DÁIL ÉIREANN

AN COMHCHOISTE UM SHLÁINTE AGUS LEANAÍ

JOINT COMMITTEE ON HEALTH AND CHILDREN

Déardaoin, 16 Aibreán 2015

Thursday, 16 April 2015

The Joint Committee met at 9.30 a.m.

MEMBERS PRESENT:

Deputy Regina Doherty,	Senator Colm Burke,
Deputy Robert Dowds,	Senator Thomas Byrne,
Deputy Peter Fitzpatrick,	Senator John Crown,
Deputy Sandra McLellan,	Senator Imelda Henry,
Deputy Dan Neville,	Senator Jillian van Turnhout.

In attendance: Deputy Michael Conaghan..

DEPUTY JERRY BUTTIMER IN THE CHAIR.

The joint committee met in private session until 9.47 a.m.

Intellectual Disability and Ageing: Discussion

Acting Chairman (Deputy Robert Dowds): I apologise for the fact this meeting is clashing with Question Time with the Minister for Health in the Dáil. It is frustrating as it means some members cannot be here. I welcome the witnesses, including Professor Mary McCarron, the leader of the research team for the intellectual disability supplement to the Irish Longitudinal Study on Ageing, TILDA, Ms Máire O'Dwyer, research fellow and pharmacist on the TILDA project, Ms Eilish Burke, project manager for the TILDA project, Dr. Niamh Mulryan, consultant psychiatrist at the Daughters of Charity and Mr. Pat Clarke, CEO of Down Syndrome Ireland. I also welcome the many people in the Visitors Gallery. I remind everybody to ensure mobile phones are switched off because if they are not switched off, it can cause serious problems for broadcasting and for the editorial and sound staff.

The committee invited Professor Mary McCarron to discuss the challenge of ageing and care in our intellectually disabled population. As many members know, Professor McCarron is internationally recognised for her research in the areas of intellectual disability, ageing, chronic illness, dementia and palliative care. She currently leads the research team for the intellectual disability supplement to the Irish Longitudinal Study on Ageing, TILDA. This is the most comprehensive study on ageing in persons with intellectual disability ever carried out in Ireland, and the first of its kind internationally. People with intellectual disabilities are now living much longer. This has significant implications for the policies that support their quality of life, including the policies on community living and living in congregated settings. Professor McCarron will be assisted in her presentation by Ms Máire O'Dwyer and Ms Éilish Burke. I acknowledge also the members of the research team in the Visitors Gallery.

I advise the witnesses that by virtue of section 17(2)(*l*) of the Defamation Act 2009, witnesses are protected by absolute privilege in respect of their evidence to the committee. However, if they are directed by the Chairman to cease giving evidence on a particular matter and they continue to do so, they are entitled thereafter only to a qualified privilege in respect of their evidence. Witnesses are directed that only evidence connected with the subject matter of these proceedings is to be given and they are asked to respect the parliamentary practice to the effect that, where possible, they should not criticise or make charges against any person, persons or entity by name or in such a way as to make him, her or it identifiable. Members are reminded of the long-standing ruling of the Chair to the effect that they should not comment on, criticise or make charges against a person outside the Houses or an official either by name or in such a way as to make him or her identifiable.

I invite Professor McCarron to make her opening statement.

Professor Mary McCarron: I thank the Acting Chairman and the members of the Joint Committee on Health and Children for the opportunity to discuss ageing of people with an intellectual disability and to understand the implications of this ageing for the design of policies and the support of their quality of life. The intellectual disability supplement to the Irish Longitudinal Study on Ageing, follows a representative sample of 753 people with an intellectual disability aged 40 years and older. It compares their ageing to that of the general population with data yielded by TILDA. This is the first time in history that we have had a population of people with intellectual disability reach old age. The average lifespan of people with Down's syndrome has increased from nine years in the 1930s to 60 years and older today and while this advance is to be celebrated, there are some serious health concerns that we need to better understand. A recent study here found that mortality among people with an intellectual disability is almost four times higher than that among the general population, with the average age of death at 55 years which is 19 years earlier than the 74 years average age of death for the general population. There are some serious gaps in our knowledge about what is driving this higher mortality rate and about the health and well-being of this population.

Other countries have not been successful in including people with intellectual disability in their longitudinal studies on ageing but Ireland has. It is the first country in the world to include people with intellectual disability in tandem with a generic study on ageing.

I would like to draw members' attention to a number of areas, on which greater detail can be found in the submission and in the relevant reports from IDS-TILDA. I will first draw members' attention to the area of dementia. Recent findings from the IDS-TILDA found that over a three year period from 2010 to 2014, the prevalence of dementia has doubled in people with Down's syndrome from 15.8% to almost 30%. We know the average age of onset of dementia among this population is about 51 years, so we are looking at a much younger and at much higher prevalence of dementia than that reported among the general population, which is estimated to be between 4% and 8% in people aged 65 years and over. Many of the comorbidities which develop or co-exist with dementia in this population are also quite different. For example, almost 80% of people with Down's syndrome who develop Alzheimer's dementia will also develop new-onset epilepsy or seizure activity. This is unique to this population. We see about 10% new-onset seizure activity developing in dementia in the general population.

Assessment and diagnosis of dementia in people with Down's syndrome or with intellectual disability at large is complex and there are various reasons for this. There is no quick five minute screening for dementia in this population. I very much welcome the national strategy on dementia which has specifically identified people with Down's syndrome as a priority area for improvements in services. It is 20 years, however, since there were international guidelines on care issues and recommendations on the care and assessment of dementia in persons with an intellectual disability. Unfortunately, in Ireland and in other countries, many people with intellectual disability fail to get a diagnosis. When there is a diagnosis, often the intellectual disability services feel they do not have the know-how, the resources or the expertise to continue to provide care. When people seek assistance from generic services, such as health services, generic memory clinics and even palliative care providers, these services also feel they do not have the expertise or resources to support this population. Older people with intellectual disability and dementia are falling between two care systems, often with no one accepting responsibility.

That this population is developing dementia should not be a surprise. The data are very clear. The data from IDS-TILDA confirm that dementia is experienced earlier and more frequently in people with intellectual disability. There are some models of best practice developed in Ireland, particularly those of the Daughters of Charity and St. Michael's House. We need to look at these models and roll out similar models on a regional basis, ensuring there is equity of access to diagnoses and care.

I will now turn to the area of bone health and osteopenia or osteoporosis, often known as brittle bones. In wave two of IDS-TILDA we found that rates of diagnosed osteoporosis were 16.4%, slightly higher than that reported by TILDA for the general population, at 14.3%. However, what was very concerning was that when measured objectively, we found very high levels of osteopenia, 37% compared to 14% among the general population, and of osteoporosis, 35%

compared to 28% among the general population. This meant that seven out of ten people in Ireland with an intellectual disability and who were over the age of 40 had poor bone health and most were undiagnosed. With the added risk loading for poor bone health among this population, it is also concerning that screening levels were low at about 25%. Given the evidence now emerging from IDS-TILDA, specific strategies around regular screening, objective assessment, targeted prevention and intervention programmes and education are imperative.

It is important to understand that seven out of ten people who participated in our study reported that they could not read instructions, such as those on medicines or in health promotion material. A similar number of participants could not read accessible information or easy read information and over 50% could not sign their own name or recognise basic numbers. This means that many people with intellectual disability will not understand information given by a doctor, a nurse or other health care professionals. It is not good enough to display easy read material in a waiting room. We recommend, as demonstrated by the data, that health care professionals need additional education around the development of communication with people with intellectual disability. Many health care professionals fail to communicate in a manner that enables a genuine understanding of the care being offered and we need to address this urgently.

I will now highlight the issues for family carers. The family networks of older people with intellectual disability look very different to that of the general population. People with intellectual disability are generally single, unmarried and do not have partners, children or grandchildren to assist with their care as they age. Almost 68% of adults with intellectual disability continue to be cared for at home, many by family carers who are themselves ageing and dealing with their own health care needs. IDS-TILDA has also found that many are being cared for by sibling carers. We talk about the sandwich generation among the general population but the sibling carers of people with an intellectual disability are part of what we might call a triple-decker sandwich generation who care not only for their own families and their ageing parents but also for the family member with an intellectual disability. Two thirds of family members gave approximately 60 hours of care per week and 48% spoke of feeling completely overwhelmed.

The IDS-TILDA evidence strongly suggests that a critical component in reducing reliance on congregated settings will be the quality and resourcing of supports for family carers. We already know that one of the major policy initiatives is to move people with intellectual disability from congregated settings into more community-based alternatives. Given the data, one of the first things we must ensure is that those who are already living in the community are supported to continue to do so. During the period 2010-2014, approximately 120 people reported having moved residence. However, it is concerning that only 30 of those moved from congregated settings to community-based settings. The majority of those moves were lateral moves to the same type of setting.

IDS-TILDA demonstrates that there is a need to understand the progress, the facilitators, the barriers and the outcomes of community-orientated services for people with intellectual disability. The first wave of data from IDS-TILDA provides data and baseline information on people's quality of life, relationships, and health prior to the move. There must be a commitment to monitoring and tracking what happens after the move. Forthcoming waves of IDS-TILDA offer that opportunity.

As Ireland launches its health reform agenda, key policy documents, including Healthy Ireland – A Framework for Improved Health and Well-Being 2013-2025 and the Move from Congregated Settings, have set forth priorities and challenges for the ageing of people with an intellectual disability. Just as The Irish Longitudinal Study on Ageing, TILDA, is gathering and presenting general population data to inform these efforts, IDS-TILDA is ensuring that there is the same high quality data on people with intellectual disability. The data are raising the visibility of the needs and experiences of persons with intellectual disability as they age and encourages the cross-walking of that information between specialist intellectual disability services and generic public health environments. It ensures there is evidence to underpin policy so that we can ensure not only that we have added years to life for people with intellectual disability as they grow old but also, critically, that we have added life to years.

It is my hope that this committee will accept the challenge of ensuring that the data being gathered by IDS-TILDA are utilised effectively in the formulation of policies around disability, health and ageing. I thank the committee for the opportunity to make this presentation and I am very happy to answer any questions.

Acting Chairman (Deputy Robert Dowds): I thank Professor McCarron. Would Ms Burke or Ms O'Dwyer like to make a contribution before I open the discussion to the floor?

Ms Eilish Burke: My study is in the area of osteoporosis. I engaged people in the field in the health assessment. I advocate making health promotion accessible, readily available and easily understandable for people with an intellectual disability. They are capable of engaging in these types of assessment, but for the diagnosis of osteoporosis, for example, the DEXA scan is used. I used a quantitative heel ultrasound, which was like a foot spa, with which people were familiar, so it was a quick and easy assessment to do and it suited people with intellectual disability. In ensuring that their health is promoted, it is important health promotion itself is made accessible for people with intellectual disability.

Ms Máire O'Dwyer: My study examined medication use and patterns of multiple medicines in older people with intellectual disability. We found there was a very high rate of polypharmacy and excessive polypharmacy. A fifth of the population in wave 1 were taking ten or more medicines, which contrasts with a figure of about 2% in The Irish Longitudinal Study on Ageing. We also found a very different pattern of use of medicines. Our most frequently reported medicines were anti-psychotics, which were reported by 43% of the population, followed by anti-epileptics and laxatives. This reflects, to some extent, the different pattern of morbidity in people with intellectual disability, with a higher prevalence of mental health and neurological conditions. We also noted less use of agents to treat cardiac conditions while in the general population, the focus in polypharmacy and appropriate medicines would be more in that area. There needs to be more focus on appropriateness of prescribing and examining this.

Deputy Sandra McLellan: I welcome the witnesses and thank them for their presentations. I apologise on behalf of Deputy Ó Caoláin who would have taken the lead this morning but he is in the Chamber because of the clash with Question Time. The presentations were very interesting. The witnesses have outlined a number of issues but they have also made many clear recommendations. There are a few things I noticed while reading the presentation last night, namely, that there are serious gaps in our knowledge as to how people with intellectual disability age, that no one accepts responsibility and that people with intellectual disability fall between care systems. It is something we need to look at and deal with because we have an ageing population, with and without intellectual disabilities.

I want to ask a question about elderly parents looking after an ageing son or daughter, where they may have health issues themselves. When a son or daughter is diagnosed with dementia at 50 or 55 and are being cared for by an elderly parent, what happens? I read in one of the submission's that traditional intellectual disability service providers often feel they lack expertise in needed care and when they seek assistance from general health care memory clinics, hospitals and palliative care providers, they find little help and they fall between care systems. If an elderly parent needs to make alternative arrangements, how easily can that happen and what are the pathways? Are they clear?

I dealt with a case in Cork, which I will raise because I think it is relevant, of an elderly man looking after a son with an intellectual disability. The man was in his 80s and he passed away. It transpired that he had never claimed for carer's allowance or anything like that, so when another sibling took on the role of carer and applied for the allowance, they were refused because officials could not understand why someone would need a carer now when they had never had one, even though the man had looked after his son for over 40 years without a carer's allowance. I felt I needed to raise that.

Reading through some of the reports, I see that just 7% of adults in the Republic of Ireland with an intellectual disability are in paid employment. Is there scope for developing light work with some of the multinational companies as in the US? Could the Government propose co-operation with some supermarkets, for example, for this type of work? Three out of four adults with an intellectual disability have never written, texted, emailed or used social media to contact family or friends. In addition, less than 60% of adults with an intellectual disability use the telephone to contact family and friends. This group was also less likely to own a mobile phone than other adults in the Republic. The sense of isolation worsens conditions for people with learning disabilities. Have studies been done which provide evidence that increased social contact improves older people's well-being? Can this type of evidence be used to encourage the Government to invest in new programmes? Is there scope perhaps for third level students or volunteers to visit people who are isolated on a regular basis to ensure human contact?

With regard to the under-diagnosis of osteopenia and osteoporosis, Professor McCarron said strategies are needed for objective assessment and targeted interventions for people with intellectual disabilities. What body is best placed and equipped to drive this?

She also said, "The IDS-TILDA evidence strongly suggests that a critical component in reducing reliance on congregated settings will be the quality and resourcing of supports for family care givers. Those needs must be addressed in public policy responses". Public policy supports decongregation but the funding switch to community supports is not followed as much as we may like. How must the Government act to ensure this transition in funding and, therefore, in the focus of care occurs?

Senator John Crown: The TILDA process is phenomenally great research. It is a credit to all involved that, unlike much research, it will provide useful data. Are the issues related to the increased prevalence of dementia in this population real or are they related to changes in diagnostic criteria or people taking the problem more seriously? Were assumptions made about folks who had intellectual disabilities in the past and was insufficient effort put into assessing whether a dementia complication arose as well?

I am reminded of a bigger issue, which the research will address. People engaged in public policy formation will have to think about this, even though they are not good at it. I refer to long-term planning and thinking past the next election specifically. We will have a significantly changed demographic over the next 20 to 30 years. As a result of improvements in health policy, people will live much longer. A higher incidence and prevalence of certain diseases will emerge because people will live long enough to get them. The good news part of that equation is that people who live longer will live better. We have arbitrarily decided that many people can or, in many cases, must become former workers and dependants on the State or pension policies of one kind or another. These people may in extreme cases wish to continue working and, in other cases, could continue working, although they would gratefully accept the offer of retirement based on the criteria originally formulated in 1880s Germany, which was that people should retire at the age of 65. At that time the average age of death was 41 and the average life expectancy of a 65 year old was another two years whereas now it is approximately 18 years.

The reality that is going to have to dawn on people who examine public policy writ large is that we will have inevitably an increasing population of citizens who are wholly or partially dependent on the effort and care of others, which is good news. They will need the help of others because of their own infirmity, illnesses or various challenges and disabilities but the number of people on whom they depend is getting smaller proportionately. We will need to critically examine social policy in the area of the able elderly and whether it is sustainable to force people into retirement who wish to continue working and not be additional dependants. The harder question that will arise is a necessary corollary of that, which is whether optional retirement should be provided for people who have reached an arbitrarily defined age set 130 years ago when we need the resource of people continuing working to deal with those who have no discretion about the level of dependence they have. Professor McCarron should keep up the good work and I hope it inspires a few more thoughtful debates. I also hope the message gets through to full-time politicians that they need to start to think about big picture issues in public policy planning.

Senator Colm Burke: I thank Professor McCarron for her presentation and for all the work that everyone has done in this area. It is important that all the issues are examined, especially in respect of people with intellectual disabilities. How many people with intellectual disabilities are affected? How many are looked after at home with the support of the health services and how many are in full-time structured care? What are the challenges for the future? Hopefully, life expectancy will continue to increase because of improved health services but there is increased demand for services as we try to support ageing parents, for example. Over the next ten years, how many people will require structured care? This is a major issue in the context of elderly care. The number of people aged 65 will increase by approximately 20,000 per annum in coming years. A new Government will be elected in 2016 and by the time it leaves office five years later, another 100,000 people will be aged over 65. How many people with ID are being looked after at home at the moment? Given the age profile of their carers, there will be further demands on structured care for them.

I have worked with a number of families to file complaints with the Ombudsman for Children. On the one hand, significant support and care is provided by the health service. For example, in Cork, the Cope Foundation has been extremely helpful to parents of children with both physical and intellectual disabilities. On the other hand, the local authority is saying they are just numbers. In one case I am dealing with, the person is aged 20. In July 2008, the local authority wrote to the family and said the local authority house they were living in needed to be adapted. In November 2008, the family submitted the plans outlining the changes that were needed but six and a half years later, nothing has been done. I am dealing with another case where the child who is now an adult has to be physically lifted out of bed every morning, washed and looked after. The disability is so severe that the person has to be tube fed. On the one hand, State services are extremely helpful while, on the other, some State services are not doing anything to help. Is the co-ordination of services being examined? There seems to be a lack of co-ordination in services for people with intellectual disabilities who live at home. I may be dealing with 50 cases in this regard. Has Professor McCarron come across this issue?

How does Professor McCarron believe this matter can be dealt with as we move forward? The cases of the families I am dealing with have gone to the Ombudsman for Children. I hope that procedure will assist in bringing some conclusion. Perhaps Professor McCarron has some ideas on the matter. I thank Professor McCarron again for the comprehensive study and the work she is doing.

Acting Chairman (Deputy Robert Dowds): I will let Professor McCarron reply and then I will bring in Senator van Turnhout and Deputy Neville.

Professor Mary McCarron: Thank you very much, Chairman. All of these are critical and important questions. I will address the first question in respect of elderly parents looking after ageing family members with dementia. This is a common problem and it is likely to be an increasingly common problem. If we are serious about continuing to support people with intellectual disability to live at home and in the community, we need to develop robust services, including respite to support family members.

The Daughters of Charity model is currently supporting a family member who is living at home with her elderly father, who is in his 90s. She has advanced dementia but she is able to come to the specialist service which has been developed for regular respite. This has enabled the family to continue to care for her at home because of this outreach support. It is not always about bringing people into services. Services also need to move out. We need appropriate services to support people.

A question was asked about diagnostics. I will combine my comments with Senator Crown's question on diagnosis. It is a number of years since we began to understand the risk of dementia in people with intellectual disability. Now, assessment tools and diagnostics have substantially and critically improved. Unfortunately, many generic professionals undertook little diagnostics training as part of their undergraduate qualifications, whether medical or nursing degrees or training in other areas. Many people working in the generic area in the specialist memory clinics simply do not have the toolkit or the expertise to diagnose. Good expertise has built up in some specialist intellectual disability services now but these are only in pockets. There is considerable inequity throughout the country and whether people can get a diagnosis depends on where they are living. Elderly people have travelled from Cork to Dublin to see me and establish whether I could assess the family member. That should not be happening today. We should be building up services of excellence in the various regions.

Reference was made to the issue of employment. This has come up in several formats. The big issue for people with intellectual disability is that only 7% of this population are in paid employment. Many of these people have never been employed. Many among this population have few assets to support them in their old age. This is a critical issue.

We absolutely need to consider robust supports and serious efforts. This must include the mainstreaming of this population into real jobs and paid employment. We need to consider what type of education and additional support will be required to equip them for employment, including third level education. There are some examples of these initiatives under way. This is a serious concern. Naturally, education is central to preparing people with intellectual disability for the workplace.

The question of which body is best placed to support osteoporosis assessment was raised. We need cross-working between intellectual disability specialist services and generic health care professionals. Many people with intellectual disability find it challenging to walk into a busy clinic and understand the procedures, for example, for something like a dual energy X-ray absorptiometry, DEXA, scan. These diagnostic tests can be very cumbersome and frightening for those among this population. If we are serious about having screening and testing, we need to look at how we can organise these generic health care clinics. Perhaps we could have a slot at a given time of the day when it is not so busy in order that people with intellectual disability can be afforded the time they require to get used to unfamiliar environments. They can be daunting for this population.

There was a question on the issue of people not having used social media and limited use of mobile telephones, etc. There is ample evidence of this and we are seeing in our study the critical nature of social media and technology for improving social connectedness and quality of life. The data are clear. Loneliness is a big issue. Moving people with intellectual disability into the community without the skills, expertise and supports to retain contact is a matter of concern. We need to build up robust structures in the community and in the education and training sectors to support the use of this technology, on which the rest of us in society are so highly dependent. We know it substantially improves our connectedness and quality of life. This is a critical issue.

I have commented on the changing demographic in Ireland. People with intellectual disability are living longer. There is an issue here. There are people in congregated settings currently. We are now trying to move them out into the community and into more independent living accommodation. The majority of these are in the older age cohort. They tend to have more health problems. Given the slow pace of moving people with less severe intellectual disability, those who are younger and those with fewer health problems in the community, we have some work to do to help transition the many others who continue to live in these settings into the community. Not only that, but much remains to be done to sustain them within the community, because being in the community does not equate in any way to living in the community. They are two very different things. Changing geographical location does not necessarily equate with a change in quality of life. We need robust structures in place to address and support that aspect.

There was a question from Senator Burke on the numbers living at home. We know that approximately 67% of the total intellectual disability population registered on the international intellectual disability database continue to live at home. We know that approximately 15% live in congregated settings, 17% live in residential settings and approximately 15% live in community group homes. The majority of people with intellectual disability continue to live at home. As we said earlier, we are tracking those who are living at home. Many are being cared for by sibling carers. We need to consider whether we are serious about not reintroducing congregated settings. Another model of congregated setting comes under the guise of the nursing home model. We need to be very careful and understand the types of robust structures that we are going to have to put in place to support family members. To answer Senator Burke's question, approximately 67% of the total intellectual disability population continue to live at home. We know from the last report of the database that there are over 2,000 people looking to move out of home. Families are actively looking for alternative accommodation for them. That is an important issue.

Senator Colm Burke: What numbers are we talking about? Professor McCarron referred to 67%. Do we have any idea of the numbers?

Professor Mary McCarron: There are approximately 18,000 people currently living at home over the age of 40 years.

Senator Jillian van Turnhout: I thank the deputation for the presentations. Professor McCarron has reiterated the importance of having this study and of having the data. We can see the richness of our understanding. I hope we will evolve as we appreciate and understand more about what the data are telling us. It speaks to what many of us felt in our guts but we did not have the evidence to actually demonstrate it. As the deputation was presenting this morning, the question of whether we look beyond intellectual disability struck me. Sometimes I feel that if the diagnosis is intellectual disability, the box is ticked as far as the health plan is concerned and we do not look beyond that. Certainly, that is the evidence. Another thought struck me when I was listening. We tend to feel that it is great that people are living longer, rather than actually stating what our expectation should be. We are almost applauding ourselves when we look at the figures, but it probably speaks volumes about what we did in the past.

Eilish Burke gave a very good illustration of how to make health promotion more accessible and how we might do things differently and recalibrate. Mary McCarron spoke about creating a space or to make room, parallel with the settings we have, in clinics and in other places to ensure that we make it accessible. The issue of literacy and how we view literacy is extremely important. Pat Clarke from Down Syndrome Ireland is in the Visitors Gallery. During the children's referendum that group produced a leaflet to explain the children's referendum to its members. In fact, I found it useful for a much wider audience than just the group's members. Have the witnesses found evidence of engagement with advocacy or membership organisations in designing or providing those community settings or on how we are going to do this? We are getting some of the figures, but how do we create these models? How do we really understand what is best? Perhaps we should talk to parents, support groups and advocacy organisations.

I have a question about the figures on dementia. How is that in the context of the general population? As Senator Crown asked, is it our growing understanding or is it about how we diagnose generally? I am trying to understand the increase in dementia. Is it that we are now looking beyond the intellectual disability?

In the research that has been done have the witnesses found any issues regarding disclosure of abuse emerging later in life? It is certainly something we have seen with the older population when we look at nursing home care. The evidence we have been given is that when people are in a safe setting they tend to disclose if there has been domestic violence or childhood abuse, due to being in that safer environment. Nursing homes have pluses and minuses but sometimes when one is changing that context a person can feel the ability to speak out. Is that something that has emerged?

I agree about the quality and resourcing of supports to families. I am concerned about the CARDI report and the living arrangements for older people with intellectual disabilities. It shows a total redesign is needed of how we provide community supports. We allow people to live where is best for them, but the reality is that most people are living in residential centres so we cannot ignore that fact either.

Deputy Dan Neville: Have any studies been carried out on the level of mental ill-health among the group, in other words on the areas of psychosis and depression? It would be an interesting study given the experience of most of those with an intellectual disability. Obviously there a level of stigma surrounding mental ill-health and mental disability, but society often does not distinguish between intellectual disability and mental illness. It is something I find hard to break through. People with an intellectual disability do not in any circumstances have an illness; they have a condition from birth like most of us have, be it physical or mental. Is there research or have studies been done on that area, because over a number of years I have encountered a misunderstanding about intellectual disability?

Senator Colm Burke: On the co-ordination of services, I asked about local authorities and all other services. There is no single co-ordinator. The health service is doing it but we are also talking about housing, health care, support care and physical care such as physiotherapy and so forth. There is co-ordination in certain areas but not in terms of an overall package. Have the witnesses dealt with any aspect of that?

Acting Chairman (Deputy Robert Dowds): I congratulate you on the quality of your work. With regard to employment, there is a provision whereby businesses are encouraged to take on a certain percentage of people with disabilities. That might not necessarily be intellectual disability. Have you a sense of the extent of that in practice? You mentioned that 7% are in employment, according to the study. I presume you would be of the view that many more of that cohort of people could work. Have you any suggestions on how best to encourage employers to take on people with intellectual disability as employees?

Professor Mary McCarron: I thank the members for a number of pertinent and critical questions. Regarding what we should do to make health promotion more accessible and to deal with the literacy issue for people with intellectual disability, we should not spend the next ten or 15 years trying to teach this population how to read and write. That is the first thing to say. If we do that, we would waste many valuable years. I am not saying that is not important. We should be considering adult literacy classes and so forth for this population, but we must also look at technology and other areas which will be more accessible. There are big efforts now in Ireland, particularly with a doctorate around technology and intellectual disability, in trying to make technology accessible for this population.

As part of IDS-TILDA we worked a great deal with people with intellectual disability. When we started this study it was said that these people would not be able to participate and that they would not be able to engage in this protocol, yet we have had a 98% retention rate from wave 1 to wave 2. We involved people with intellectual disability in the design of the study. They helped us to develop the accessible materials. Not only that, if members of the committee have a chance to look at the IDS-TILDA website, people with intellectual disability have acted out the key findings of the study. This is an effort to make things accessible to people. It has been a big focus. While a very strong conceptual framework underpinned this study, there was also a very strong values framework. That values framework was about making this study accessible to people with intellectual disability to enable them to take part. We have shown that this can be done. It has happened and we certainly can roll out the learning from IDS-TILDA to other walks of life. It is something that can happen.

The next question was about dementia and whether there was a difference with the general population. Yes, there is. People with Down's syndrome have a far increased risk of dementia. Overall, if one looks at all of the international studies, we are looking at a prevalence rate of 15% to 40% of people with Down's syndrome over the age of 40 years having Alzheimer's disease. The prevalence in the generic population is 4% to 8% in people aged 65 years and over. One of the over-riding reasons that people with Down's Syndrome are at increased risk is that in 95% of people with Down's syndrome the Down's syndrome is caused by having a triple copy of chromosome 21. We now know that key sites located in chromosome 21 are implicated in the cause of dementia, particularly the location of the amyloid precursor protein gene which is located on chromosome 21. This puts people with Down's syndrome at increased risk. They have an increased loading. Of course, there are also other factors.

Now that we know this population is at increased risk, we must begin to look at prevention. We must begin to examine what is happening around brain health for the general population. Very little has happened in this field. A PhD student from Trinity College, Eimear McGlinchey, is part of the team. We have started the first brain training programme with financial support from Down Syndrome Ireland and in conjunction with University College Cambridge. It is looking at brain health in people with Down's syndrome. We know that things like physical activity, exercise and social connectedness are implicated in brain health. As we know that a genetic risk loading is associated with this population, we need to look at what we can do to prevent these problems from developing.

Senator van Turnhout also asked about issues relating to disclosure of abuse. This has not necessarily come through in the data we have collected to date. As we prepare for the third wave, we may want to look at some different areas that may help if they were uncovered. Certainly, issues of abuse have not emerged to date among people with intellectual disability who have self-reported.

Deputy Neville asked about mental ill-health, which is a major concern. Over 45% of the population enrolled in this study had mental health problems. Dr. Niamh Mulryan, who is present at this meeting, is studying the prevalence of mental health problems among this population in great detail. We know this is a serious issue. We can see that from the types of medications these people are taking. Ms O'Dwyer has spoken about the high use of psychotropic medications. Mental health problems represent a serious issue for this population. We also have other issues which we need to unpack as well. Sometimes there are problems with diagnostics, challenging behaviours and other environmental issues that can be misinterpreted. We spoke about the very high prevalence of things like osteoporosis. We know that people who have these conditions are at greater risk of fractures. It is very common for people in this population to have vertebral compressions. Very often, they are not able to complain of things like pain. Perhaps some of the mental health problems we are looking at can be attributed to things like an inability to report problems or undiagnosed pain. Mental health is a serious issue. Diagnostics can be complicated. It is certainly something we are looking at. Approximately 47% of this population presented in the first wave with a mental health problem.

Senator Burke asked whether there is a single co-ordinator in terms of an overall package. We need much more joining up of the various systems in areas like housing, health and disability services. It is often the case that these groups never come together in the same room to discuss how to solve some of these problems. We have systems which are probably fragmented. We need a much more co-ordinated approach to how we tackle and address some of these issues. Certainly the housing issue is a big problem. We are looking to move people from congregated settings out into community-based accommodation. Many services are struggling to get on the housing list. Perhaps people with intellectual disability will be at the bottom of the pile when it comes to things like the housing list. We need to look at that. Various working groups are actively trying to address those problems. The value for money working group is certainly looking at that at present.

The Acting Chairman asked me to suggest how people could be supported when it comes to employment. We certainly need to prepare people for employment. Education is one way of doing that. It is really critical. It was evident from this study that many people in this population do not even have primary education. Very few of these people had an opportunity to go to third level education. I am working in a third level institution, Trinity College, that has a certificate in contemporary living. It is open to very few people, however. We need to broaden out the educational opportunities for this population at primary, secondary and third levels. There have been some very successful efforts to support people in small pockets. These have involved bridge workers and support workers, etc. It can happen. Other countries have demonstrated that people with intellectual disability can be supported to have real jobs as long as the right supports are put in place. People want real jobs. It is really important that we commit to supporting that to happen. That is critical.

Acting Chairman (Deputy Robert Dowds): The thrust of my question related to encouraging employers to give serious consideration to taking on people with disabilities. Before I was elected to this House, I was a member of South Dublin County Council, which had a very active policy of employing a proportion of people with disability - not necessarily intellectual disability, but a variety of different disabilities. I think there is some level of encouragement to try to attain a certain percentage. I forget what the percentage is. I think it is in the region of 3% to 5%. Work probably needs to be done to make employers realise that it is possible to take on people with any kind of disability.

Professor Mary McCarron: Absolutely. I totally agree. People with intellectual disability are sometimes caught in the benefits trap. When they go into mainstream employment, perhaps they lose many of the other benefits that are critical and essential for them in support of their disability. We need to look at how we can address that issue to ensure people do not automatically lose some of the health or other benefits they currently have when they go into employment.

Acting Chairman (Deputy Robert Dowds): Will we conclude there?

Senator Colm Burke: I would like to raise a further question. I apologise for raising the issue of the local authorities once more. Under the Disability Act 2005, a local authority that does not have an access officer is in breach of legislation. I know of a local authority that has posted on its website that it is pleased to advise that it has two access officers. I have spent eight weeks trying to find out the names of those access officers. I am sorry for coming back to the same question. What can we do to get local authorities involved? On the one hand, they are obliged by legislation to have access officers, who are supposed to look after the whole issue of people with disabilities. On the other hand, we cannot seem to get any answers. I do not suggest that all local authorities are like this, but I know of a local authority that is like this. What can we do to highlight this issue while at the same time forcing people to comply with legislation?

Professor Mary McCarron: I do not have any easy answer for that, unfortunately. This issue is not unique to Cork. It arises in the rest of the country as well. There are various things that need to be done. The first thing is to get people with intellectual disabilities onto the agenda. Very often, they are not on the agenda. There needs to be a real effort to work to get this commitment from public bodies and other groups. I am afraid the data sources we have at the moment do not provide quick answers to the Senator's question.

Acting Chairman (Deputy Robert Dowds): I welcome the Chairman of the committee back to the meeting. I thank our witnesses for their most interesting presentation.

Deputy Jerry Buttimer took the Chair.

Chairman: I apologise for being late. I thank the witnesses for the work they are doing. They made the relevant point that we need to take a collective and collaborative approach to highlighting this issue and putting it on the agenda. I know we have people in the room from

Down Syndrome Ireland. I am involved with the Cope Foundation in Cork. We all need to channel our energies to put this on the agenda and keep it there. There is a role for public bodies and the State to be visible in raising that profile, appointing people and creating the opportunity and space through public policy. I thank the Acting Chairman. I apologise for being late.

Sitting suspended at 11 a.m. The joint committee resumed in private session at 11.18 a.m. and adjourned at 12.13 p.m. until 9.30 a.m. on Thursday, 23 April 2015.