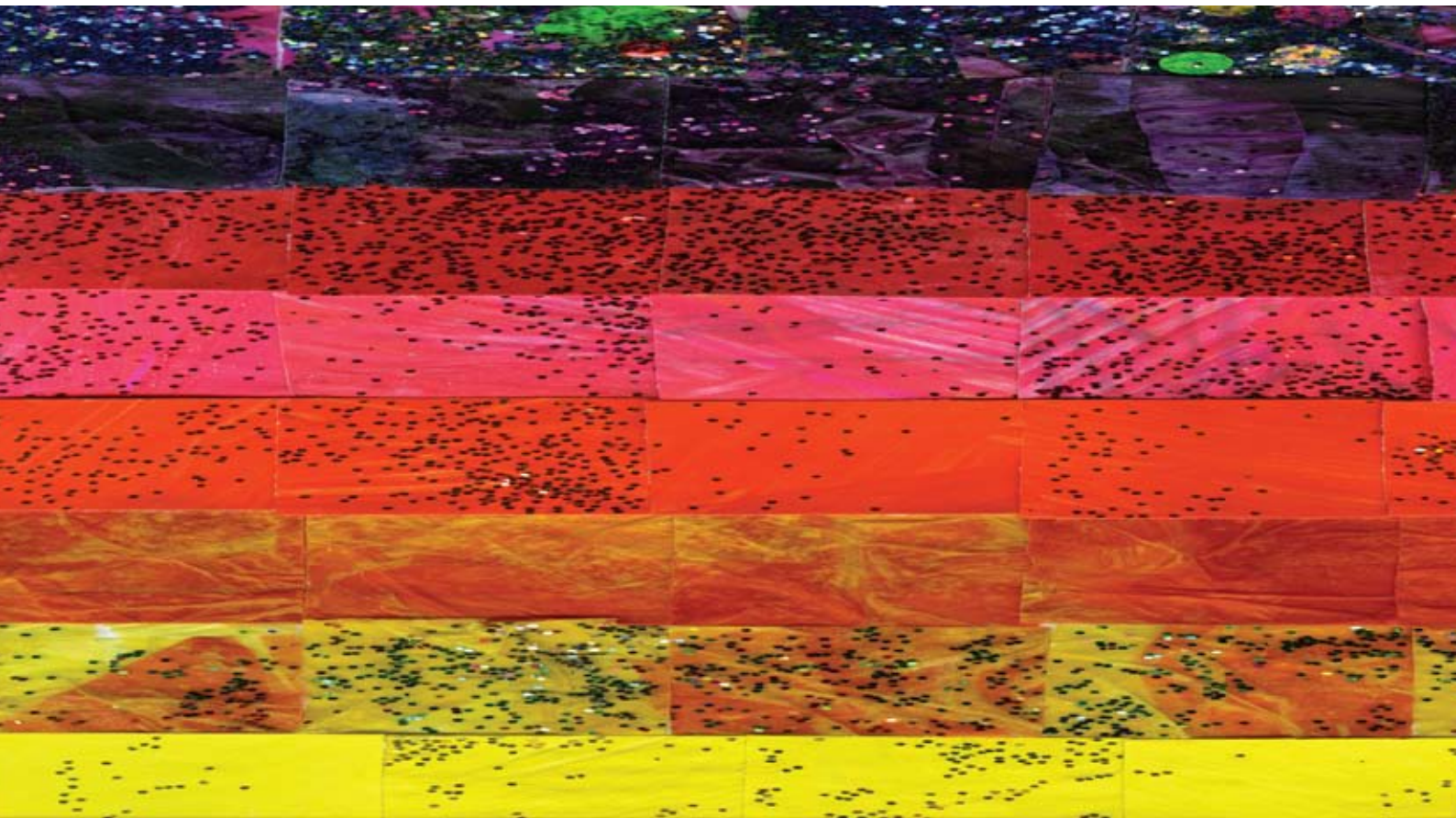


An Intellectual Disability Supplement to The Irish longitudinal Study on Ageing

Pilot Report December 2009



The gradation of colour represents our journey through life

Citation: McCarron, M., Swinburne, J., Andrews, V., McGarvey, B., Murray, M., Mulryan, N., Drummond, E., Sheerin, F. & McCallion, P. (2009) Intellectual Disability Supplement to TILDA. Pilot Report. Dublin: School of Nursing & Midwifery, Trinity College Dublin.

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Preface



On behalf of the research team I am delighted to publish the pilot report of the Intellectual Disability Supplement to TILDA. This study represents the first attempt, nationally or internationally, to include people with intellectual disability in a longitudinal study on ageing. Uniquely, it will be first study with the potential to compare the health and well-being of people with intellectual disability as they age directly with other population groups.

This report highlights feasibility and implementation issues, and the lessons learned will now facilitate the effective roll-out of future waves of this national longitudinal study. The long-term goal of the Intellectual Disability Supplement is to provide data that will support the promotion of lifelong health and independence, and postponement of the development of secondary concerns among people with intellectual disability.

It will advance our knowledge of the health-related attributes of this older population group and their distinctive health risks, including those linked to aetiologies. On a practical level, this supplement will ensure that the ageing of people with intellectual disability will receive full consideration at a national level.

In conclusion, I would like to thank each participant for taking the time to complete the survey and the research team for their diligence and commitment, and to pay particular thanks to Ms. Janet Swinburne, Project Manager. I would also like to acknowledge the artwork submitted by people with intellectual disability, which is featured throughout this report.

Prof. Mary McCarron.

Professor Mary McCarron
Principal Investigator
Intellectual Disability Supplement to TILDA

Acknowledgements

The IDS-TILDA team would like to thank the people with intellectual disability who participated in the pilot study. Special thanks also to the family members, staff and administrators in the participating organisations who all gave so willingly of their time to support participation.

The ongoing support of Prof. RoseAnne Kenny and the TILDA team is gratefully acknowledged.

We would also like to thank members of The Walkinstown Advocacy Group, the Clare Inclusive Research Group (CIRG), the Showcard Review Group from Áras Attracta Services, Swinford, Co. Mayo, and The Foley Street Advocacy Group for assisting us with the planning, design and development of the questionnaires and supplementary materials used in the pilot study.

Others have played critical roles prior to and during implementation of the pilot study and we extend to them our appreciation:

- The members of the IDS-TILDA Scientific Advisory Committee who helped design, develop and guide this study from the inception phase through to the present.
- The staff at the National Intellectual Disability Database (NIDD) at the Health Research Board.
- Health Service Executive Regional Disability Database Managers, Anna Larkin and Karen Judge.
- Brian Soohan, School Attendant, School of Nursing & Midwifery, Trinity College Dublin.
- All those who participated in the logo design competition and photographic exhibition.
- Illustrators Keith Jones, Emma Greenhalgh and Ronald Wilson.

We would also like to thank the Department of Health and Children and Mr. John Moloney, T.D., Minister for Equality, Disability and Mental Health, the National Federation of Voluntary Bodies and Inclusion Ireland for their ongoing support.

Funding and other support provided by the Health Research Board, the Center for Excellence in Ageing Services Innovation Fund, University at Albany, New York, and the School of Nursing and Midwifery, Trinity College Dublin are also gratefully acknowledged.

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Introduction

The Intellectual Disability Supplement to the Irish Longitudinal Study on Ageing (IDS-TILDA) has been funded by the Health Research Board and the Department of Health and Children. Its aim is to identify the principal influences on successful ageing in persons with intellectual disability (ID) and determine if they are the same or different as for the general population. A second aim is to develop a baseline picture on ageing in persons with ID among a cohort of subjects that will then be followed longitudinally.

The project's aims are to be achieved by addressing the following objectives:

1. To understand the health characteristics and status of persons with intellectual disability as they age.
2. To examine the service needs and health service utilisation of older persons with intellectual disability as compared to the general population.
3. To identify disparities in the health status of older persons with intellectual disability as compared to findings yielded by TILDA for the general population.
4. In preparation for longitudinal follow-up, to determine potential:
 - risk factors for ill health
 - facilitators of good health and longevity
 - biological and environmental components of successful ageing.
5. To assess the health and well-being of informal carers.

The study will follow a representative sample of about 800 people with intellectual disability aged 40 years and over from across Ireland over a 10 year period. The sample will be randomly selected from the National Intellectual Disability Database (HRB, 2008). Detailed information will be collected on all aspects of their lives including health (i.e. physical, mental, service needs and usage), social (i.e. friends and family, formal and informal care, social participation) and economic circumstances (i.e. employment, living standards).

This report addresses the pilot phase of the project which had specific aims of determining (a) the feasibility of the sampling and recruitment strategies, and (b) whether the research measures initially developed are acceptable to survey respondents and feasible to administer to persons with ID.



Section 1 - Context and Background to the IDS-TILDA

Understanding Ageing in Ireland

A longitudinal investigation of ageing for the general population has been identified as the most important research programme proposed in Ireland (Kenny, 2006) given Ireland poor ranking (number 22) in a WHO healthy life expectancy survey of 23 countries (WHO, 2001). There are also dramatic increases projected in the proportion of persons over 65 years in the coming years -15% by 2011 and 19% by 2031, and concerns about the dearth of social, psychological and health information on older persons in Ireland (Farmleigh, 2005).

The highlighting of these concerns has led to the successful funding in Ireland of a four wave, 10-year longitudinal study (TILDA) with a sample of 8,000-10,000 people aged 50 years and over, charting their health, social and economic circumstances. It is anticipated that the understanding of ageing that will result from this study will influence the design and redesign of policy, health care and service provision for persons who are ageing in Ireland. However, as TILDA is using the GeoDirectory to select their sample, many people with intellectual disability will effectively be precluded from participating in this national study. It is unknown if policy and service delivery decisions based upon TILDA would benefit or negatively influence the experience of ageing for persons with intellectual disability (ID).

Yet, Ireland has an established National Intellectual Disability Database (NIDD) from which a representative sample of people of intellectual disability can be included. This supplemental study on ageing people with intellectual disability (IDS-TILDA) (McCarron & McCallion, 2006) will therefore, unique among longitudinal studies to date, collect primary data to more fully understand the health consequences and mortality risks associated with ageing in persons with intellectual disability. Close harmonisation between the Intellectual Disability Supplement and TILDA will ensure that the differences and similarities between the population groups nationally are systematically ascertained, so that future policies, services, and resources meet the needs of both respective groups as they age in Ireland.

Similar to the general population, marked changes in the life expectancy of persons with ID have occurred among all age cohorts but in particular, among those aged 55 years and over

(Kelly et al, 2008). A steady increase in the proportion of persons aged 35 years or over has been observed in each iteration of the Health Research Board maintained National Intellectual Disability Database (NIDD) from 37.9% in 1996 to 48.4% in the 2008 dataset.

Additionally, almost half of people with a moderate, severe, or profound intellectual disability are aged 35 years or over. These trends can be expected to continue in the years ahead. However, the life expectancy of persons with ID remains less than that of the general population, with the average age of death in an Irish population with ID reported at 46 years (Lavin et al, 2006). Longevity in Ireland is also less compared to cohorts of persons with ID identified in international reports, e.g., 66 years for New York State, (Janicki et al, 1999) and 58 to 74 years depending on level of disability in the UK (Bittles, 2002). However, there is a dearth of social, psychological and health information on older persons with ID and the possible explanations for mortality differences have not been investigated longitudinally.

This is an important concern; as is true for the general population, there is a need to ensure that future planning, policies, services, support and allocation of resources are sufficient to meet the changing needs of ageing persons with ID. To date within Ireland, there have been no national population-based research studies on health status that have included a representative sample of persons with ID. Reports on the health status of persons with ID have been typically extrapolated from international studies; these studies have rarely included control or comparative groups of people without an intellectual disability.

Current and future changes in the age profile of people with ID therefore has major implications for service planning, potentially increasing demand for full-time residential services, support services for ageing caregivers, and services designed specifically to meet the needs of older people with ID. Specific concerns include:

- Additional formal supervised living arrangements will be needed as the carers of adults with ID themselves age beyond their caring capacity.
- Increased pressure for the creation and support of residential placements is already being experienced by residential services.

- There is increased demand on health services as life expectancy improves among adults with a more severe intellectual disability.
- Increased longevity means that fewer residential places are becoming free over time, a higher degree of support is required within day and residential services, and specific support services for older people with ID are needed.

Planning for the future care of these individuals and avoiding crisis situations when family carers can no longer provide care is of paramount importance. These concerns are very much a day to day reality for services as echoed in the following quotes.

“It is now more imperative than ever before that the needs of people with an intellectual disability are adequately addressed. The study being undertaken by IDS-TILDA will help us plan for the future needs of people with an intellectual disability and will provide us with very important and very necessary information. It is a much welcome development.”

Ms. Deirdre Carroll, CEO,
Inclusion Ireland 2009

“As people with intellectual disability age their needs change, this often occurs quite quickly and in many cases somewhat earlier than other population groups. The need to plan services and supports around this reality is self evident. The National Federation of Voluntary Bodies views the IDS - TILDA study as being of critical importance in this context”.

Mr. Brian O'Donnell, CEO,
National federation of Voluntary Bodies 2009

Key areas for understanding the ageing of persons with ID include (1) their physical and psychological health status, (2) their use of health services, (3) their social networks and supports including living arrangements and income available, and (4) their experience of a subjectively defined quality of life.

Health Status of Older People with Intellectual Disability

There is a dearth of systematically gathered data in Ireland. International studies provide some clues, suggesting that as a group, individuals with ID have a greater variety of health care needs compared to those of the same age and gender in the general population (U.S. Department of Health and Human Services, 2002). Also that health problem experiences may vary by level of disability (Moss et al, 1993). Van Schrojenstein Lantaman-De Valk et al (2000) compared 318 people with ID within a general practice with others and found that people with learning disabilities had 2.5 times the health problems of those without ID. They found that some conditions seemed more related to external circumstances, such as lack of information, lack of exercise, poor mobility, poor eating habits, medication use etc. characteristic for people with ID. Given the complexity of influences on health, an ID-specific exploration of the experience and history of health conditions and the environmental and health practice factors that may be of influence appears warranted.

Health Service Needs

There has been controversial evidence that the experience of poor health and early mortality among people with ID may be related to the location and types of health care services people with ID receive (see for example Strauss et al, 1998). It is reported that:

- People with ID are more likely to lead unhealthy lifestyles which contribute to the development of physical ailments in later life (Evenhuis et al, 2001, WHO, 2001).
- Health problems of persons with ID not being recognised (Merrick, et al, 2002).
- There is a lack of specialist knowledge and training amongst multidisciplinary team members (Gilbert et al, 1998; Kerr et al, 1996, Singh, 1997).
- People with ID do not access health promotion and health screening services to the same extent as non-disabled peers (DoHC, 2001; Kerr et al, 1996; Jones & Kerr; 1997).
- Given that people with ID are often reliant on health management by proxy, there are many access barriers that may prevent health needs identified at screening from subsequently being met (Cooper et al, 2006).
- Gathering information on barriers to accessing healthcare and understanding efforts toward the promotion of health for people with ID may help to understand these issues better in an Irish context.

Psychological Health

Among the population of older adults with ID, there is a reported high incidence of mental health problems (Cooper, 1997, 1999). In a review of available studies, Parry (2002) reported that depending on the instruments and definitions of old age used, 20-40% of older persons with ID have a mental health problem. Similarly, Cooper (1997) found higher psychiatric morbidity (61.9%) among elderly (compared with younger) adults with intellectual disabilities. Social, cultural, environmental and developmental factors and stressors appear to have significant impact on the expression of both psychiatric and behavioural disorders in older people with ID (Day & Jancar, 1994) as well as the consequence of polypharmacy (Reiss & Aman, 1997) and inadequate medication review (Beange et al, 1995). The initiation of a longitudinal study of ageing persons with ID will offer some answers.

Social Networks and Supports

People with ID are reported to be typically socio-economically disadvantaged (Webb et al, 2002) and often, the only discretionary income for people in residential care services is a small personal allowance (Rogers, 2002). People with ID are more likely to experience poverty than the general population (DOH, 2001; Martin et al, 1997) and have the lowest average incomes and highest out-of-pocket expenses of all population groups (Batavia & Beaulaurier, 2001).

Living situations are also of concern. Many people move to institutional settings as they age (NIDD, 2008) although people with ID living in community settings have been shown to display increased adaptive behaviour and better outcomes (Felce & Emerson, 2001; Felce et al, 1998), better health as compared to those living in nursing homes (Heller et al, 1998), and improved quality of life when they move from large group homes with institutional features to community settings (Howard & Spencer, 1997). Living with family has also been reported (Webb & Fritsch, 1999) to offer a community based lifestyle, natural social networks, continuity and constancy, environmental familiarity, and greater acceptance and respect. Work is clearly needed to understand the community features that will encourage maintenance of older persons with ID in communities and settings where they have always lived.



Section 2 - Methodology

Using a cross sectional study design, information was gathered on a select sample of persons with intellectual disability (ID) who were 40 years or older living in a variety of settings and, where appropriate, their informal carers.

Aim of the Pilot Study

As stated earlier the pilot study aims were to determine (a) the feasibility of the sampling and recruitment strategies, and (b) whether the research measures initially developed were acceptable to survey respondents and feasible to administer to persons with ID.

Objectives of the Pilot Study

1. To test the feasibility of sampling and recruitment strategies.
2. To test the feasibility of the consent procedure.
3. To test the utility of the research measures and to ascertain whether they were acceptable to survey respondents and feasible to administer.
4. To ascertain the number of people with intellectual disability who were able to self report, and the number who required assistance from a proxy.
5. To test the utility of accessible showcards developed to support administration.
6. To test the utility of the easy read information booklets and materials.

Methods

Ethical Approval

Ethical approval was sought and granted from the Faculty of Health Sciences Research Ethics Committee in Trinity College Dublin, and from the ethics committees of the 3 participating services.

Sample and Recruitment

The National Intellectual Disability Database (NIDD) was the sampling frame and therefore the starting point for recruitment. NIDD collates information on all people with intellectual disability in the Republic of Ireland eligible for or receiving services and currently there are in excess of 26,000 people with ID registered (Kelly et al 2008). For the purpose of the pilot study three large service providers across urban (Dublin) and rural (Mayo) were purposively selected. The sample included persons with different levels of intellectual disability and the settings reflected a range of living accommodations including family homes, independent living, community settings, and residential/institutional type settings.

Staff at NIDD randomly selected 160 'PINS' from data held on the pilot sites. This was in anticipation of a 50% response rate or less commonly reported in social research (O'Brien et al, 2006). Those selected met the following inclusion/exclusion criteria;

Inclusion Criteria

To participate in this study, a person must:

- Age \geq 40 years with intellectual disability
- Registered on the National Intellectual Disability Database (NIDD)
- Provide written consent, where possible
- Provide family/guardian written agreement, where required

Exclusion Criteria:

A person will be ineligible to participate in this study if he/she is under 40 years of age with ID who is registered on the National Intellectual Disability Database.

Informing potential participants about the nature of research is critical in ensuring that opportunities to make an informed decision are provided. For many people with ID given underlying disability and lifelong limits in educational opportunities, reading can be difficult. The IDS-TILDA team wished to make this process as easy as possible and support people with ID to make an informed decision about whether or not to participate in the study. As a result, illustrators were sourced to develop images which could be used alongside text in all information sheets regarding the study. Similarly, all information leaflets and study materials were reviewed for clarity by advisory groups (consisting of people with intellectual disabilities), and subsequently adapted.

The IDS-TILDA team forwarded the invitation packs to the Regional Disability Database Managers in both of the pilot site regions (Dublin & Mayo). The Regional Disability Database Managers then matched the 'PINS' to the names of people selected; extracted addresses and posted the invitation packs to the potential participants on the agreed date issued by the IDS-TILDA team. Each invitation pack contained a letter of support from the respective organisation, an accessible letter of invitation, an accessible information booklet, and a consent form and stamped addressed envelope. The family/guardian pack (where required) included a letter of support from the respective organisation, a briefing letter, an information leaflet, agreement form and stamped addressed envelope.

People who wished to participate and were able to independently give consent were requested to return the consent form to the research team in the envelope provided. It was acknowledged that some people would not be able to independently give consent and would require support. In such cases, we advised that someone who knows the person well (i.e. family member/guardian/support worker) discuss the study materials with the person with intellectual disability. If the person with intellectual disability and/or family member/guardian/support worker wished to discuss participation or gain additional clarity on the study they were asked to contact the research team. Contact details were provided in the invitation packs and on all the study materials issued. Where the person was unable to give informed consent and did not object to participating in the study, family/guardian agreement was sought. Once the consent/agreement form was received, the research team placed a thank you call to the person with intellectual disability/family member/guardian/support worker and worked to schedule an interview.

Operational Protocol

A detailed operational protocol was developed to ensure consistency, standardisation, and accuracy of data collected, ensuring comparability with the main TILDA study (Kenny, 2006), yet addressing the unique issues in inclusive intellectual disability research.

The fieldwork was carried out by two research assistants, three PhD students and one M.D. student. All were selected because of their extensive experience of interviewing and working with people with intellectual disabilities and their commitment to enabling empowerment in this population. Each team member completed a comprehensive 3 day training in the administration of the protocol that addressed understanding the aims and objectives of the research; key components and main purpose of each module; pertinent issues in relation to consent, confidentiality, participant well-being, data security and data entry; the minimisation of inconsistency and standardisation of face to face interviewing; training in administering specific scales included in the interview; and strategies to resolve anticipated difficulties in face-to-face interviews. Internationally certified anthropometry training was also completed by the fieldworker conducting the measurement visits.

The Interview Protocol

The single wave interviewing protocol is a combination of a Pre-interview Questionnaire (PIQ), a face-to-face interview style questionnaire called the Main Questionnaire, and anthropometric measurements taken on an agreed date after the interview.

Pre-Interview Questionnaire

A pre-interview questionnaire was sent to each participant before the interview. This questionnaire covers demographical information, health status, healthcare utilisation and medication usage. The purpose of placing these questions in a separate questionnaire was to give respondents time to source the information required and increase reliability.

Pre-Loads I & II

Pre-Loads I & II serve to confirm the identity and contact details of the respondent and their proxy if present. Pre-load II also documents all contact made between the interviewer and respondent/proxy in order to gather information in respect to time spent specifically with each individual respondent.

Main Questionnaire

Main questionnaire consisted of 17 sections which were administered at a face-to-face interview with each participant. This questionnaire asks questions covering further demographical information, such as type of residence and religion; cognitive health is measured using the Test for Severe Impairment (TSI) scale; happiness; physical health; Instrumental activities of daily living and support needed to undertake these activities; mental health; employment situation; lifelong learning; day services; behavioural health; social participation; social connectedness; life satisfaction; ageing perceptions; personal choices; sources of income; evaluation questions and a final checklist for interviewers.

Carer Self-Completion Questionnaire

Carer's Self-Completion Questionnaire: The purpose of the questionnaire is to assess if and how carers have been affected in terms of employment, financially, emotionally or in terms of health through caring for the person with intellectual disability. The questionnaire also gathers data on any support or services the carer feels they would benefit from and ascertains if the carer has any worries or concerns about the future.

Anthropometric Measurements

Measurement visit: Participants were invited to have their height, weight, mid-upper arm, forearms, waist and hips measured, where possible. The purpose of the measurement visit was twofold: (a) to assess the feasibility of undertaking anthropometric measurements; (b) to improve our understanding of the links between the general build, diet and health of people with intellectual disability aged 40 years and over.

Data Collection Process

There was a three stage process:

- **First Stage:** A Pre-interview Questionnaire was sent to the person with intellectual disability approximately seven days prior to the interview with a follow-up phone call after five days to ensure receipt and scope progress with completion. An appointment for the interview was also made during this contact.
- **Second Stage:** The Main Questionnaire was administered face-to-face by the interviewer and was arranged to take place in a location that the person with intellectual disability/proxy chose and felt comfortable in. At the commencement of the interview, the interviewer collected the Pre-interview Questionnaire and ensured that all relevant sections were completed.
- **Third Stage:** Towards the end of the interview, interviewers introduced the last stage of the study, outlined its importance, provided the accessible measurement booklet supplied and reaffirmed the participants consent [family/guardian agreement, where applicable] to have some important measurements taken, such as height and weight. Interviewers explained that a fieldworker (accredited anthropometrist) would be telephoning shortly to arrange an appointment to visit them in his/her home/place of choice over the coming weeks. At the end of the interview, informal carers (where applicable) were invited in person or via post to complete the Carer's Self-Completion Questionnaire. Prior to issuing, permission was sought from the person with intellectual disability, where possible.

Supporting Participation

Each person with intellectual disability could request the support of a person they knew well (and at least longer than 6 months) to complete the pre-interview questionnaire and provide support during the interview. The interviews were undertaken:

- independently with the participant with no proxy present,
- with the support of a proxy, or
- the proxy answered on the participants behalf.

Showcards were also developed (see section 3) to aid communication and maximise participation and potential for empowerment of people with intellectual disability. The following quote from a support worker further supports this approach;

“As a key worker I was delighted to assist a client who chose to participate in the pilot study. I am particularly delighted to see people with intellectual disability included in such a big way in this very important research”.

Ms. Mary McCann - RNID, Staff Nurse
Aras Attracta Services 2009



Section 3 - Participation of Stakeholders

People with intellectual disabilities (ID) were actively involved in the study design to help ensure that questions were easy to understand, relevant, meaningful, and addressed issues that were truly of concern. A scientific advisory committee, consultation with stakeholders, a review of stakeholder comments and concerns during the pilot, and the involvement of large number of persons with ID in the promotion of the study were the principal mechanisms utilised.

Scientific Advisory Committee

A scientific committee was established in 2007 to guide the development of the research. Members included family members, nurses, general practitioners, psychiatrists, psychologists, social workers and PhD/MD students as well as several nationally and internationally noted researchers in ageing and ID.

Consultations Meetings Involving People with Intellectual Disability

The development of alliances between people with ID and researchers as a key characteristic of participatory research is well established (Cocks & Cockram, 1995; Williams & Simmons, 2005). Consistent with Warde and Simmons (1998) consultations on the content and design of materials were organised with several groups of people with ID.

Focus Groups

Consultative Focus Groups were organized with members of the Clare Inclusive Research Group (C.I.R.G), Brothers of Charity, Clare and the Walkinstown Advocacy group, Walkinstown Association, Dublin.

It was explained to each group that the study team was interested in their perspective on 'ageing' and what is important as people get older. From a review of the transcripts and notes several key themes and concerns emerged around health, falls, retirement, education and happiness that were already being pursued in the development of the pilot questionnaire. This helped to validate the relevance to people with ID of the items being developed. Several other issues not yet included were identified and resulted in questions being added on ageing perceptions and loneliness. Several additional questions on transportation and barriers to health care also emerged and were added.

In addition a **Consultative Review Group** of people with ID over 40 years of age from Áras Attracta Services in Swinford, Co. Mayo reviewed and advised on the showcards to be used in combination with the questionnaire and the measurement visit. The showcards for the questionnaire combined pictures and symbols to help depict question specific topics. The Review Group's recommendations included adding images and response options; making the images bigger and increasing font size; using landscape layout on non-glossy paper, not using lamination and adding the text for response option under the relevant image.

Plain English

The Foley Street Advocacy Group from Dublin reviewed the materials in the invitation packs for potential participants (e.g. letter of invitation, information booklet etc). The group examined the materials in terms of their accessibility for people with ID and the relevance of the illustrations used. Suggested changes were reviewed and incorporated, where possible. Also, throughout various stages of the review process all the materials in the participants invitation pack, including the family/guardian pack, were reviewed and edited by the Plain English Campaign to make the information as clear as possible.

Engagement of People with Intellectual Disability in the Project's Promotion

The IDS-TILDA team elicited the help of people with intellectual disability (ID) across Ireland to design the logo for the study and to take part in the first national photographic exhibition "*Celebrating Ageing in Persons with Intellectual Disability*" and in the launch of this landmark study.

A competition inviting people with ID to enter designs for the study logo was very successful and the winning design from a group of people with ID from Áras Attracta Services, Swinford, Co. Mayo now represents the study. The IDS-TILDA then invited people with ID to submit entries for the national photographic exhibition on the theme "Happy, Healthy, Ageing", which again proved very successful with just over 200 submissions.

To help promote the study, the photographic exhibition has been travelling to festivals, art galleries, conferences, services and other key events throughout Ireland. A DVD of the photographs is now being developed by the Camera Club Group from Peamount Day Services in Dublin with submissions for music compositions to accompany the DVD being sought from people with ID across Ireland.

Over 250 people with wide representation of people with ID, families, services and other key stakeholders participated in the study's formal launch by John Moloney, T.D., Minister of State for Equality, Disability and Mental Health on December 3rd 2008. Speaking about the study, Minister Moloney said *"It is very fitting in my view that we here in Ireland can mark the day in such a special way with the announcement of this significant endeavour"*.

Mr. John Moloney, T.D.
Minister for Equality, Disability and Mental Health 2008



Section 4 - Pilot Study Findings and Lessons Learned

The findings reported here address implementation issues such as sample selection, reach, utility of questions, consent and the ethics approval process. These issues are likely to be critical to the successful launching of the first wave of data collection. Some preliminary findings from the completed interviews are also presented.

Sample Selection Process & Response Rate

The sample selection process was successful in that a representative sample emerged and response rates were comparable to other studies. The National Intellectual Disability Database and the Regional Disability Database Managers reported no difficulty with managing the distribution of the invitation packs to potential participants. Useful information did emerge on the time needed to address and send out the invitation packs and this will be incorporated into the timeline for the first wave data collection.

The recruitment efforts achieved a response rate of 47% (nine of the seventy-five responses received did not participate in the data collection process); however there were some issues of concern. Of 160 people randomly selected, 42 (26%) potential participants lived with an informal carer or relative but only five choose to participate. Total numbers in the Dublin sample were smaller but it did appear that participation rates were higher (33% versus 8%).

Discussions with families, support staff and service providers identified that:

- Some family members were reluctant to consent because they thought that participants would be required to undertake the full interview process by themselves without support, and in one continuous session.
- Other family members and support staff thought that in order to participate in this study it was necessary for people to be functioning within the higher range of ID, and that persons functioning within the more severe to profound range of ID were excluded, hence a number did not engage any further with the consent process.
- There were also suggestions that some families were just unfamiliar with research and research practices.

- Some issues were also identified by support staff. For example, invitation packs got mislaid, filed for the return of key workers on leave and not briefed on return, and potential participants and/or families/guardians were on holidays at time of release.

All of this was helpful and useful information and as a result, in preparation for Wave One, materials have been revised to highlight that the study wishes that all selected people with intellectual disability participate in the study and to state more clearly that participants may choose to have as much support and time to complete the questionnaires as they deem necessary.

To further successful outreach to potential participants and their relatives for Wave One, the IDS-TILDA team has developed a poster that will be distributed to all services and keys sites. Additionally, we will continue to utilize the widespread recruitment and advertisement efforts of the main TILDA study and will continue presentations of the photographic exhibition detailed in Section 3. There are also plans to secure radio interview and newspaper features on the study during the recruitment phase of Wave One.

Supporting the quality management of the sampling frame will also be critical for Wave One. The National Intellectual Disability Database relies on individuals, family members and service providers to update information regarding those listed on the database. This was mostly the case but in the pilot study it was found that there were some participants who had moved house, others who had in the meantime passed away; and a few others were spending time in convalescence homes. This was a small minority of cases but the IDS-TILDA team intends to work with service providers to further encourage timely updating of information and to inform the NIDD of any discrepancies it notes.

Consent Process

Currently in Ireland there is no legislation which specifically addresses the issue of consent for adults with intellectual disability who are considered not to have the capacity to self-consent. In practice, it frequently falls to family members, service providers and guardians to determine whether the person has the capacity to make this decision. As such, service providers often have their own policies regarding the giving of consent/agreement for research. Within each of the three pilot sites there were different policies regarding the consent/agreement process which required discussion on occasion.

Every effort was made to empower the person with ID to self consent if at all possible and they were considered to have had the capacity. It was felt that if the information materials and consent forms were as accessible (as discussed in section 3) that many people, with appropriate support if necessary, could indeed decide whether or not to participate. In the pilot, 48% of people with intellectual disability consented to participate and signed the consent form. In all other cases, assistance/agreement was sought from families and key staff. Such a high number personally consenting supported the value of the accessible materials developed for the study. Personal assent was always ascertained at time of interview and throughout the interview for all participants regardless of capacity status. Again the success experienced here in implementing these protocols would suggest that the training developed for the interviewers was also successful.

The research team documented all difficulties and successes throughout the recruitment and consent process. For example, several support staff reported difficulty in understanding what to do with the consent/agreement forms. More specific instructions for support staff have now been developed and will be included in the invitation packs.

Assessment of Reach

For the main study to be successful in terms of providing data on a representative sample of people with ID over age 40 it was important to establish if efforts would reach persons able to speak for themselves, persons for whom a proxy would be willing to complete the questionnaire, and persons in a variety of living situations and from across the spectrum of disability. Approximately 25.8% completed questions without any assistance; 25.7% required some assistance from proxy; and 47% of questionnaires were primarily or totally completed by a proxy. It did not appear that having a proxy who knew the person for at least 6 months was a barrier to participation.

As shown in Figure 1, the sample was representative of people living in a variety of care type settings; living at home with family or living independently, residential and community based settings. Also, the full range of ID was represented in those who participated with (22.7%) within the mild ID range, (37.9%) moderate, (22.7%) severe, (4.5%) profound and (12.2%) unknown.

Figure 1- Living Circumstances

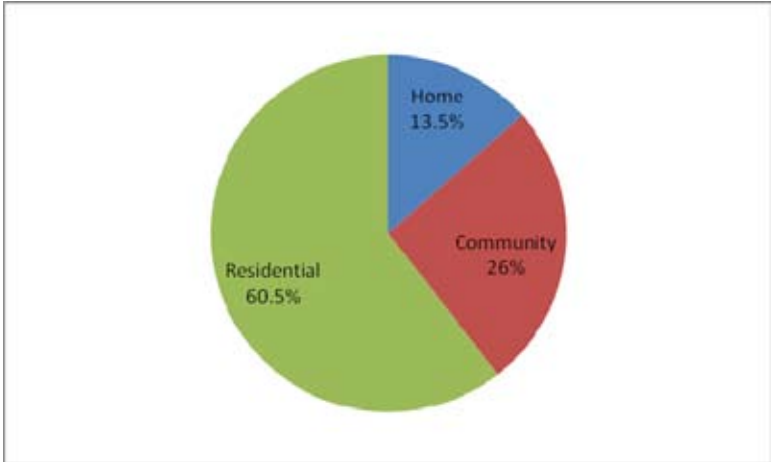
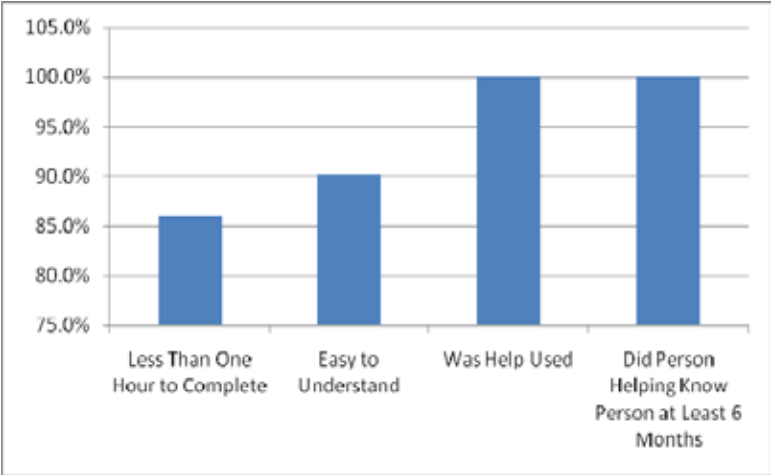
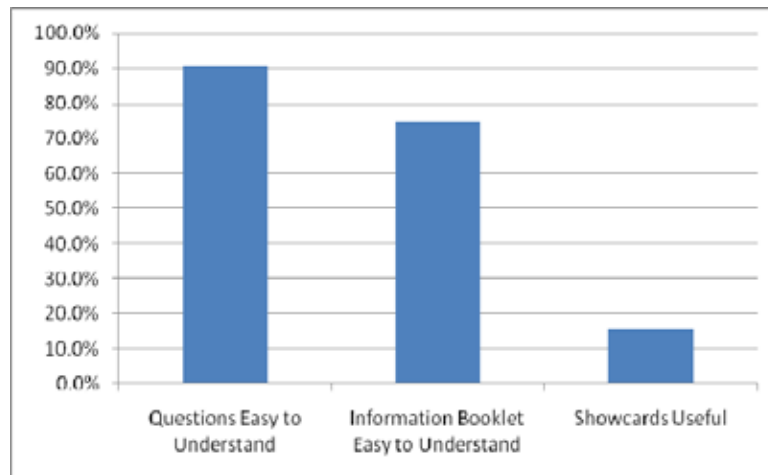


Figure 2 - Evaluation of Pre Interview Questionnaire (PIQ)



A range of questions were asked to evaluate ease of completion of the PIQ and ascertain any difficulties, see Figure 2 above. The time frame for completion was considered reasonable with 85% of participant’s completing it in less than one hour, and 90% indicating that it was easy to understand. All people required some assistance and this was given by people who had a long standing relationship with the participant.

Figure 3 - Evaluation of Main Interview Questionnaire



A range of questions were also asked to evaluate ease of completion of the main questionnaire and ascertain any difficulties. The time frame for completion was considered reasonable taking approximately two hours if completed independently by the participant, one and a half hours if the person required assistance; and on average less than one hour if completed solely by a proxy.

Ninety percent of participants rated questions as easy to understand, with approximately 75% indicating that they found the information booklet useful and easy to understand. The following quote from a study participant further supports this; *“It was a privilege, I was proud to tell her all about me, and how I was getting on and all the things I do in my life. I liked it when she came to visit me because I like people to visit me, I liked her company and I told her I was very happy”*.

Barry Griffin, Pilot Study Participant,
Western Care Association 2009

While it appears that only 15% found the accessible showcards useful, it is important to understand that all people who used the showcards found them useful; participants who completed the questionnaire independently and those questionnaires completed solely by proxy’s did not use the showcards at all.

A review of fieldworker notes suggested some problems with the showcards, specifically, there were too many, and they were too bulky to be used frequently or easily. While it might appear that the numbers who found the showcards useful was relatively small at 15%, it is important to note however that these people may have had significantly more difficulty answering questions themselves if the showcards had not been available and may have been excluded from participating. The consensus with the scientific advisory committee and the interviewers produced recommendations for scaling back on the number of showcards but recommended their retention and additional training for the interviewers on their effective use.

Utility of Questions and Revisions

In general, sequencing, skip questions and other aspects of the administration of the protocol worked well. However, interviewers reported concerns that some questions at the end of the protocol seemed poorly placed as they required a level of engagement from participants that was difficult if persons became tired. Conversely there were items early in the protocol such as the happiness scale that would benefit from later placement as rapport and a certain level of trust needed to be developed between the interviewer and participant before attempting to answer. There were recommendations to remove the self report life satisfaction scale as participants had significant difficulty with the somewhat abstract concepts presented and life satisfaction was captured in more understandable terms in some questions in the happiness scale. The language used in a number of questions was also adapted to more plain English.

Proxies in particular noted that there were very few questions relating to life planning, personal choice and decision making. After discussion with the scientific advisory committee a new section was added informed by the HIQA Standards for Residential Services for People with Disabilities (2009). The Sources of Income section was also expanded. Few participants or proxies were found to be aware of income and expenditures, requiring proxies to check with other staff, yielding information for 44% of participants. This encouraged the addition of questions for Wave 1 regarding control over and information about income and expenditure.

Questions identified as difficult for participants and/or proxies to answer during the interview such as ‘how long have you lived here?’ and ‘what is your highest level of education?’ were reassigned to the pre-interview questionnaire and additional questions added regarding the barriers that participants face when accessing healthcare services.

Other Key Findings

The value of many of the findings is restricted by sample size and representativeness concerns. For the purposes of the pilot the interest was much more in exploring the usefulness and feasibility of specific items and scales. Nevertheless an overall picture of the sample does emerge and is briefly described here. There were 66 participants (32% male and 68% female) in the study with an average age of 56.5 years with a range between 42-93 years. Table 4 provides additional information on age.

Figure 4 - Age in 5 year categories

Age	Frequency	Percent
40 - 44	8	12.1
45 - 49	9	13.6
50 - 54	9	13.6
55 - 59	18	27.3
60 - 64	7	10.6
60 - 65	2	3.0
65 - 69	9	13.6
70 - 74	3	4.5
90 - 95	1	1.5

Participants had lived on average 15 years at their current residence, usually a single story setting (67%), with almost 76% able to get around their home independently. Twenty-four hour support was provided to approximately 65% of the sample and 62% had their own bedroom. All but four were born in Ireland, 95% were Catholic and 68% attended services at least once a week.

Activities of Daily Living

This was a population who appeared to require significant support with basic activities of daily living (ADLs) such as bathing, dressing, eating etc, as well as requiring significant support in instrumental activities of daily living (IADLs), such as shopping, using the telephone, preparing meals. As can be seen in Figure 5, while 30% of people required no support over 35% had four or more ADL needs with more than 70% of participants requiring assistance in IADLs Figure 6.

Figure 5 - Number of ADL Support Needs

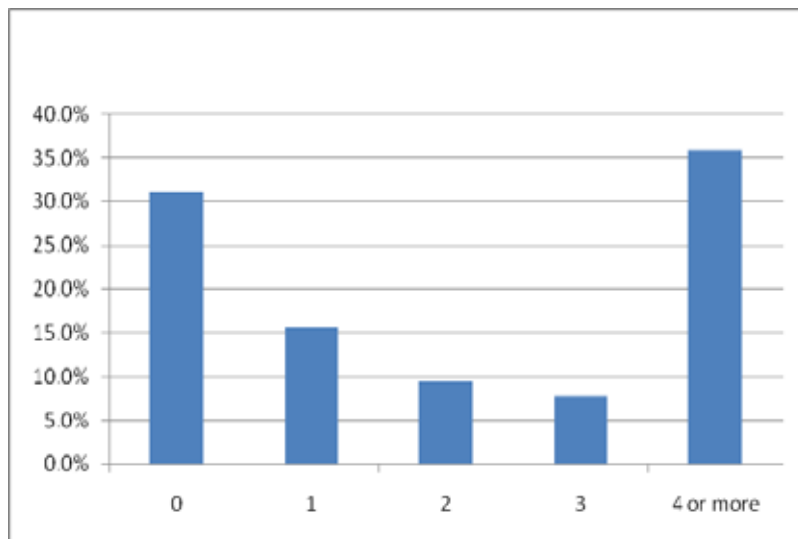
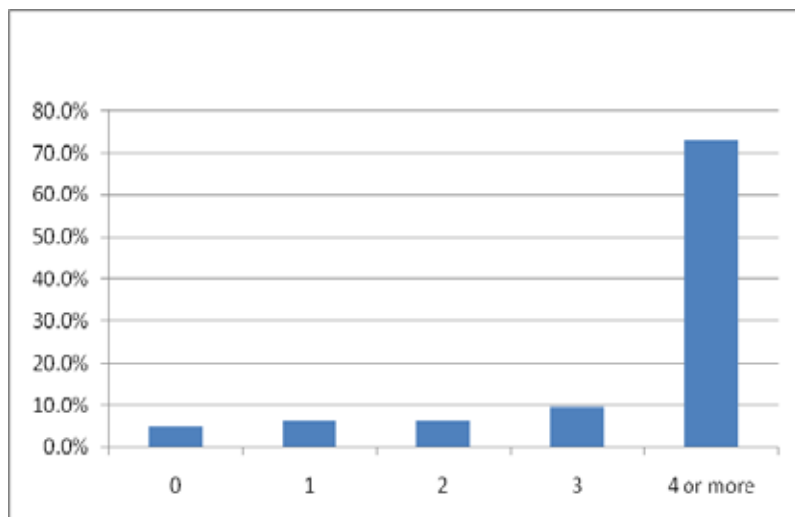


Figure 6 - Number of IADL Support Needs



Consistent with the living locations identified, it was established that most assistance came from staff, with 94% of the population requiring at least some level of support with IADLs, see Figures 7 and 8.

Figure 7 - Support with Activities of Daily Living

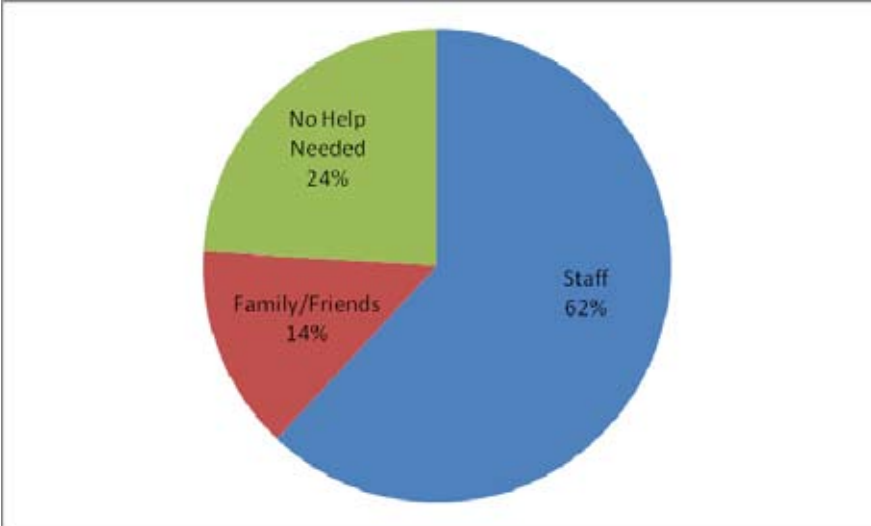
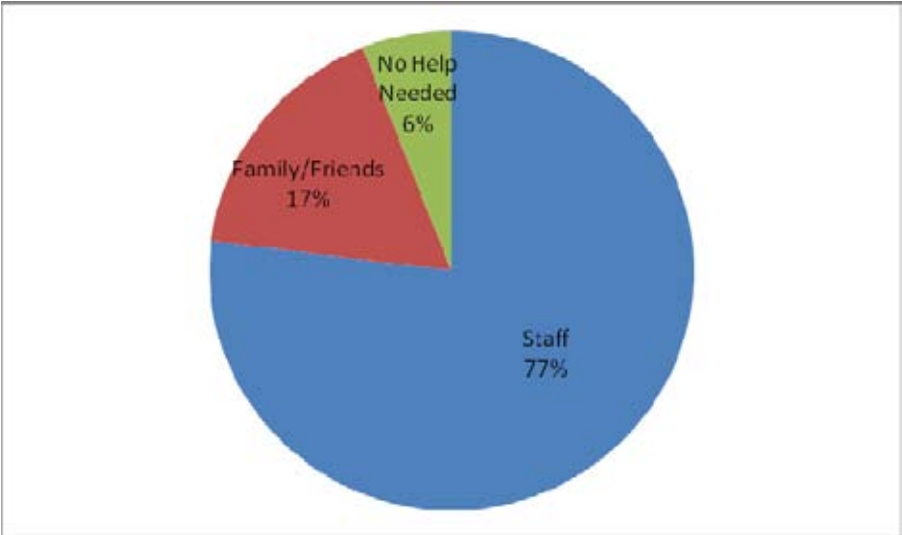


Figure 8 - Support with Instrumental Activities of Daily Living (IADLs)

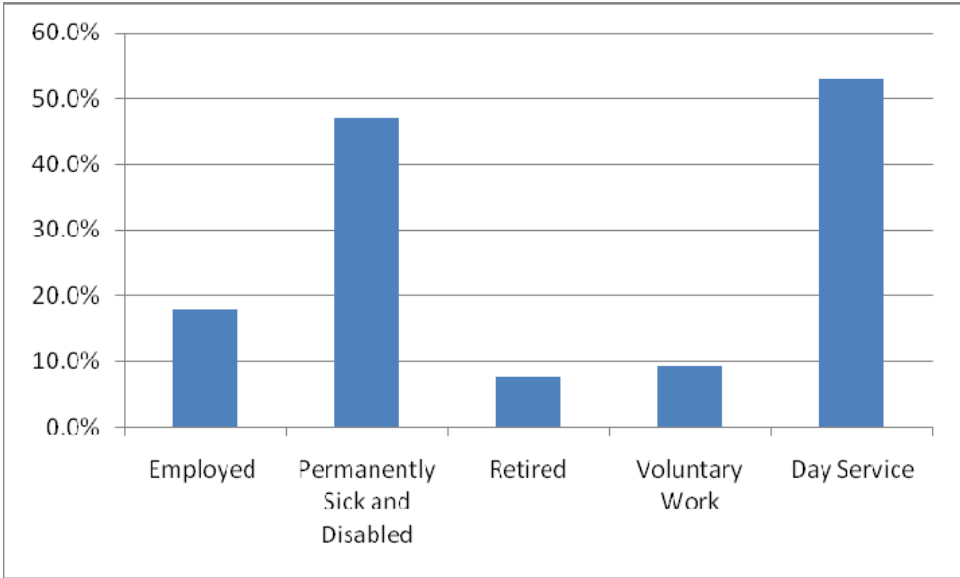


Bearing in mind that the population ranged in age from 40 -93 years old, there is a level of ADL and IADL need that greatly exceeds that reported for other population groups.

Employment and Daily Activities

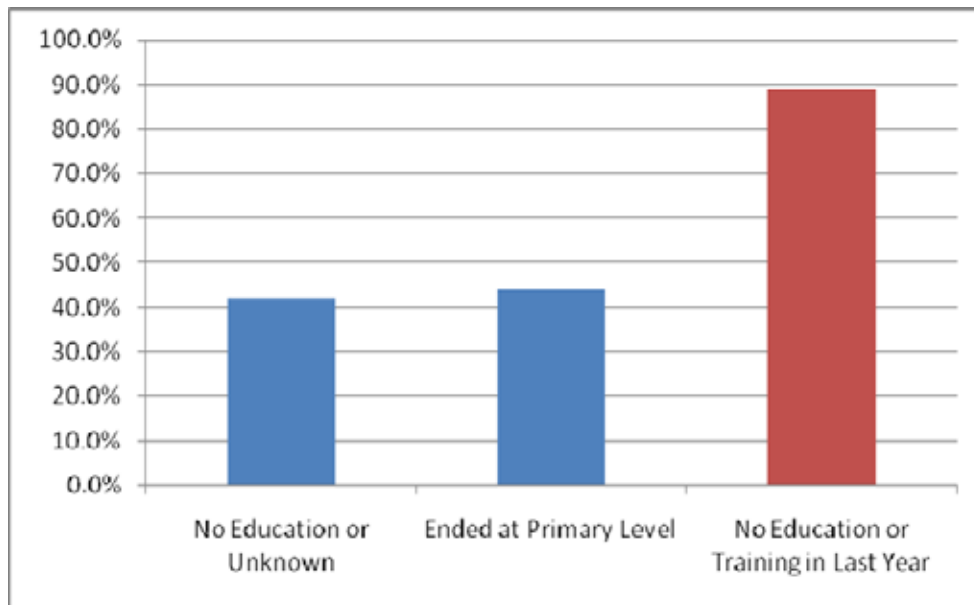
Less than 20% indicated that they were employed with almost half reporting that they were permanently sick or disabled and almost 10% indicating that they had retired (see Figure 9). Only two participants indicated that they were actively looking for work. However almost 10% indicated that they were active in voluntary work and over 50% indicated that they attend a day program (numbers add to higher than 100% because some people who were sick or disabled or engaged in voluntary work also attended day programs).

Figure 9 - Employment



The most frequent activities reported for day programme participation were music, arts and crafts, multi-sensory and health therapies, cooking/baking, swimming and horticulture.

Figure 10 - Life Long Learning

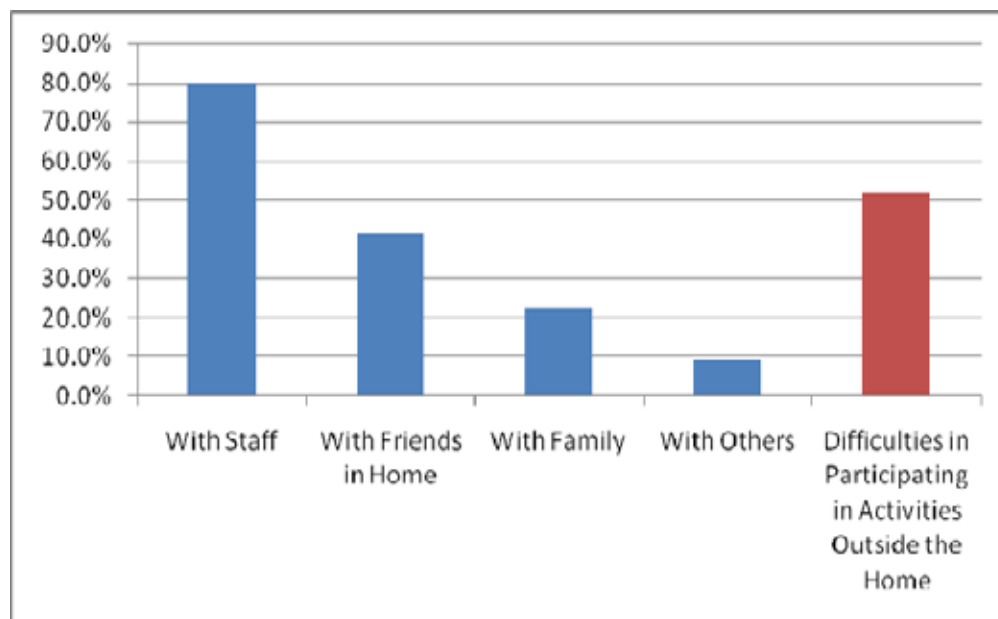


In addition, in terms of participation in educational programmes, 40% reported having received no formal educational programming and a similar percentage reported that educational programming ended at the primary level. Almost 90% reported that they had not participated in any education or training activities in the last year as shown in Figure 10.

Social Participation and Supports

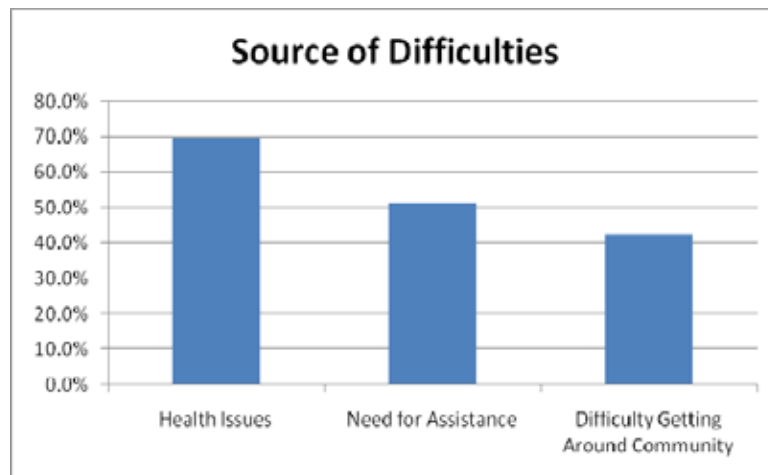
Participants did report an active social life with most belonging to at least one organisation or club and participating in several different types of activities. However, as seen in Figure 11, almost 80% reported that such activities were with staff, 40% with friends in their living situation and just over 20% with family members. Less than 10% indicated that these social activities were with others outside the home and over 50% reported difficulties in such outside activity.

Figure 11- Social Activities



Among the difficulties participants cited were health barriers (70%), their need for assistance (over 50%) and just general difficulty getting around in the community (over 40%).

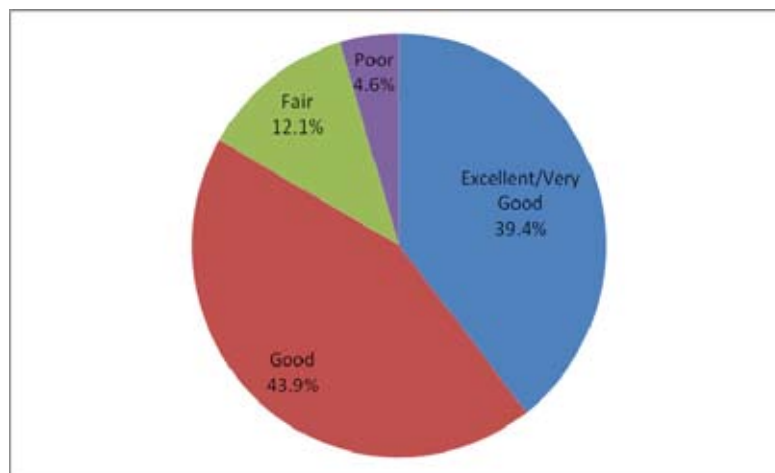
Figure 12 - Sources of Difficulties



Health Issues

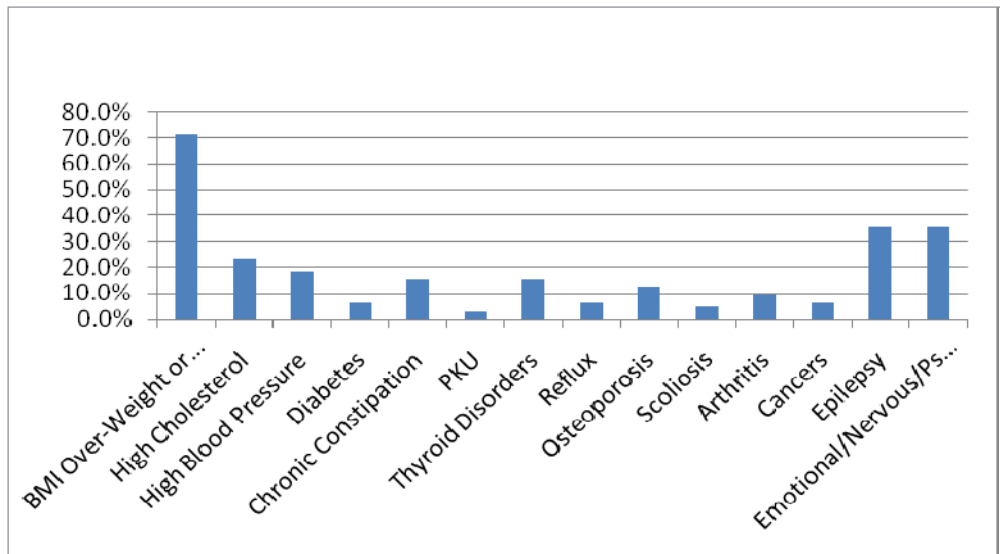
For participants who were able to self report, the majority (over 80%) felt they had good, very good or excellent health and 76% saw their health as good or better than that of other people they knew (see Figure 13). The majority saw themselves as happy, levels of smoking and alcohol use were low and all reported eating three meals a day - all usually contributors to good health.

Figure 13 - Perceptions of Physical Health



However, as can be seen in Figure 14 this was not a group without health concerns. Of particular note are rates (ranging from 9% to 36%) of high cholesterol, high blood pressure, chronic constipation, thyroid disorders, osteoporosis, arthritis, epilepsy and emotional/ nervous/ psychiatric conditions.

Figure 14 - Health Concerns



Of particular note was that 39% reported being often troubled by pain with 10 participants speaking of experiencing severe pain most of the time. In relation to the history of falls, 24% reported that they had fallen in the last year. Also, based on self-reported height and weight for the 49 participants for whom it could be calculated, 63% had a Body Mass Index (BMI) in the overweight or obese category. However, it is important to note that BMI should be interpreted with caution in any nutritional assessment of older people.

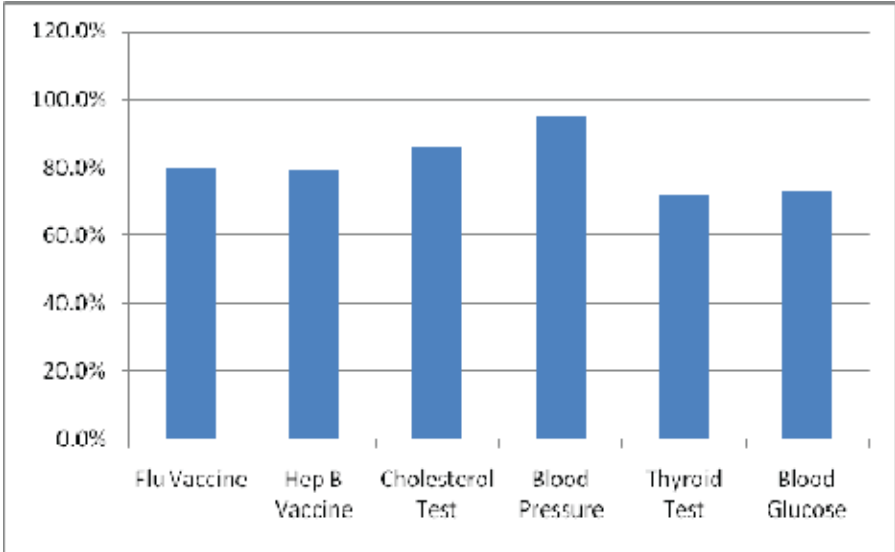
This was also a population that accessed health services and appeared involved in preventive health care and practices see Figure 15.

Figure 15 - Health Care Utilization

Health Care Utilization	
Health Care Contact	Mean (SD)
GP Visits	7.66 (9.32)
Emergency Department Visits	0.28 (0.74)
Outpatient Hospital	1.71 (2.53)
Nights in Hospital	0.79 (3.06)

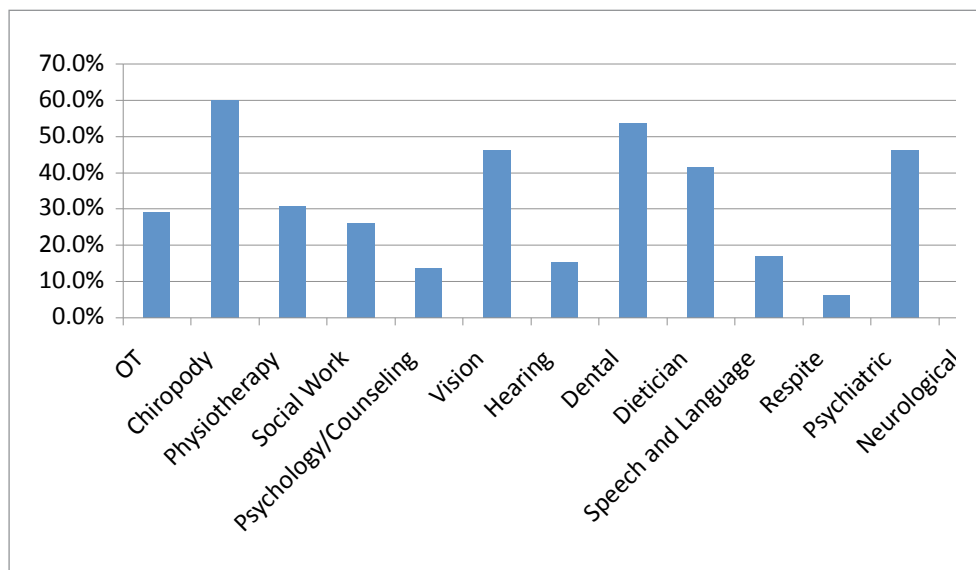
Over the prior 12 months participants regularly accessed their general practitioners and had some usage of emergency departments, hospitals and outpatient services. Participants were also a group who accessed preventive healthcare with over 90% reporting blood pressure screening and between 60% and 85% accessing vaccines and tests (see Figure 16).

Figure 16 - Preventative Health Care in the last Two-Years



This was a group who also accessed a range of other allied health services from vision and hearing to neurological and psychiatric. Perhaps one explanation of the high utilisation of these services (see Figure 17) is that many participants were attached to formal services. It will be interesting to explore service utilization with samples where larger numbers live in community and family settings.

Figure 17 - Allied Health Services accessed



The levels of dental access are of particular note given that 30% of the sample reported they had no teeth or dentures.

The completion of first wave data collection with a much larger sample will permit examination of the relationship between service use and participants' health, mental health and other needs.

Ethics Approval Process

For the pilot study approval was successfully obtained from the Faculty of Health Sciences ethics committee, Trinity College Dublin and from the organisations where the potential participants lived. As the study moves to the first wave the process of obtaining ethical approval from additional organisations has begun and represents a significant time commitment for the research team. Service providers usually have their own specific application forms and procedures for completing same. This is a requirement that studies of the general population do not face but is a necessary and staff intensive task for the IDS-TILDA if sufficient numbers of respondents are to be located in subsequent waves. At a minimum the pilot study established the research team's ability to meet these requirements.



Conclusion and Next Steps

The pilot study met its aims to determine (a) the feasibility of the sampling and recruitment strategies, and (b) whether the research measures initially developed would be acceptable to survey respondents and feasible to administer to persons with ID.

The sample selection process proved acceptable, feasible and viable for all members of the process, including the Regional Disability Database Managers. Furthermore the sample included representation from all types of living circumstances and all ranges of intellectual disability. A concern did arise about the recruitment of people living with family/informal carers. Revisions to recruitment materials to allay noted concerns and more extensive advertisement of the study are planned to more effectively reach this group.

The consent procedure used was also very successful with nearly half of respondents independently consenting to participate. A few issues with the forms themselves emerged during the pilot and have been addressed through a number of minor amendments to the information leaflets and consent forms. All changes have been reviewed by various consultative groups.

Respondents were also able to complete the research measures and questions and they proved both acceptable to respondents and possible to administer successfully. The feedback from fieldworkers post interviews did identify some areas of difficulty and recommendations for the reordering of items which, after discussion with the scientific advisory committee, have now been addressed. The fieldworkers also reported on successful strategies during interviews to create a pleasant and comfortable environment for persons with intellectual disability. These ideas will be incorporated into the training of fieldworkers for subsequent waves of the study.

A further important success for the pilot study was the obtaining of ethical approval but this success also pointed up the challenges in obtaining approval from multiple organisations in the subsequent waves of the study and such realizations are already guiding decisions for preparing to implement the first wave.

Work is now underway to prepare for implementation of the Wave One data collection including completion of revisions to protocols, identification of the Wave One sample and the obtaining ethical approvals from organisations. Additionally, funding has been secured from CARDI to explore the feasibility of extending the IDS-TILDA study to Northern Ireland.

“It is very important that people with intellectual disability are included in this study and I have no doubt the findings will enhance the quality of their lives in their latter years. I strongly recommend the continuance of the project and congratulate all involved”.

Mr. John O’Dea, Director of Services,
Western Care Association 2009



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Intellectual Disability Supplement to TILDA

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The research team is also supported by a number of advisors from a wide range of disciplinary backgrounds with particular expertise and experience in research.

Entrants of the Logo Design Competition

Ann O'Brien, Ann Glynn, Betty Jago, Patricia Dunne, Philomena Murray, Audrey Downs, Geraldine Gray, Kathleen McGannon, Meave Murphy, Mary Gillen, Orla O'Brien, Philomena O'Brien, Pauline O'Connor, Bernadette O'Connell, Bridget Farrelly, Roseanne Houston, Christina Mooney, Marie Therese Corbett, Mary McCormack, Enda Hegarty, Mary Ellen McHugh, Tom Wilson, Gerard Moran, Martin Quinn, Mary Walsh, Brian Slevin, Patricia Maloney, Mark Duffy and Bernie Fox.

Together let's work towards making Ireland the best place to grow older

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