

What It's Like to Grow Older: The Aging Perceptions of People With an Intellectual Disability in Ireland

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Abstract

The Intellectual Disability Supplement to The Irish Longitudinal Study on Ageing is a national longitudinal study on the aging of people with an intellectual disability (ID) using a randomly selected sample of people with ID over the age of 40. In total, 367 people with an ID completed the aging perception self-report only section. Over 57% of people described their health as very good to excellent with no significant difference in health perceptions found for gender, level of ID, or living circumstance. Exploring people's perceptions utilizing PASW Text Analytics for Surveys 4.1 perceptions often supported negative views of the consequences of aging. These findings suggest challenging negative aging concepts is essential to promote positivity with associated improved health and wellbeing.

Key Words: *intellectual disability; aging perceptions; successful aging; aging; aging experience; text analysis*

Global aging has seen an unprecedented increase over the last number of decades. In fact, the World Health Organization (WHO) estimates this trend to continue, and, by 2050, there will be 2 billion people over the age of 60 years worldwide (Beard et al., 2011). Until recently, the lifespan of people with an intellectual disability (ID) was far shorter than the lifespan of the general population. Now, the number of older people with an ID worldwide is steadily increasing. In Ireland, for example, figures from the National Intellectual Disability Database (NIDD) show an average 30% increase in the population of people with an ID over the age of 35 years from 1974 to 2010 (Kelly & Kelly, 2011). Such a remarkable success story is reflective of a better education, public health improvements, economical contributions, and medical advancements. However, adding years to life does not only reflect success on its own. Indeed, the European Senior Citizens Union (2003) advocates for not only adding years to life but life to years. Over the past decade, the World Health Organization (WHO) has focused policy development toward a life course approach to active aging (WHO, 2002, 2011, 2012). In this, the WHO has identified broad determinants of aging well and has suggested that these determinants extend major influence on how

people age. One of these major determinants of aging well is how a person perceives themselves as they grow older. The WHO suggests that a person's perceptions of aging can influence how they approach their later years and the likelihood of them experiencing positive outcomes as they age (WHO, 2002).

Aging well is unique for each individual and can depend on past and present experiences, socioeconomic status, environment, or health (Shephard, 1997). It is becoming increasingly recognized that one's own perceptions of aging also influences how one ages, and much research has been undertaken on aging perceptions among the general population (Bowling, 2008; Dillaway & Byrnes, 2009; Duay & Bryan, 2006; Horton, Baker, Côté, & Deakin, 2008; Lee & Fan, 2008; Sargent-Cox, Anstey, & Luszcz, 2012; Wurm & Benyamini, 2014). In summary, these articles reported that positive perceptions most often result from an interactive process that involves the surrounding environment, images, and life experience with an older generation. It is notable that Huber (2005) specifically identified the power of media images as strongly influential in shaping how people perceive themselves. Unfortunately, contemporary Western society is dominated by messages placing value on

visual perfection, with visible signs of aging in human beings seen as synonymous with decline and loss (Blaikie, 1999; Ellison, 2014). Older people therefore are often represented as frail, forgetful, and sickly (Featherstone & Hepworth, 2005). Likewise, older people with an ID are often viewed as nonproductive vulnerable adults who require care, especially as they age (Davies, 2013; Llewellyn, Balandin, Dew, & McConnell, 2004). This situation is often exacerbated by individuals with ID being overprotected (Jackson & Irvine, 2013; Todd, 2003), withheld from experiencing risk of life, and having minimal experience of control of their lives (Wehmeyer & Abery, 2013).

There is also evidence that positive perceptions of self in turn reflect positively on one's attitude, approach to life, and overall well-being (Sargent-Cox et al., 2012; Sarkisian, Prohaska, Wong, Hirsch, & Mangione, 2005). Studies such as Levy and Myers (2005) and Levy, Slade, and Kasl (2002) have noted that holding positive perceptions of aging directly contribute to aging well. Jenkins (2010) highlighted that for people with ID, negative roles and experiences in their lives often affect their sense of self, and "their passage into old age may not be so significant" (Jenkins, 2010, p. 37). The concept of aging perceptions is attracting more attention, and as one of the pillars of healthy aging and a determinant of aging well, it deserves closer scrutiny. For people with ID, however, there is a paucity of studies on the perceptions of aging, and subsequently identifying the influences on aging well is an area that has been relatively unexplored.

Finally, consideration of the perceptions of aging among people with ID in Ireland at this time is particularly pertinent. The Irish Longitudinal Study on Ageing (TILDA) recently measured older people's perceptions of aging (Barrett, Savva, Timonen, & Kenny, 2011). The measure used was the Ageing Perception Questionnaire (Barker, O'Hanlon, McGee, Hickey, & Conroy, 2007), an instrument guided by Leventhal's self-regulation model, which posits that an individual's ability to reflect on actions and consequences guides their response to illness and change (Leventhal & Cameron, 1987). The model is attractive precisely because reflection may influence the balancing of both positive and negative aspects of perceptions of aging. The value of this model has not been established among people with ID. The Intellectual Disability Supplement of TILDA (IDS-TILDA) has chosen to explore this topic among

people with ID in a more open-ended manner (McCarron et al., 2011) to better capture the dimensions of the aging representative among this population. The aim of this article therefore, was to explore and describe the perceptions of aging among people with ID, including their concerns and expectations, and to present a comprehensive representation of their aging experience.

IDS-TILDA

The IDS-TILDA study is a national longitudinal study on aging and ID. After pilot testing, the first wave of the study commenced in 2010. A random sample of 753 participants—comprising 8.9% of the total registered population of people with an ID aged 40 years and over—took part in the study. On core demographics, the sample drawn and consented is representative of the larger population frame (NIDD) from which it is drawn. More women ($n = 415$; 55%) than men ($n = 338$; 45%) came from a variety of living circumstances that included independent/semi-independent living (5.1%); living at home with family (11%); community living (34.1%); and living in a residential (49.5%), which implies living in a center along with more than 20 other people. Most people (99%) were not married, and although 23% reported they were in some form of employment, on further examination just 6.6% ($n = 50$) were in paid employment. Overall education levels attained were low, with a significant number (27.4%; $n = 206$) having never attended any formal education and a further 26.3% ($n = 198$) having benefited only from some primary education. All levels of ID were represented in the sample, with the highest percentage (44%; $n = 346$) falling within the moderate range ID. Table 1 presents an overall demographic profile of the participants in IDS-TILDA, and the demographics of those who answered the aging perception section are also presented.

For the purposes of the study, ID is defined as a disability characterized by significant limitations of both adaptive behavior and intellectual functioning (Schalock, Luckasson, & Shogren, 2007). The internationally recognized terms mild, moderate, severe and profound ID are used as descriptive terms only.

Methods

Sampling and Informed Consent

People age 40 years and over registered on the NIDD of Ireland were randomly selected for the

Table 1
Overall Demographical Characteristics of Participants from IDS-TILDA and Those Who Self-Reported for the Aging Perception Section

Demographic characteristics		Total no. IDS-TILDA (<i>N</i> = 753)		Total no. aging perceptions		Total per question
		%	<i>n</i>	%	<i>n</i>	
Gender	Male	45	338	42.5	156	<i>n</i> = 367
	Female	55	415	57.4	211	
Age	40–49 years	36	271	36.8	135	<i>n</i> = 367
	50–64 years	46	346	46.5	171	
	65+ years	18	136	14.9	55	
Level of ID*	Mild	23.9	166	44.0	142	<i>n</i> = 322
	Moderate	46.5	323	53.1	171	
	Severe/Profound	29.5	206	4.6	15	
Living Circumstances	Independent/Semi Independently	5.1	38	17.2	63	<i>n</i> = 367
	Living at home with Relatives	11	82	10.4	38	
	Community Setting	34.1	257	47.7	175	
	Residential Setting**	49.5	373	22.9	84	
Occupational Status	Employed***	23.1	174	40.1	146	<i>n</i> = 364
	Unemployed	43.2	250	3.3	12	
	Retired	6.1	46	8.2	30	
	Unable to work due to long term illness	37.6	283	48.4	176	
Self-Rated Health****	Excellent	12.2	91	14.8	53	<i>n</i> = 358
	Very Good	36.2	270	43	154	
	Good	37.6	278	34.6	124	
	Poor	10.6	79	5.6	20	
	Very Poor	3.8	28	2.0	7	
Level of Education*****	No Education/Did not attend school	27.4	206	10.2	34	<i>n</i> = 333
	Some Primary Education-not completed	26.3	198	38.4	128	
	Primary or equivalent	19.7	148	32.4	108	
	Junior/Intermediate Certificate	3.0	10	2.4	8	
	Leaving Certificate	0.4	3	0.6	2	
	Certificate/Diploma/Degree	0.8	6	1.8	6	
	Other	9.6	72	14.1	47	

*Not all participants identified their level of ID □ missing obs 58.

**Residential setting refers to a situation where there are over 20 people living in the one setting e.g. large congregated organisation.

***Employment was defined to include supported employment schemes, sheltered workshop/training schemes, apprenticeships and temporarily away from work.

****Not all people reporting completed the self-rated health section □ 7 obs missing.

*****Not all people answered both the education and ageing perception questions.

IDS-TILDA study. Ethical approval was obtained from the university and the individual service providers. A gatekeeping system, in the form of the database administrators of each region in the

country, was used to maintain anonymity of the potential participants until they had furnished consent. The invitations were sent to the database coordinator, who addressed and forwarded them to

the individuals. To fully promote the inclusion of people with all levels of ID, all material sent was in an “easy-to-read” format emphasizing plain language and pictorial representation (compiled and reviewed in collaboration with a number of advocacy groups composed of people with ID). The invitation consisted of an easy-to-read cover letter and information booklet on the study, an easy-to-read consent form, stamped addressed envelope, and a family information pack. The purpose of the family information pack was to inform the participant’s families on the study and provide them with the opportunity to support their family member in making the decision to take part or not. To indicate their wish to participate, each selected person was invited to return their easy-to-read written consent.

Interviewer Training

Each field researcher was chosen because of their extensive experience interviewing and working with people with ID. After completion of a structured comprehensive training program on the administration of the overall protocol, the field researchers “shadowed” an experienced interviewer to enhance the standardization of the face-to-face interview.

Data Collection

On receipt of the written consent form, the interviewer telephoned the potential participant to thank and inform them of the next steps of the study. A preinterview questionnaire was then sent for completion, after which the interviewer arranged for a face-to-face interview at a date and time that were convenient for and chosen by the participant. The use of computer-assisted personal interviewing (IBM, 2011) at the face-to-face interview facilitated verbatim recording of open-ended responses as well as completion of closed-ended questions. The face-to-face interview took approximately 90 minutes to complete. The style and support required during the interview were determined by the participant’s level of communication and level of ID, a self-report-only interview, an interview supported by a proxy, or an interview completed by a proxy on behalf of the person with ID (the proxy was a person who knew the person with ID a minimum of 6 months).

The questions addressed demographic characteristics; cognitive health maintenance (measured

using the Test for Severe Impairment, a validated and reliable instrument among people with ID; Albert & Cohen, 1992; Cosgrave et al., 1998; Mulryan et al., 2009); happiness; physical health; activities of daily living and instrumental activities of daily living and related support needed; mental health; employment situation; lifelong learning; day services; behavioral health; social participation; social connectedness; life satisfaction; aging perceptions; personal choices; and sources of income.

Specific sections of the overall IDS-TILDA protocol, including the Ageing Perception Section, were self-report-only; therefore, this article addresses the demographic characteristics and reported aging perceptions of those individuals ($n = 367$) who were able to independently answer at least some of these questions. On the day of the interview, consent was verbally confirmed by the interviewer, and interviewers reaffirmed willingness to proceed before each section of the interview.

Aging Perception Section

The aging perception section consisted of seven closed and five open-ended questions (see Table 2) that included opportunities for both positive and negative opinions on aging. Initial questions were developed to represent key constructs of aging perceptions and are reflective of the broader aging literature (Atkinson, 2005; Bowling, 2008; Buys et al., 2008; Levy & Langer, 1994; Levy & Myers, 2004; Levy et al., 2002; McCarron & Lawlor, 2003) and recommendations of the IDS-TILDA international scientific advisory committee. Next, consistent with the projects values framework of choice and empowerment (McCarron et al., 2011), questions were presented and further refined by focus groups of people with ID and through pilot testing. The focus groups helped both in determining ID-specific areas to be included in the interview protocol and in testing out questions in ways likely to encourage the fullest response by the greatest number of people with an ID (McCarron et al., 2009). As Stancliffe (1999) noted, “the individual is the best source of information provided that s/he can understand the questions and respond without marked bias” (p. 192). To that end, questions were finalized to capture people’s beliefs about aging and its impact on all life domains.

Data Analysis

All data were entered into SPSS version 19 for the purposes of analysis, and all verbatim text from

Table 2
Aging Perceptions

Closed questions	Reply options		
How would you describe yourself?	Young	Middle age	Old
Are there any good things about getting older?	Yes	No	Don't know
Would you say as you get older, things are ☐ ?	Better	Worse	Stays the same
Do you have any concerns or worries about getting older?	Yes	No	Don't know
Do you think older people can do most things like work, go out, play sport, or use the computer?	Yes	No	Don't know
Do you think older people can support you?	Yes	No	Don't know
How often did R receive assistance with answers?	Never	A few times	Most/all of the time
Open questions (text typed verbatim)			
When you hear someone described as "old" what do you think that it means?			
What would you say are the good things about getting older?			
What might these concerns be?			
What activities do you think older people like to do?			
Have you any other information to add?			

the open-ended questions were then exported into PASW Text Analytics for Surveys 4.1 software (TA; IBM, 2010a, 2010b). This software permits unstructured survey data to be transformed using natural language processing technologies; the extraction of core concepts and the enabling of linguistic analysis thus allowed the discovery of the sentiment and the development of insight as the open-ended responses were analyzed (Pennebaker, Mehl, & Niederhoffer, 2003). In other words, TA permits questions to be answered about "what themes occur, what semantic relations exist among the occurring themes and what network positions are occupied by such themes or theme relations" (Roberts, 2000, p. 270).

In TA, open-ended text data were analyzed and mined to extract key ideas and concepts. The program allows the linguistic analysis and combination of automated linguistic and statistical techniques to identify patterns and contexts that provide insights into (in this case) the nuances of people's perceptions of aging. The process involved a five-step approach, starting with the initial importing of the survey data into the application. Next, the automatic extractor engine extracted the most salient terms and patterns expressed for each open-ended question. This was followed by preliminary analysis and refinement, which involved reviewing the extracted terms and fine-tuning the extractions by directly manipulating the libraries containing the linguistic constructs such as word

types, terms, and synonyms. The fourth step involved categorizing the findings, which entailed the researcher manually or automatically using classification techniques to create categories of the data. Finally the categories were imported back into SPSS for further analysis and graphing (IBM, 2010a, 2010b).

Applying these techniques, concepts, and patterns were first extracted, and these key terms were refined and expanded by the researcher to fine-tune the libraries and dictionaries constructed for this dataset. Responses were then categorized manually using category rules, code frames, and other category-building techniques. Categories represented higher-level concepts that captured the chief ideas and attitudes on aging expressed by the participants who share closely related concepts, opinions, or attitudes. Categories were then independently and manually reviewed by two independent reviewers who checked for coding errors and reaffirmed the categorizations (IBM, 2010a, 2010b; Mason, 2010). Common errors included spelling mistakes and unusual terminologies that were uncategorized. The independent reviewers then compared final categorizations before agreement was finalized. The TA software also captured people's shared opinions and enabled mapping of the most common links through Web visualizations. Such an approach enabled the demonstration of multiconceptual opinions about growing older among people with ID.

Table 3
People's Perception of Their Own Age and Health

	40–49 Years	50–64 Years	65+ Years
Perceived age by actual age (<i>n</i> = 345)			
Perceived age			
Young			
(<i>n</i> = 130)	48.4% (<i>n</i> = 63)	33.6% (<i>n</i> = 44)	18% (<i>n</i> = 23)
Middle aged			
(<i>n</i> = 130)	34.7% (<i>n</i> = 45)	39.5% (<i>n</i> = 51)	25.7% (<i>n</i> = 34)
Old			
(<i>n</i> = 85)	20.0% (<i>n</i> = 17)	42.0% (<i>n</i> = 37)	38.0% (<i>n</i> = 31)
Self-reported health by age (<i>n</i> = 339)			
Excellent			
(<i>n</i> = 50)	23.6% (<i>n</i> = 29)	10.8% (<i>n</i> = 18)	6.0% (<i>n</i> = 3)
Very good			
(<i>n</i> = 145)	39.0% (<i>n</i> = 48)	45.8% (<i>n</i> = 76)	42.0% (<i>n</i> = 21)
Good			
(<i>n</i> = 119)	32.5% (<i>n</i> = 40)	37.3% (<i>n</i> = 62)	34.0% (<i>n</i> = 17)
Fair			
(<i>n</i> = 19)	2.4% (<i>n</i> = 3)	5.4% (<i>n</i> = 9)	14.0% (<i>n</i> = 7)
Poor			
(<i>n</i> = 6)	2.4% (<i>n</i> = 3)	0.6% (<i>n</i> = 1)	4.0% (<i>n</i> = 2)

Not all participants provided information for each of the items in the questionnaire. These missing data are highlighted in the demographic table and include level of ID and people's reported self-rated health.

Results

Demographics

Respondents to the aging perceptions questions (see Table 1) were between 41–90 years of age, with a mean age of 54.1 years (*SD* = 8.836). Most people (57.8%; *n* = 207) reported experiencing very good to excellent health with just a small number (2%; *n* = 6) reporting their health as poor. No significant differences in health perceptions were found for gender, level of ID, and type of residence. Significant differences at the .05 level were found for age ($F = 4.236$, $df = 2$, $p = .015$). Those in the oldest age category rated their health significantly worse than those in the other two age groups. Although people perceived themselves fairly healthy overall, many reported chronic health concerns, including mental health (43.3%, *n* = 159) and neurological conditions (29.2%, *n* = 107) as well as joint (20.2%, *n* = 74), gastrointestinal

(15.5%, *n* = 57), and thyroid conditions (21.8%, *n* = 47).

Overall Aging Perceptions

People were asked if they felt young, middle aged, or old, and the majority of respondents (70%; *n* = 260) reported perceiving themselves as young to middle aged, with just 23% (*n* = 85) describing themselves as old. As can be seen in Table 3, 20.0% (*n* = 17) of people ages 40–49 years felt they were old, whereas 43.7% (*n* = 57) of people age 65+ years thought of themselves as young to middle aged. When asked how they felt about things as they got older, most people (71.6%; *n* = 263) felt things stayed the same or got better as they advanced in years, with only 20.2% (*n* = 71) feeling things in their life deteriorated. People also rated the own health, and overall the majority reported good to very good health, with the largest proportion of better health reported by the 50–64-year-olds (see Table 3).

When asked if there were good things about getting older (see Table 4), opinions were split fairly evenly, with 49% (*n* = 146) offering a positive opinion and 47% (*n* = 142) indicating a negative opinion. A small number of people (4.0%; *n* = 12)

Table 4
Dichotomous Closed Aging Perception Items

Question	Yes		No		Did not understand the question		No. of respondents
	%	<i>n</i>	%	<i>n</i>	%	<i>n</i>	
Are there any good things about getting older?	48.8	146	47.4	142	4.0	12	300
Do you have any concerns or worries about getting older?	24.7	90	71.7	261	3.6	13	364
Do you think older people can do most things like work, go out, play sport or use computer?	62.6	209	33.5	112	3.9	13	334
Do you think older people can support you?	64.7	211	29.4	96	5.8	19	326

did not fully understand the question. Regardless of gender, 24.7% of people ($n = 90$) reported having concerns about growing older. Most people (62.6%; $n = 209$) felt that older people could do most things such as play sport, work, or use the computer, and a further 64.7% ($n = 211$) felt that older people could provide support for them.

Aging Perception Categories

The TA program identified a number of categories from the open-ended responses (see Table 5). Considering the four open-ended questions, the results are presented under the following headings (a) the meaning of growing old, (b) good things about aging, (c) concerns about growing older, and (d) activities older people like to do. It is noted that on occasion people said or noted something that did not relate to the topic in question. On these occasions the category “not applicable” is utilized; for example, one person said “I like smoking” when asked what growing old meant to her; this reply did not fit into any of the categories.

The meaning of growing old. Overall 38.8% of people identified physical changes as their predominant perception of what it meant to grow older. One participant summed this up by saying “people change and move slower they get wrinkly and their hair turns grey and they get crippled.” From the vignettes, women made a greater connection with the occurrence of physical change as a descriptor of aging compared with men. Associating aging with “grey hair, wrinkles, or difficulty in getting about” are examples of the 39% of comments made by women.

In total, 19% of respondents identified chronological age as a marker of aging, succinctly expressed by one participant as growing old being “someone in their 70s.” Others related aging to the passing of time: “getting on in life, people of 50 are old.” Growing older was also associated with a time of sadness in one’s life, with 17% of the responses making comments such as “I think it’s pretty awful, but I suppose there is nothing that we can do about it,” or “you haven’t got long to live.”

Unique to the TA software is the ability to map Web visualizations to examine shared themes and portray the multicategorical nature of responses (Mason, 2010) in this study, allowing deeper examination of people’s opinions and strengthening the overall representation of the voices of people with ID. As an exemplar, figure 1 is the Web visualisation graph of people’s perception of what growing old means to them. The threads or connecting lines in the web identify their shared responses, and the thickness of each line represents the number of participants who shared particular response categories. For example, those who identified “physical change” as one of their concepts of aging also related strongly with “time passing” and “feelings of sadness,” suggesting an overall negative view of what growing old meant. A representative quote from one of these participants to portray this is “a person in their 80s, some people live in a nursing home, can’t live by themselves, some people go into a hospital and don’t come home.” Here the person equates aging to a “chronological marker” and having to live in a nursing home, which may imply the loss of

Table 5
Text Analysis Categories for Each of the Open Questions, in Descending Order of Frequency

When you hear someone described as old, what do you think it means?			What would you say are the good things about getting older?			What might be your concerns about getting older?			What activities do you think older people can do?		
Category	No. of responses	%	Category	No. of responses	%	Category	No. of responses	%	Category	No. of responses	%
Physical changes	139	38.83	Social activities	28	22.58	Physical changes and illness	31	29.52	Social activities	88	23.34
Age related	68	18.99	Wisdom	19	15.32	Fear and vulnerability	23	21.9	Sports and physical activity	82	21.75
Sadness	61	17.04	Fulfillment	16	12.9	Death and Bereavement	20	19.05	Not capable	47	12.47
Don't know	26	7.26	Independence	16	12.9	Loss of independence	20	19.05	Sedentary	40	10.61
Family	26	7.26	Miscellaneous	14	11.29	Future care	8	7.62	Domestic and shopping	32	8.49
Positive	16	4.47	Retirement	10	8.06	Depression	3	2.86	Cognitive activities	25	6.63
Retirement	16	4.47	Free time	8	6.45				Unrestricted activities	21	5.57
Not applicable	6	1.68	Don't know	7	5.65				by age	16	4.24
			Assistance	6	4.84				Arts and crafts	15	3.98
									Work	6	1.59
									Don't know	5	1.33
									Not applicable		
Total Number Responses	358				124			105			377
Total Number Respondents	281				110			75			256

Note. Count implies the number of responses for each of the categories.

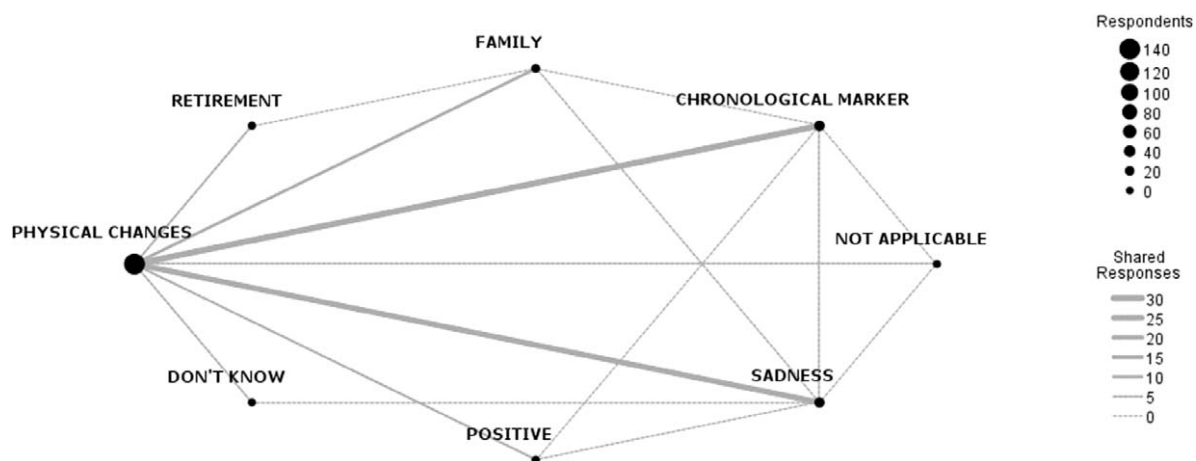


Figure 1. Web visualisation of the relationships between concepts describing what growing old means to people.

independence and also indicates a physical change and, finally, death. The visual representation of such multicategorical responses further demonstrates the depth of thought among people with ID. Atkinson (2005) argued for the importance of obtaining and exploring these insights from people with ID as it has the potential to empower this marginalized group.

“Physical changes” was the highest-rated response associated with aging regardless of gender, age, type of residence, or level of ID. Interestingly, of those who related age to an older family member, 58% of the comments were made by people in the youngest age group (40–59 years), for example, “my father, he has pains and aches and grey hair.” Retirement-related comments were predominately made by men ages 50–64 years, although many were not employed. The second most frequently identified category was a chronological marker. As an exemplar, one person noted “I think of someone in their 60s, 70s or 80s, I see them in Mass and they would have a walking stick.” This was commonly identified across all age groups: 40–49 years (17%), 50–64 years (20%), and 65 years+ (25%).

Given research that suggests that a more positive self-perception of aging is associated with more favorable functional health, a more positive outlook on one’s own aging, and healthier outcomes (Bowling, 2008; Levy et al., 2002a), self-rated health was also considered in relation to the aging themes. To that end, no matter how people rated their health, “physical changes” emerged as the highest ranked category of people’s perception

of aging. Notably, of those who rated their health as poor, 40% ranked the categories “sadness” and “physical changes” as their predominant meaning of aging, as did 28% of those who rated their health as fair. On the other hand, associating aging with a chronological marker ranked second for those who rated their health as good to excellent, and the category “sadness” ranked third for those with good, very good, and excellent self-rated health.

Good things about aging. A number of people did identify good things about growing old; 77% ($n = 110$) provided examples of “increased social activities,” “having wisdom,” “being more fulfilled,” “being independent,” and “retirement.” Collectively, people identified “engaging in social activities” as their highest-ranked positive aging category, with 23% of comments noting activities like “you can travel” or “you have time to dance and you can sing,” or “time to go for a walk and for getting out.” “Wisdom” was the second-highest-rated category, with 15% of respondents identifying that as they got older they felt they had wisdom both to offer and to gain. One respondent captured this eloquently when he stated that “experience and brain power is what is important to me; I’m the oldest here and X is 19, I can help him talking to him and telling him about things.” Such statements strengthen the idea that older people are an invaluable resource and that people with ID have something to contribute.

Concepts of “fulfilment” and “independence” also emerged as categories describing what was good about growing older; one participant noted that

their “good thing” was “helping around the house and getting more confident.” Retirement as a category emerged as a preferred “good thing” of growing older, with 80% of the retirement comments made by men such as “when a person gets older they can retire and relax and take it easy.” “Free time” was more highly rated by women, with 75% of the free time category comments made by them; one participant noted “I’m able to do things that I want to do now because I’m older.” In terms of self-rated health, 50% of those who rated their health as poor identified retirement as their good thing, but only 6.7% of those who rated their health as excellent viewed retirement in this way. Conversely 33% of those who rated their health as excellent identified independence as their highest-ranked good thing about aging but no one with poor health agreed independence was their good thing. Finally, no matter how people rated their health they identified social activities as a good thing about getting older.

Concerns about growing older. People were also asked to identify what concerned them most about growing old. Twenty-five percent of respondents ($n = 75$) identified they had concerns about growing older. Categories to emerge included concerns about physical change and illness, fears of what growing older might bring, loss of independence, and death.

People’s highest ranked concerns were “physical change and illness” (29.5%); one participant explained their concerns by saying “well if I got to 99 I would be hardly able to walk, cause I see other people walking very slow when, if I get older I’d really slow down and I have to be careful and you’d have to be careful getting off the bus and when I’d be out walking.” Another clearly identified particular conditions she feared and the consequences that worried her: “If you got cancer or a stroke or a heart attack anything might happen, and if anything happened to my family I wouldn’t be able to go to them anymore.” People’s fear of what might happen as they got older left them feeling vulnerable; one person said, “I’m nervous about really old, frightened about it, scared that I might be sick.” Finally, some participants expressed their vulnerability and sense of despair when they stated, “I’d be a nuisance to some people,” or “I don’t want to be a burden to anyone, and I don’t want to be in a nursing home at all.”

“Death and bereavement” was another concern to emerge, with 19% of participants’ comments

reporting issues like fear of their own death: “I don’t want to die. I would like to live for a long time,” and death of close family or friends: “When the old people die, when they go up under the clouds; I don’t like it at all. When you saw someone die, if you could cry very hard, I wouldn’t like it at all. I’d cry without stopping.” Loss of immediate carers was particularly noted and related to concerns for their future care. One participant said “I’m concerned about who will look after [me] when mammy and daddy pass on,” and “I worry about where you will be when you might be, like a nursing home. I don’t want to be in one of those places. I would worry about that.”

There were no consistent category rankings for this question across self-rated health. For those who rated their health as excellent, “death and bereavement” (31%) emerged as the highest concern and, of this group, 23% also noted depression as a concern. Those who rated their health as very good were more likely to highly rank the theme of “physical changes or illness” (34%) that may occur as one ages and, for another 23%, “loss of independence.” “Death and bereavement” (50%) emerged as the highest-ranked theme for those who rated their health as good. Finally, for those who rated their health as poor, “loss of independence” was the only theme that emerged.

Activities older people like to do. In total 71% ($n = 256$) of respondents identified social activities and physical or sports type activities as things older people like to do. One person noted: “I know older people who can do more things than younger people they are able to go out socializing and meet friends and enjoy themselves going to bingo. They would be able to do activities.” The importance of getting involved and meeting people socially was evident: “They can go on day trips and stuff to get them out of the house. Going into the day centers and meeting people like, if they were lonely or sad.” However, a small number of participants (12.5%) commented that older people were not capable of engaging in activities: “Old people are not able for outings, as you know. They couldn’t walk at all. They’d stay inside all day and look at television all day.”

Just over 10% of participants’ comments highlighted sedentary activities such as watching TV, listening to the radio, or sitting around relaxing; men and those under 50 years old tended to highlight sports and physical activities, and women and those over 50 years old preferred more social activities. Regardless of self-rated

health status, respondents largely supported the notion that social activities and sports or physical pursuits were activities older people were capable of undertaking.

Discussion

The opportunity to actively engage in life, both physically and socially, were among the strongest themes to emerge in participants' views of what they believe life will be like as they age. Such desires and attitudes are consistent with other research on successful aging (Dew, Llewellyn, & Gorman, 2006; Walker, 2002). The WHO (2002, 2011, 2012) has identified that older people who are prepared for later life approach this phase with greater confidence, do not vary significantly in their ability to cope, and are better able to adjust to the challenge. The data from this study support previous findings that people with ID are not adequately prepared for later life issues (Buys, Aird, & Miller, 2012; Fesko, Hall, Quinlan, & Jockell, 2012; Kåhlin, Kjellberg, Nord, & Hagberg, 2013). There is also a body of evidence linking physical activity with improved physical and mental health (see, for example, Buys et al., 2008).

Overall, people with ID in this study viewed aging in positive terms, with a high percentage noting that older people could do most things younger people could. Recognition of the loss of youth associated with aging was indisputable, but a picture also emerged of the elderly being unburdened by the constraints of life and being open to slowing down. The findings on aging are similar to those reported by Pennebaker et al. (2003), but with additional recognition of opportunities for active pursuit of social and physical activities. Even where participants highlighted restrictions, there was recognition that aging does not define a person. This sentiment was best expressed by a person who said, "I think old people are wise and have more experience and can do some of the activities that all other people can do of course in my case running is out cause I get too tired, I prefer to walk at a nice pace." Such a view of aging as positive bodes well for quality of life in older years.

Equally, despite a high prevalence of chronic conditions, overall, people rated their health highly. Levy and Myers (2004) note that positive self-perceptions help improve efforts to increase health behaviors. Overall, people were positive about their futures and felt things improved as they aged. People

with ID identified aging with particular years, acknowledged their own advancing years, and had expectations of living to older age. General population participants in the larger TILDA study (Barrett et al., 2011) also noted an awareness that they were getting older, but the majority did not agree that they viewed themselves as old.

There were fears evident in the data regarding loss of independence, physical compromise or illness, uncertainty about the future, and death. The category of "sadness" noted in 17% of comments was particularly associated with concerns about physical changes and illness expected in old age. Fears were also shared and expressed by people with ID about who would care for or what would happen as they aged, concerns that parallel those expressed by the general population in other studies (Barrett et al., 2011; Sargent-Cox, Anstey, & Luszcz, 2013).

Steverink (2001) previously argued for an association between a person's personal circumstances and their views on aging, noting that those with better education, better health, more income, and less loneliness had a more positive view. In this study, despite Irish people with ID generally having lower educational attainment and income (McCarroll et al., 2011), their appraisal of aging was similar to that of the older general population in Ireland (Barrett et al., 2011). Yet the passage into old age for people with ID was experienced as significant, and it is concerning that a dominant feeling about aging for many focused on negative physical change (Demakakos, Gjonca, & Nazroo, 2007; Demakakos, Hacker, & Gjonca, 2006). As Ory, Kinney Hoffman, Hawkins, Sanner, and Mockenhaupt (2003) concluded, societal expectation of older adults to slow down as they age leads to some taking on this role despite their knowledge of the positive health benefits of staying active. This suggests that people with ID are at particular risk in older age.

Retirement proved an interesting concept, with men in particular linking it to aging, implying adherence to stereotypical views of men as the traditional bread winners. Given that very few of the participants had directly experienced employment and retirement, further investigation of views and understanding of retirement appears warranted.

In summary, the findings of this study suggest that people with ID appear ready overall to embrace the physical activity concepts of active aging, and service providers need to consider how best to support such desires.

Practice Implications

The findings have implications for service providers in facilitating meaningful later life transitions and life planning. Helping people with ID keep active and counteracting stereotypical views of the “frail old” will equate to a healthier outlook (Levy & Langer, 1994, 2004; Levy et al., 2002). Therefore active aging programs specifically tailored for the ID population need to be emphasised.

The concept of successful aging for this growing cohort is a major challenge for service providers and entails gaining a better understanding of individuals’ personal preferences. As Buys et al. (2008) noted, although people with ID have dreams and aspirations toward active engagement, their circumstances may not always meet these dreams. From examination of the verbal responses provided by participants in this study, it was clear that older adults with ID had accumulated a rich reservoir of knowledge and experience that could contribute toward better service development. Approaching service change in this manner will ensure that people with ID become more central to decision making and policy development. However, as McCarron and Lawlor (2003) noted, services are ill prepared to respond to the challenges increasing numbers of older people with ID present. Inclusion of the opinions of people with ID may help provide better answers to what will ultimately have to be faced. It is imperative therefore for service providers to embrace Bowling’s (2008) concept of “intervention with prevention” and not merely be services delivering programs that are too late to be effective.

Future Research

Aging is a multidimensional process; one’s perception of aging impacts greatly on efforts to cope and, in turn, on outcomes in older age. There is a paucity of investigation on aging perceptions among people with ID. In response, the approach taken here was to give people with ID an opportunity to voice their opinions on aging and to act on recommendations that people with ID be research contributors (Nierse & Abma, 2011). Categories and themes that emerged provided new and important information about the ideals and opinions regarding aging among older adults with an ID in Ireland, some of which are consistent with the self-regulating model (Leventhal & Cameron, 1987) and tap areas similar to the Aging Perception Questionnaire (Barker et al., 2007), raising possibilities for the development of

more quantitative and cross-comparative approaches to measuring this phenomenon.

Limitations

There were several limitations to this study: textual analysis is dependent on typing the verbal responses of the participants accurately as it will exclude data with spelling errors and manually assign and reassign individual responses to categories. The use of a second reviewer helped overcome these potential limitations. Reliance on only the typed verbal responses noted in the interview also meant there was no opportunity to expand or probe further into what was said. The research team was aware of these potential concerns and worked to ensure that they did not overly influence or impede the analysis process. A further limitation was that, although the purpose was to give an overall view of aging perceptions of older adults with ID, it was not possible to capture the perceptions of those who could not self-report. Future studies using more visual prompts and aides may increase the numbers interviewed, but there will always be challenges in including those without communication. Finally, as representative as the IDS-TILDA sample is, there may still be a population living in the community who are unknown to service systems, and their experience of aging may be very different.

Conclusion

In summary, this article is rich in its inclusion of the voice and opinion of people with ID and their involvement as active contributors to this research. A tentative picture has emerged. What it is like to grow old is individual, and the findings support that people with ID themselves are indisputably the best source of opinion on such a subjective issue. One notable comment that continues to influence was from a lady who, in acknowledging her own age, yearned for respect: “She calls me an old one, and I don’t like that at all.”

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