
<td>IWER: SHOW CARD PH11*.</td>
</tr>
<tr>
<td></td>
<td>IWER: Which best describes the teeth you have?</td>
</tr>
<tr>
<td></td>
<td>IWER: READ OUT AND CODE THE ONE THAT APPLIES</td>
</tr>
<tr>
<td></td>
<td>I have all my own natural teeth – none missing</td>
</tr>
<tr>
<td></td>
<td>I have my own teeth, no dentures – but some missing</td>
</tr>
<tr>
<td></td>
<td>I have dentures as well as some of my own teeth</td>
</tr>
<tr>
<td></td>
<td>I have no teeth but wear full dentures</td>
</tr>
<tr>
<td></td>
<td>I have no teeth but don’t wear/use dentures</td>
</tr>
<tr>
<td></td>
<td>I have dentures but don’t wear them</td>
</tr>
<tr>
<td></td>
<td>Unclear response</td>
</tr>
<tr>
<td></td>
<td>Don’t know</td>
</tr>
<tr>
<td></td>
<td>Refused to answer</td>
</tr>
<tr>
<td>PH35</td>
<td>IWER: Have you had dentures fitted by a dentist?</td>
</tr>
<tr>
<td></td>
<td>Yes</td>
</tr>
<tr>
<td></td>
<td>No</td>
</tr>
<tr>
<td></td>
<td>Unclear response</td>
</tr>
<tr>
<td></td>
<td>Don’t know</td>
</tr>
<tr>
<td></td>
<td>Refused to answer</td>
</tr>
<tr>
<td>PH36</td>
<td>IWER: Why do you not wear your dentures?</td>
</tr>
<tr>
<td></td>
<td>I did not like having dentures</td>
</tr>
<tr>
<td></td>
<td>The dentures did not fit properly</td>
</tr>
<tr>
<td></td>
<td>The dentures caused pain/ discomfort</td>
</tr>
<tr>
<td></td>
<td>I wasn’t able to put them in.</td>
</tr>
</tbody>
</table>
I wasn’t able to care for them

I lost them

Other, please tell us

**PH37 (IDS-TILD A)**

IWER: Would you like to have replacement of your missing teeth?

Yes [1]

No [5]

Unclear response [97]

Don’t know [98]

Refused to answer [99]

**PH38 (Adapted from SLAN)**

IWER: How often do you brush your teeth or dentures/have them brushed OR how often do you clean your mouth/have it cleaned for you?

IWER: READ OUT AND CODE THE ONE THAT APPLIES

<table>
<thead>
<tr>
<th>Frequency</th>
<th>Code</th>
</tr>
</thead>
<tbody>
<tr>
<td>Once or more a day</td>
<td>1</td>
</tr>
<tr>
<td>2 to 6 times per week</td>
<td>2</td>
</tr>
<tr>
<td>Once per week</td>
<td>3</td>
</tr>
<tr>
<td>Less than once per week</td>
<td>4</td>
</tr>
<tr>
<td>Never</td>
<td>5</td>
</tr>
</tbody>
</table>

Unclear response [97] (Go to PH 40)

Don’t know [98] (Go to PH 40)

Refused to answer [99] (Go to PH 40)

**PH39 (Adapted from SLAN)**

IWER: When was the last time you visited a dentist or dental hygienist?

IWER: READ OUT AND CODE THE ONE THAT APPLIES

<table>
<thead>
<tr>
<th>Frequency</th>
<th>Code</th>
</tr>
</thead>
<tbody>
<tr>
<td>Less than a year ago</td>
<td>1</td>
</tr>
<tr>
<td>1-2 years ago</td>
<td>2</td>
</tr>
<tr>
<td>More than two years</td>
<td>3</td>
</tr>
<tr>
<td>Never</td>
<td>4</td>
</tr>
</tbody>
</table>

Unclear response [97] (Go to PH 41)

Don’t know [98] (Go to PH 40)

Refused to answer [99] (Go to PH 40)
### PH40

**IWER:** Can you tell me the reasons why you haven't seen a dentist or dental hygienist recently?

**IWER:** READ OUT AND CODE ALL THAT APPLY

- The environment is not accessible e.g. the chair is too high, no wheelchair access [ ] 1
- I think I don’t need to go [ ] 2
- I don’t get enough time at my appointment [ ] 3
- Waiting list is too long [ ] 4
- I am afraid of the dentist [ ] 5
- I need help to get there, but this is not available [ ] 6
- Other please tell us

### PH41

(Adapted from OK Health Check)

**IWER:** Do you have any obvious problem with teeth or gums? (e.g. painful or sensitive teeth, bleeding gums when you brush your teeth)

**IWER:** PROBE IF NECESSARY - ‘WOULD YOU SAY YES OR NO?’

- Yes [ ] 1
- No [ ] 5

### PH42

(Adapted from OK Health Check)

**IWER:** Do you use any of the following to make dental treatment easier?

**IWER:** READ OUT AND CODE ALL THAT APPLIES

- Verbal reassurance [ ] 1 (Go to PH 43)
- Oral medication such as Diazepam [ ] 2 (Go to PH 43)
- Gas and air sedation [ ] 3 (Go to PH 43)
<table>
<thead>
<tr>
<th></th>
<th></th>
<th>(Go to PH 43)</th>
</tr>
</thead>
<tbody>
<tr>
<td>IV sedation</td>
<td>4</td>
<td></td>
</tr>
<tr>
<td>General Anesthesia</td>
<td>5</td>
<td></td>
</tr>
<tr>
<td>Don’t use any of these</td>
<td>6</td>
<td></td>
</tr>
<tr>
<td>Other, please tell us</td>
<td></td>
<td>(Go to PH 43)</td>
</tr>
</tbody>
</table>

PH43  Any Other Information (Oral Health):
**Table S3c Wave 3 Computer Assisted Personal Interviews Oral Health items**

<table>
<thead>
<tr>
<th>Code &amp; Source</th>
<th>Item, instructions to data collector and response categories</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>INTRO:</strong> I would now like to ask you some questions about your oral health. <strong>IWER</strong>: SHOW CARD PH11*. <strong>IWER</strong>: Which best describes the teeth you have? <strong>IWER</strong>: READ OUT AND CODE THE ONE THAT APPLIES</td>
<td></td>
</tr>
<tr>
<td>PH34 (Adapted from SLAN)</td>
<td>I have all my own natural teeth – none missing 1 (Go to PH 38)</td>
</tr>
<tr>
<td></td>
<td>I have my own teeth, no dentures – but some missing 2 (Go to PH 38)</td>
</tr>
<tr>
<td></td>
<td>I have dentures as well as some of my own teeth 3 (Go to PH 38)</td>
</tr>
<tr>
<td></td>
<td>I have full dentures 4 (Go to PH 38)</td>
</tr>
<tr>
<td></td>
<td>I have no teeth or dentures 5 (Go to PH 38)</td>
</tr>
<tr>
<td></td>
<td>Unclear response 97 (Go to PH 38)</td>
</tr>
<tr>
<td></td>
<td>Don’t know 98 (Go to PH 38)</td>
</tr>
<tr>
<td></td>
<td>Refused to answer 99 (Go to PH 38)</td>
</tr>
<tr>
<td><strong>IWER</strong>: SHOW CARD PH12. <strong>IWER</strong>: How often do you brush your teeth or dentures/have them brushed OR how often do you clean your mouth/have it cleaned for you? <strong>IWER</strong>: READ OUT AND CODE THE ONE THAT APPLIES</td>
<td></td>
</tr>
<tr>
<td>PH38 (Adapted from SLAN)</td>
<td>Once or more a day 1 (Go to PHNEW1)</td>
</tr>
<tr>
<td></td>
<td>2 to 6 times per week 2 (Go to PHNEW1)</td>
</tr>
<tr>
<td></td>
<td>Once per week 3 (Go to PHNEW1)</td>
</tr>
<tr>
<td></td>
<td>Less than once per week 4 (Go to PHNEW1)</td>
</tr>
<tr>
<td></td>
<td>Never 5 (Go to PHNEW1)</td>
</tr>
<tr>
<td></td>
<td>Unclear response 1 (Go to PHNEW1)</td>
</tr>
<tr>
<td></td>
<td>Don’t know 98 (Go to PHNEW1)</td>
</tr>
<tr>
<td></td>
<td>Refused to answer 99 (Go to PHNEW1)</td>
</tr>
</tbody>
</table>
**IWER: SHOW CARD PHXX.**

**IWER: Which of these tools do you use to clean your mouth?**

**IWER: READ OUT AND CODE ALL THAT APPLY**

<table>
<thead>
<tr>
<th>Tool Description</th>
<th>Code</th>
</tr>
</thead>
<tbody>
<tr>
<td>I use floss / an interdental cleaner</td>
<td>1</td>
</tr>
<tr>
<td>I use a standard toothbrush</td>
<td>2</td>
</tr>
<tr>
<td>I use a modified toothbrush (like a superbrush or a brush with a special handle)</td>
<td>3</td>
</tr>
<tr>
<td>I use an electric toothbrush</td>
<td>4</td>
</tr>
<tr>
<td>None of the above (please specify)</td>
<td>5</td>
</tr>
</tbody>
</table>

**Go to PH_117.3**

**IWER: SHOW CARD PHXX.**

**IWER: What best describes the physical assistance you get from someone else to clean your teeth?**

**IWER: READ OUT AND CODE THE ONE THAT APPLIES**

<table>
<thead>
<tr>
<th>Assistance Description</th>
<th>Code</th>
</tr>
</thead>
<tbody>
<tr>
<td>I clean my teeth without assistance</td>
<td>1</td>
</tr>
<tr>
<td>I clean my teeth with assistance</td>
<td>2</td>
</tr>
<tr>
<td>I am totally dependent on another person to clean my teeth</td>
<td>3</td>
</tr>
<tr>
<td>I have teeth but do not clean them</td>
<td>4</td>
</tr>
<tr>
<td>I don’t have any teeth</td>
<td>9</td>
</tr>
</tbody>
</table>

**Go to PH11X**

**IWER: Which of these best describes your tooth cleaning?**

**IWER: READ OUT AND CODE ALL THAT APPLY**

<table>
<thead>
<tr>
<th>Tooth Cleaning Description</th>
<th>Code</th>
</tr>
</thead>
<tbody>
<tr>
<td>I don’t allow people to clean my teeth at all</td>
<td>1</td>
</tr>
<tr>
<td>I allow people to clean my teeth when I am held still</td>
<td>2</td>
</tr>
<tr>
<td>I bite down and this interferes with tooth cleaning</td>
<td>3</td>
</tr>
<tr>
<td>I gag and this interferes with tooth cleaning</td>
<td>4</td>
</tr>
<tr>
<td>Another person cleans my teeth after I clean them</td>
<td>5</td>
</tr>
<tr>
<td>Another person places their hand over my hand to improve my cleaning</td>
<td>6</td>
</tr>
<tr>
<td>I am supervised while I clean my teeth</td>
<td>7</td>
</tr>
<tr>
<td>I am reminded / encouraged me to clean my teeth</td>
<td>10</td>
</tr>
</tbody>
</table>

**Go to PH39**

**Adapted from SLAN**

**IWER: SHOW CARD PH13.**

**IWER: When was the last time you visited a dentist or dental hygienist?**

**IWER: READ OUT AND CODE THE ONE THAT APPLIES**
### PHNE W3 (IDS-TILDA)

**IWER:** What treatment did the dentist give you in the last year?

**IWER:** Read out and code all that apply

<table>
<thead>
<tr>
<th>Treatment</th>
<th>Code</th>
</tr>
</thead>
<tbody>
<tr>
<td>Check up – and was unable to properly examine my mouth</td>
<td>1</td>
</tr>
<tr>
<td>Check up – and was able to properly examine my mouth</td>
<td>2</td>
</tr>
<tr>
<td>Gum cleaning (Scaling)</td>
<td>3</td>
</tr>
<tr>
<td>Other preventive work like fissure sealants / fluoride varnish</td>
<td>4</td>
</tr>
<tr>
<td>Extraction</td>
<td>5</td>
</tr>
<tr>
<td>Filling</td>
<td>6</td>
</tr>
<tr>
<td>Other, please tell us</td>
<td></td>
</tr>
</tbody>
</table>

**Unclear response** | 97  
**Don’t know** | 98  
**Refused to answer** | 99  

### PHNE W4 (TILDA Wave 3)

**IWER:** In the past 6 months, have any problems with your mouth, teeth or dentures caused you to have any of the following?

**IWER:** Read out and code all that apply

<table>
<thead>
<tr>
<th>Problem</th>
<th>Code</th>
</tr>
</thead>
<tbody>
<tr>
<td>Difficulty eating food</td>
<td>1</td>
</tr>
<tr>
<td>Difficulty speaking clearly</td>
<td>2</td>
</tr>
</tbody>
</table>

**Unclear response** | 97  
**Don’t know** | 98  
**Refused to answer** | 99  

317
Problems with smiling, laughing and showing teeth without embarrassment  □ (Go to PHNEW5)

Problems with emotional stability, for example, becoming more easily upset than usual  □ (Go to PHNEW5)

Problems enjoying the company of other people such as family, friends, or neighbors  □ (Go to PHNEW5)

None of these  □ (Go to PHNEW5)

British Regional Heart Study – 30 year follow up https://www.ucl.ac.uk/pcph/research-groups-themes/brhs-pub/tools/pdfs/Rescreen_2010_Final_UCL_Logo.pdf

---

**IWER:** [SHOW CARD YXXX].

**IWER:** Do you currently have any of the following?

**IWER:** READ OUT AND CODE ALL THAT APPLY

<table>
<thead>
<tr>
<th>Condition</th>
<th>Code</th>
</tr>
</thead>
<tbody>
<tr>
<td>Dental decay</td>
<td>1</td>
</tr>
<tr>
<td>Gum disease</td>
<td>2</td>
</tr>
<tr>
<td>Bad breath</td>
<td>3</td>
</tr>
<tr>
<td>Dental Pain</td>
<td>4</td>
</tr>
<tr>
<td>Unclear response</td>
<td>97</td>
</tr>
<tr>
<td>Don’t know</td>
<td>98</td>
</tr>
<tr>
<td>Refused to answer</td>
<td>99</td>
</tr>
</tbody>
</table>

**PHNE W6** *(TILDA Wave 3; Modified)*

**IWER:** If you needed a routine visit for dental care, which one of the following would you attend?

**IWER:** READ OUT AND CODE ALL THAT APPLY

<table>
<thead>
<tr>
<th>Option</th>
<th>Code</th>
</tr>
</thead>
<tbody>
<tr>
<td>A general dental practice as a private patient</td>
<td>1</td>
</tr>
<tr>
<td>A general dental practice through the Medical Card or PRSI scheme</td>
<td>2</td>
</tr>
<tr>
<td>A private dentist comes to my home/work</td>
<td>3</td>
</tr>
<tr>
<td>A HSE dentist at my home/work</td>
<td>4</td>
</tr>
<tr>
<td>A HSE dentist at the local clinic</td>
<td>5</td>
</tr>
<tr>
<td>A dental hospital</td>
<td>6</td>
</tr>
<tr>
<td>A dental technician</td>
<td>7</td>
</tr>
<tr>
<td>Unclear response</td>
<td>97</td>
</tr>
<tr>
<td>Don’t know</td>
<td>98</td>
</tr>
<tr>
<td>Refused to answer</td>
<td>99</td>
</tr>
</tbody>
</table>

**PHNE W7** *(TILDA Wave 3)*

**IWER:** Would you say your dental health (mouth, teeth and/or dentures) is

**IWER:** READ OUT AND CODE THE ONE THAT APPLIES

<table>
<thead>
<tr>
<th>Rating</th>
<th>Code</th>
</tr>
</thead>
<tbody>
<tr>
<td>Excellent</td>
<td>1</td>
</tr>
<tr>
<td>Very good</td>
<td>2</td>
</tr>
</tbody>
</table>

318
<p>| | | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Good</td>
<td></td>
<td>3 (Go to PH 43)</td>
</tr>
<tr>
<td>Fair</td>
<td></td>
<td>4 (Go to PH 43)</td>
</tr>
<tr>
<td>Poor</td>
<td></td>
<td>5 (Go to PH 43)</td>
</tr>
</tbody>
</table>

PH43  Any Other Information (Oral Health):
Appendix 3: Figure S9 Extended coding framework

Motivation
- Reducing restrictive supports
- Tools are complementary
- Tools are an alternative
- Tools reduce need for
- Ego
- Driven by Dentist
- Vocation
- Success
- Success is complex
- Acceptable
- Failure
- Back up available
- Lower expectation for success
- Acknowledge limits

Application
- Acceptable when indicated
- Create an atmosphere
- Versatility
- Play
- Carers
- Team
- Attuning

Selection
- Skill Development
- Education
- Experiential learning
- Adapt paedeiatric skills
- Trial and Error
- Observation
- Maturation
- Cost to patient with no reward
- Avoid

Assessment
- Information
- Patient / Carer
- Organised / disorganised
- Receptive non-verbal communication
- Knowledge
- Rational
- Intuitive
- Adaptability
- To situation
- To patient response

Leadership & communication
- Expressive communication skills
- Modify non-verbal communication
- Organised / disorganised
- Swapping out
- Nurse
- Team

Cost to patient
- Demoralising to dentist
- Adaptability
- To situation
- To patient response

Adapt
- paediatric skills
- UG/PG

Aptitude
- Intuition
- Education