DÁIL ÉIREANN

AN COMHCHOISTE UM NITHE A BHAINEANN LE MÍCHUMAS

JOINT COMMITTEE ON DISABILITY MATTERS

Dé Céadaoin, 6 Samhain 2024

Wednesday, 6 November 2024

Tháinig an Comhchoiste le chéile ag 5.30 p.m.

The Joint Committee met at 5.30 p.m.

Comhaltaí a bhí i láthair / Members present:

Teachtaí Dála / Deputies	Seanadóirí / Senators
Dessie Ellis,	Fiona O'Loughlin.
Frankie Feighan,	
Jennifer Murnane O'Connor,	
Pauline Tully.	

I láthair / In attendance: Senator Victor Boyhan.

Teachta / Deputy Michael Moynihan sa Chathaoir / in the Chair.

Future-proofing to Improve Life and Longevity for Persons with Disabilities: Discussion

An Cathaoirleach: Apologies have been received from Deputy Brian Leddin, and Senators Tom Clonan, Erin McGreehan and Mary Seery Kearney.

The purpose of today's meeting is to discuss future-proofing to improve life and longevity for persons with disabilities. On behalf of the committee, I welcome representatives from the Intellectual Disability Supplement to The Irish Longitudinal Study on Ageing, IDS-TILDA, the Trinity Centre for Ageing and Intellectual Disability, Trinity College Dublin. We have Professor Mary McCarron, director, Dr. Eilish Burke, co-director, Dr. Martin McMahon, associate director, and Dr. Eimear McGlinchey, assistant professor. I welcome them all to the meeting.

Before we begin, witnesses are reminded of the long-standing parliamentary practice that they should not comment on, criticise or make charges against a person or entity in such a way as to make him or her identifiable or otherwise engage in speech that might be regarded as damaging to the name of a person or entity. Therefore, if their statements are potentially defamatory in relation to identifiable persons or entities, they will be directed to discontinue their remarks. It is imperative that they comply with any such direction.

Members are reminded of the same long-standing parliamentary practice that they should not comment on, criticise or make charges against any person or an official outside the House, either by name or in such a way as to make him or her identifiable. Members must be physically present within the confines of Leinster House complex if they are contributing to the meeting remotely.

Without further ado, I invite Professor McCarron to make her opening remarks.

Professor Mary McCarron: I am delighted to have the opportunity to present some of the insights from the IDS-TILDA study and, briefly, The Irish Longitudinal Study on Ageing for people with intellectual disability. I hope this will help to inform important deliberations.

IDS-TILDA examines ageing among people with an intellectual disability aged 40 years and over in the Republic of Ireland. It is the first study of its kind in Europe, and the only study in the world with the ability to compare ageing in the general population with data yielded by TILDA. The study commenced in 2008 and one of its key strengths is its ability to track initiatives and reforms intended to support change in the lives of people with an intellectual disability. We have seen that there has been a number of important achievements during this period. Our first report, in wave 1 in 2008, reported that 47% of participants lived in residential or congregated settings. By wave 5, in the overall population this figure had reduced to 28.5%. The change was even more dramatic when we looked at those aged 40 to 50 years. In wave 1, almost 45% of participants in this age category lived in residential or congregated settings. By wave 5, this had dropped to 7.7%. Our data supports that continuing to deliver on movement to and engagement in the community must continue to be a key priority. We have found that quality of life is lower for people living in congregated settings than those living in the community and those living in the community are less likely to have choice and self-agency across many life domains. We are aware that around 2,000 people continue to live in congregated settings so we need to continue to work on that.

We have found increases, as compared with wave 1, in the proportion of participants who had regular contact with both their family and friends, more people living full social lives with rich interpersonal relationships and engaged in their communities. Again, the most notable in-

creases were among those less than 50 years of age, those with mild intellectual disability and those living in the community.

This is good news but many barriers and concerns remain. People with more severe intellectual disabilities, those living in residential or congregated settings, remain dependent on staff for support. Staff are really important in their lives. There is a huge crisis in the recruitment and retention of staff. This is a major issue in terms of the security and well-being of many people with severe to profound intellectual disability.

Approximately 20% of participants reported not leaving their house at all. For some, this was a personal choice. However, others - one in five in this group - reported this was due to a lack of staff or resources to get out of their home.

The findings of IDS-TILDA continue to highlight high rates of often manageable or preventable physical health problems, including chronic constipation in about 50% of this population, high levels of poor bone health, for example, osteoporosis which is often undiagnosed, and a high incidence of falls and fractures, all of which we know impact hugely on quality of life and increased risk of mortality.

Medication use remains higher, with patterns of prescribing substantially different from those observed in the older population by TILDA. Although we have seen a decrease over time in the use of some medications, particularly in those under 50 years, overall levels of polypharmacy and hyper-polypharmacy, which is the use of ten or more drugs, at 21%, are much higher than in the general population, at 2%.

IDS-TILDA is also shining a light on poorly understood diseases in areas such as oral health, women's health and cancer. Cancer was infrequently diagnosed across the five waves, yet it was one of the leading causes of death recorded on death certificates. We are not identifying cancers in a timely manner, which would offer people with intellectual disabilities the opportunity to avail of new therapeutics and treatments. There is also a limited understanding of their experience of survivorship.

We have also shown that women with an intellectual disability die, on average, 20 years earlier than women in the general population and they have much poorer levels of physical and mental health. Menopause occurs at an earlier age and, indeed, earlier again for women with Down's syndrome, yet many were unaware of menopausal transition. Very few had spoken to anybody about this and over 80% of them did not receive information they could readily understand. This is an area that really needs to be examined.

The IDS-TILDA study on oral health revealed stark inequalities, with high rates of oral health disease and a lack of access to essential dental care. Two in five participants aged over 65 were edentulous, which means they had no teeth at all. This rate far exceeds the rate in the general population. Of those without teeth, 70% lacked dentures compared with 5% in the general population, so they were orally disabled. Over 70% lacked functional dentition, affecting smiling and their ability to eat and chew food. Oral disease was prevalent, with nearly half of participants having cavities, two thirds experiencing swollen gums and only a quarter having clean mouths. Dental anxiety was high and although most had seen a dentist recently, these visits were often for assessment without treatment.

There is a fivefold increased risk of people with intellectual disability, particularly those with Down's syndrome, developing dementia compared with the general population. We know

that for people with Down's syndrome aged over 65, the risk of developing dementia is almost 80%. This compares with a risk of between 4.8% and 8.6% among those aged 65 years and older in the general population. The risks are, therefore, very different.

IDS-TILDA, when it comes to translation, has driven the model of dementia care in Ireland with the establishment of the national intellectual disability memory clinic, which gives everyone in Ireland a chance to access memory screening, assessment and post-diagnostic advice. I acknowledge the Minister of State at the Department of Health, Deputy Mary Butler, and the national dementia office for listening to the advice, taking it on and building a world-class memory clinic at Tallaght University Hospital.

We are working hard on areas like brain health. We must tackle things like brain health and create prevention programmes. We are positioned to engage in much-needed clinical trials for this increasingly at-risk group in our population.

More generally, our health findings support an approach that focuses on diagnosis and prevention: health promotion; the creation of care pathways and capacity building within mainstream health services; and the creation of disability-friendly hospitals and healthcare environments that truly understand and embrace what reasonable adjustments look and feel like. This will benefit not only people ageing with an intellectual disability but everyone in society. Failing to adopt such an approach may result for many in a return prematurely to institutional care and the congregated settings they have left or, even more concerning, a move into long-stay nursing homes which are often ill-suited to meet their needs due to a lack of disability-specific knowledge and training among staff. We have demonstrated this trend, with lack of resources, increasing costs and lack of capacity among the workforce, as the key driver to transfer to more supported settings.

IDS-TILDA has also been examining how the family caregiving landscape in Ireland has continued to change. Decongregation and an increased reliance on family caregivers are challenged by smaller family sizes and the progressing age of parent carers, people with intellectual disabilities and, to some extent, siblings, of whom we have seen many. This raises serious questions regarding the sustainability of care for older people with intellectual disabilities in the coming decades.

For participants in the IDS-TILDA caregivers' study, we have seen a growing generational transfer of care from parents to siblings, but many of those siblings said they were the last remnant of care and that they would not transfer that care responsibility to their family members. Although most carers strongly agreed or agreed that providing care made them feel needed, feel useful and appreciate life more, they frequently cited being constantly on call and the stress and emotional strain as difficult. Many found the role confining and expected to be still providing at least the same level of care in five years, and many of them were in their 70s or 80s. Carers expressed a lack of confidence that the State would look after their adult family member when they themselves could no longer do so. Carers' allowances and respite services were acknowledged as helpful, but there is not a comprehensive set of supports needed for caring to continue, nor are alternatives available when caring cannot be sustained in the family home.

IDS-TILDA demonstrates that the lives of people with intellectual disabilities have improved, sometimes dramatically, especially in younger age cohorts. This is particularly true for those with mild and moderate levels of intellectual disability, but not so for those with a severe intellectual disability nor for those living in residential care. Much more work is needed, particularly to address preventable and treatable mortality. IDS-TILDA is documenting the changes

in lives and continuing challenges in ways that no other survey can or does. We now have the strongest data in the world on the physical and social determinants of health and well-being for people with intellectual disabilities as they age. Let us use it wisely to inform policy and the necessary supports to ensure people with intellectual disabilities can age with dignity and pride.

I hope we have learned from the history of our past, a past when people with intellectual disabilities were segregated from their communities. We must not give up on the hard-fought gains we have made within the disability sector. A premature return to institutional care is a serious breach of Article 19 of the UN Convention on the Rights of Persons with Disabilities. Instead, our focus should be driven by the belief our work with people with intellectual disabilities is about not just adding years to life but equally, and critically, adding life to years.

We are grateful for the support we have received from the Minister of State, Deputy Rabbitte, as well as from previous Ministers and various Departments, the Health Research Board, the HSE clinical leads and the National Federation of Voluntary Service Providers, with which we so work so closely. Most critically, people with intellectual disabilities themselves have shaped our understanding of their ageing.

An Cathaoirleach: I thank Professor McCarron.

Deputy Dessie Ellis: I thank Professor McCarron and everyone else for attending. It was interesting to hear we have the strongest data in the world, which we do not normally hear, especially when it comes to people with intellectual disabilities and people who are ageing. That is very informative. Professor McCarron mentioned future-proofing to improve life and longevity for people with intellectual disabilities. What are some examples of how that is done? I would like to get a feel for how we go about that.

Women with disabilities, it was mentioned, die on average 20 years younger than other women, while the men die 15 to 25 years younger. I thought it was interesting when Professor McCarron stated that the menopause occurs at an earlier age. I never would have thought of that. She said something like 50% of women with disabilities were unaware of the transition. How do we approach that? It seems to be an area that needs further examination. How is it monitored and how did we get to that figure?

It was stated there is no system of health checks in Ireland for persons with learning disabilities. Will Professor McCarron tell us more about that? I would have thought we would have some sort of system in place to monitor them, so I am a bit surprised by that.

Will Professor McCarron expand on why people with intellectual disabilities are particularly at risk of living in a congregated setting and the need for awareness raising with regard to their capacity to live independently and contribute to society? Community settings are far better than congregated settings and give us far better outcomes. People who engage in the community tend to have better lives and live longer. Whether they go to church, the pub, a football match or something else, it seems to prolong a lot of people's lives. I do not know whether there are other areas that can be addressed to improve the longevity of people with disabilities. I understand people with Down's syndrome die much younger than other people. Are we making progress on extending their lives by introducing different methods and putting them into proper accommodation instead of residential accommodation? I always feel you are better off remaining in your community. Will Professor McCarron give us her thoughts on that?

Professor Mary McCarron: There were a lot of questions there but I might start with the

last one, about people with Down's syndrome. The ageing of people with intellectual disability is something to be celebrated. This is the first time in history when people with intellectual disabilities have lived to old age. In the 1930s, somebody with Down's syndrome could be expected to live to about 12 years old. Now people are living longer, simply because of better care, interventions, social care, education and all the other things we know are important, but they are still dying earlier than the general population and are at high risk of Alzheimer's disease, in particular. We need to be ambitious for continued longevity and ensure that, as people age, they will continue to live in good health. Moreover, many people are presenting with more complex issues well before the age of 65. Our gerontological services and so on often talk about access over the age of 65. One issue we need to look at is the use of chronological age in terms of access, whereas it should really be based on need. Those are some important issues for us to consider.

As for future-proofing services, when our decongregation started, people with higher levels of intellectual disability remained in congregated settings and we moved people with higher functioning levels out into the community first. When we moved them, it was often with no staff support during the day and there were no staff there at night. Now, as they begin to develop conditions of older age, often 20 years earlier than the general population do, we do not have the infrastructure or resources to address the changing needs. Often, for people who have been moved from the family home into a congregated setting and then out into the community, at a time in their life when they are most vulnerable, they are then moved back into perhaps a bigger congregated setting than that which they moved out of. We really need to understand how we are going to support people to age in the home of their choice independently with supports in the community of their choice. That is a big issue and the commission on care will certainly be looking for older people and examining some of those issues.

When it comes to family caregiving as well, we have to understand that the majority of people live at home with families. Many of these families are ageing. There is often no plan as to how their family member will be supported. Often when that parent or sibling passes away, it is a crisis issue. Not only do the people with intellectual disabilities lose their parent or family member who is their primary carer, they lose their house. They lose their community. They are moved out of everything so they have a multiple of losses. We need to understand. Very few residential placements are coming up. We see the waiting list that there is. We need to understand what the model of care and what mobility options will look like and how we continue to support parents who need support. When people have done lifelong caregiving, we also need to ensure that there is future planning and that there is some place for people to transition into should that happen or else that services are enabled to support that person to continue to live in the family home should that be the case. They are some of those critical issues.

In terms of menopause, menopause occurs early. There are many reasons for this. It occurs much earlier in people with Down's syndrome, at approximately 41 years of age. There is increased risk, if someone has an earlier onset of menopause, of developing other conditions, including poor bone health, but also, in the Down's syndrome population, it is associated with increased risk of dementia.

We are working now with Stewarts Care and try to translate some of these findings to make change and developing, exactly as Deputy Ellis said, educational resources. We have a PhD student who is working with Dr. Burke. Perhaps she wants to speak to that.

Dr. Eilish Burke: We have a PhD student who is working on this particular issue. We anticipate that there is atypical presentation and it may present earlier because we see that in many

other conditions. However, awareness and education are something that should be there and, unfortunately, awareness was very poor.

With my PhD student, what we are developing is inclusive, driven by people themselves. It is a patient and public involvement, PPI, model to develop these educational resources, but that is with one service. What we would envisage is that this would be adopted by the HSE and be shared and driven out among all services, which is really needed.

The Deputy referred to the health assessment. People do get a health assessment. It is a HIQA requirement that they get an annual health assessment. What services have told us is that GPs are under pressure. We know that. They have five- or ten-minute appointments, which is not sufficient to make the reasonable adjustments that people with intellectual disabilities need, but also many GPs are seeing it as outside the normal delivery of care and they are charging an extra €100 for that. People are simply not able to afford that.

An Cathaoirleach: I thank Dr. Burke and call Senator O'Loughlin.

Senator Fiona O'Loughlin: I thank Professor McCarron and the team warmly for being here and for all the incredible work that they are doing.

I was listening to Professor McCarron on KFM a month ago when she was talking about the two-day conference that she was hosting. I just thought I would have loved to have gone and spent the two days and I spoke to the Chair then about the possibility of inviting her to appear before the committee.

I know of Professor McCarron's work with Kildare Down's syndrome association, with Rita and Gráinne, who are amazing women and have done so much. Obviously, they themselves are mums, but they have done so much in terms of the wider population there.

I have a brother with Down's syndrome, who is 49 and who is very much the centre of our home. He is very high functioning, thankfully. Talking about health, my mother thought that his eyesight was failing a little so my brother and I brought him to the optician and he got glasses. Then my mother noticed - he is living with her and she is 88 - that he was not really seeing and he was not reading. He always reads, but he was using his iPad and making the words quite large. I brought him back to the optician and said that maybe his glasses were there wrong ones. They were not, but they had totally missed that he needed cataract surgery urgently. I noted the difference when I brought him home from the surgery and he was out. When he took off the patch, he was actually touching leaves. He is very bright, and the fact he could not articulate that he could not see because he did not realise himself that he was having a problem really made me worry for those who do not have someone who can recognise the signs and pick up the pieces. My mother still gets very upset about it. He is great now, thank God.

In terms of access to care, only last week I met a family I know 40 miles from where they live. It transpired in our conversation that they could not get a dentist - Professor McCarron was talking about oral care - anywhere close to them. They felt lucky that they were able to go 40 miles. Parents are ageing. If this young man did not have the parents to bring him there, he would not have been able to go and get the care that he needed. It strikes me that within the system we have, we need to be able to do better in trying to ensure better health outcomes for, as Professor McCarron said, the preventable areas. When we talk about living with dignity and with pride and living your best life, which all of us should aspire to, we need to do better there.

Through working with the Special Olympics programme, I know that their health screen-

ing is excellent. I have been at world games and European games where the health screening, which is all done by volunteers, has been able to pick up in those from the less developed countries the need for and the provision of glasses and other aids. We always think it is better in Ireland and it is not necessarily.

One of the big issues that we have come up against in all the different groups that we meet is the lack of data. It is difficult to measure and to put programmes in place, but Professor McCarron has the data.

Professor Mary McCarron: We have the data.

Senator Fiona O'Loughlin: It is significant that this is the very last meeting of the joint committee but I would say, no matter who is in place in the next Dáil and Seanad, that this needs to be first on our agenda once again because Professor McCarron has the measurement tools. She mentioned the carers element and respite care, and I completely agree. We need to ensure that carers are valued. A colleague attended the family carers' conference on Tuesday morning. She came back and said that the one thing that she really took from it was that carers felt very devalued as people in terms of what they do for their loved ones, but they need that support and the respite care. Many families are just about coping and if they were able to get access to timely respite, that would make such a difference.

We are talking about people who are living with elderly parents, as Professor McCarron said. Many would be able to live independently within sheltered accommodation. We need to do better on that because it is a worry. It is a worry for my mum. It is a worry for so many mothers and dads.

I had questions but, to be honest with Professor McCarron, she has given us so many of the answers to the questions that we have not asked about what we need to do. Maybe I will ask about two issues that she might comment on: adult safeguarding in the population that she is talking about and, as we have come across in other presentations, the tendency to over-prescribe medication, which is a concern in congregated settings.

I thank the witnesses for all their work and hopefully we will have the opportunity to work together again.

Professor Mary McCarron: Regarding over-prescribing, we are doing a lot of work with the school of pharmacy and pharmaceutical sciences. Dr. Myra O'Dwyer is leading out on that with Dr. Rosemary Gowran, the HSE national clinical programme lead. We are running a study there called EQUIP which is trying to develop a stop-start set of criteria in terms of prescribing. We are often seeing over-prescribing in some areas and under-prescribing in other areas. That is a concern. The prescribing patterns were very much driven by psychotropic drugs and laxatives. We were not seeing the same patterns of prescribing in terms of cardiovascular drugs, all of those medications. Even people who had conditions that one would expect to be painful were often not prescribed medications. This was also the case for some eye diseases. We are looking at this in great detail. Some medications are necessary. We have very high levels of epilepsy in this population, at more than 30% so we do need some of these medications. Our concern is particularly around the psychotropic medications, sedatives and tranquilisers. These certainly need to be looked at.

I want to address another point. In Ireland, we are very privileged to have specialist-trained intellectual disability nurses. These nurses should be in all our general hospitals and integrated

care teams. They should be working in GP practices so that when a busy GP has a problem, there is a specialist-trained intellectual disability nurse there to navigate the issues and support the families and support the disabled individuals to have a better encounter. When we interviewed people with intellectual disabilities they told us that they could talk to their friends and family but that they were afraid to talk to medical or healthcare professionals. We could do this very quickly to address some of those issues if we are looking at solutions. We have a huge issue in identifying sepsis in this population, for example. The question is how we pick up on and identify some of these issues. They are some of the solutions to the concerns but we need to get these people into the integrated care teams. Dr. McMahon will address the issue of safeguarding.

Dr. Martin McMahon: Safeguarding is not something we particularly focused on in our study. I want to pick up on the point about the Senator's brother and his issue with cataracts not being picked up. The progress made in Ireland on providing care for people with an intellectual disability is to be welcomed. They are now living longer. The drive in policy towards community living has created a vacuum with the provision and delivery of care in a quagmire. The issues with the Senator's brother may have to do with him not being linked into or accessing services. We are very much in favour of a social-care model but if people with an intellectual disability are then competing with the general population to access health services, they are never going to win, unless they have the support to do so.

Professor McCarron mentioned the role of the intellectual disability nurse. Traditionally, Ireland and the UK are the only jurisdictions that have registered nurses in intellectual disability. Their role is to look at health surveillance. Everything Professor McCarron spoke about in her opening statement is theoretically preventable. However, we are witnessing the outcomes of what is happening. We need to be able to intervene earlier. As Professor McCarron said, there is one thing we could do very easily and that is to ensure that community intellectual disability nurses are providing care to the person with an intellectual disability. I am not saying that everybody has to have an intellectual disability nurse but if we had a system where their health needs were under ongoing surveillance, I have no doubt that the Senator's brother's cataracts would have been picked up on earlier.

Senator Fiona O'Loughlin: He is attached to a service.

Dr. Martin McMahon: Exactly. We are beginning to see a dichotomy in that we are moving towards a complete community model, which is welcome. However, the vacuum that is created by the provision of healthcare is not being addressed.

Senator Fiona O'Loughlin: My apologies, I have to leave for a vote.

Professor Mary McCarron: Our medical colleagues, doctors, pharmacists and dentists have limited training as part of their undergraduate degrees in dealing with people with intellectual disability. It is a very small part, if any, of the curriculum.

Dr. Eimear McGlinchey: That is an important point regarding awareness and education because as Professor McCarron said, we have a lot of research and data on age- and syndrome-specific health trajectories at different stages of life. To use the example of cataracts, we know they are prevalent in people with Down's syndrome, so there should be an awareness of them at a certain age. It is important that our research and data are included in that education so that health professionals are aware of it.

Deputy Frankie Feighan: I welcome the witnesses. Professor McCarron's presentation on future proofing to improve the life and longevity of persons with disabilities was very interesting and informative. I thank Dr. Burke and Dr. McGlinchey for appearing here today. I have met Dr. McMahon many times in Roscommon and Sligo over the years and we have discussed many topics. Today's topic is very important.

I want to focus on a few areas. The witnesses have said there have been significant achievements. We must take that into account. I was very fortunate to work with Mary Butler and Anne Rabbitte in the Department. They certainly "got it", for want of a better expression. Along with the Minister, Deputy Donnelly, they were very committed. There are many great people, like the witnesses, out there who see this as a vocation. Our job is to assist as much as possible. I thank everyone for the great work they are doing.

The study on oral health and the stark inequalities mentioned by the witnesses struck me. I remember some 20 years ago trying to get an appointment for someone with a disability. Nobody seemed to be prepared to step up to the plate. I am disappointed to see that we are still not really addressing this issue. I know a lot has probably been done but to my mind it is the one downside we are looking at and we need to do an awful lot better. I do not know what can be done but somehow we need to get out of the morass of insurance difficulties or whatever. A few weeks ago we discussed the need for a dedicated team or service to address this. I think it is there but the report highlights that it is simply not good enough.

When we talk about disability awareness we can see that there has been a cultural shift in society. We need to see how people with disabilities are living independently and accessing healthcare and whether this can be initiated on a larger scale?

Will the witnesses discuss the needs of residents in group homes and people living independently who are growing older and the additional supports that aging makes necessary?

In my own area in Sligo we have St. Angela's College, which I am very proud is part of the Atlantic Technological University, ATU. We always say that it is the first university north of the Dublin-Galway line in the Twenty-six Counties and it is going from strength to strength. St. Angela's College provides certificate, postgraduate diploma and masters' courses in the area of disability. Can the witnesses elaborate on what is going on there and how we can assist and where exactly we can enhance opportunities for people getting onto these courses?

I think this will be the last meeting of the committee. The committee has been very united across the parties under the Chair and his assistants. When representatives of organisations have come before the committee they have been treated with dignity and respect. We have listened, which is what a committee should do. I thank my colleagues from the various parties and none for the work they have done. I also thank the witnesses for their work. Sometimes they do not get enough thanks and praise. Sometimes when looking at social media, you would swear the world is falling down, but it is not. It is because of people such as the witnesses who are out there working hard to make people's lives better, including special people with disabilities. I thank them.

Professor Mary McCarron: I thank the Deputy. When it comes to oral care, we are lucky that we have the Dublin Dental Hospital and School. It has taken a very active role in this, Dr. Caoimhín Mac Giolla Phádraig and his team in particular, who are really interested in the oral health or marginalised populations such as prison populations, people with an intellectual disability and the homeless. These are all very marginalised groups. Many of these people were

seeing the dentist; it was not that they were not seeing a dentist. They were seeing a dentist, but their oral health outcomes were worse. What is happening when they go to the dentist is the big issue. Many of them are struggling, as Senator O'Loughlin has said, to be able to access a dentist.

We all know that the biggest determinants of health are education and wealth. This population's ageing at this point is very much influenced by the history of our past, a past in which this population was not entitled to an education. Many of them are not employed and have very little wealth. Many of them will not have private health insurance and will not be able to buy private care. That is a real risk. How long will the wait be to get their hip operation done? Many of them will not have those resources. These are serious risks for this group, because many of them are not rich in either wealth or education. This particular cohort is ageing. It is to be hoped, and I am very hopeful, that future generations will look different, but we have to look after the population that is currently ageing and is with us now. There are some serious issues we need to address regarding the equity of that. Dr. McMahon might want to speak about the programme at St. Angela's.

Dr. Martin McMahon: Similar to us in Trinity College Dublin, St. Angela's also runs a registered nursing course in intellectual disability. That is being led by the programme leader, Ursula Gilrane. The postgraduate in disability studies is being led by Susan Carton. People with intellectual disabilities need to be visible. Historically, we have come from a point where they were marginalised. Specifically, people with an intellectual disability represented only 1.2% of the population in our last census. Even though it is every day as part of our lives, and we undertake work with people with intellectual disabilities and research, it is still a very small segment in society. What we need to do, and what the programme in ATU St. Angela's does, is raise awareness of disability within society. We need to see people with an intellectual disability and disabilities more broadly in mainstream society. By doing that, we can see that people have value and worth, but we need to increase the profile of seeing people with an intellectual disability. That programme in ATU is offered.

Sligo is an interesting area, because proportionally per head of population, there is a high level of disability due to the history of institutions such as Cloonamahon and Cregg House. Then people were put into congregated care from Roscommon, Donegal and Leitrim. Sligo has a high level of disability per head of population in comparison with other counties. That programme is very much about disability studies. I cannot comment specifically on it, but from what I know about that programme, it involves people with disabilities themselves. People with disabilities are delivering some of the content and they are participating. We have to look at the inclusion of people with intellectual disabilities within society more broadly. When the broader society sees people with disabilities and their value and their worth, we can progress a bit more. That is what the study does.

Deputy Pauline Tully: I welcome the witnesses and thank them for their presentation. I commend the work they do. It is very impressive that it is the first study in Europe and the only one in the world that compares ageing between people in the intellectual disability community and others.

As others have said, data is important, and there is an absence of data among issues relating to disability. Without proper data, one cannot plan. That is where we need to be looking at, planning for going ahead. Sometimes we hear, as soon as a child is born in other countries and it is recognised the child has a disability, that every stage of the child's life is planned for, such as the child's school place, home and so on. We need to get to that stage because the HSE in

particular seems to operate continually in crisis mode, where everything is reacting to something and no plan is put in place.

Somebody mentioned people with disabilities living with aged parents and there is no plan for those people if the parents pass away, which is something that worries the parents constantly. Next thing, the person with a disability is put into a residential setting, which may be miles from his or her home and away from everybody he or she knows. It is really hard. Some of the findings the witnesses have for health outcomes for people in congregated settings make me shudder because I am thinking what kind of life people have had in these settings for years on end, where they were locked away and basically forgotten about. It is awful.

I submitted a parliamentary question not that long ago on numbers of people in congregated settings, expecting that the numbers would be going down and that people were being moved out into the community. It has been a number of years since we have moved on from congregated settings and we have had time to move on from that and from a situation where people, unfortunately, would have passed away before that happened. People are still being put in congregated settings, however, and that is really worrying. We also have a large proportion of people under the age of 65 being placed in nursing homes, not by choice but because there is nowhere else for them to go. Again, that is down to a lack of planning, both in housing and in the supports needed to allow people to live independent lives in their own communities. The work TILDA is doing and the studies it has done are really important. Lots of other good work is being carried out by different organisations and there are lots of reports, but they are sitting on shelves gathering dust and they are not being used to plan for the future, which is what is needed.

The issue regarding the overuse of medication has been raised with me by a number of parents of young autistic adults. They are living in places that are not called congregated settings but group homes. There might be three, four or five people living in the home. I am very concerned about it because I have heard it from a number of people where the young people are being prescribed medication and nobody seems to be looking at what medication they are already on, how those medications all interact with each other and the danger that is causing to their physical health. I am not saying all of the homes are like this, but some of them seem to use medication to have an easy life for the staff. As I said, I do not want to cast that aspersion on all group homes, but some people are also being put into these homes without choice. We have the Assisted Decision-Making (Capacity) Act and other Acts. We are supposed to be moving away from wardship of court, and it seems to be taking too long to happen. I am concerned. This relates to some of the things Professor McCarron has said. The work TILDA is doing is fantastic. Many of the questions I was going to ask have been asked, but what TILDA is doing is wonderful, and we need to use it to plan for our citizens and ensure we have inclusive communities where everybody is equal, catered for and valued.

Awareness training was mentioned. That goes across the board as well. Our whole society needs to change about how we view people with any sort of disability, intellectual or physical, because there are still very old-fashioned notions out there.

Professor Mary McCarron: I thank Deputy Tully for those kind words. One comment I want to make is that we have a huge problem in the sector in terms of the recruitment and retention of multidisciplinary team members. Many people, if they are not able to access the proper therapist in terms of psychology, occupational therapy, speech and language therapy or whatever, end up in inappropriate environments or on inappropriate medications in order to manage distress for people. We have to try to understand it. This is not just for the ageing sector. We

are not able to staff the children's teams. This is a real concern. Many children with disabilities are waiting a very long time to access essential services, and that has not improved. In many areas, it has probably got worse, not better. We have a real issue on our hands as regards how to address that issue.

Deputy Pauline Tully: We need proper workforce planning. We are creating a level of dependency if we do not provide the supports to children or people at every juncture of their lives to be able to live their best lives. Even in our special schools, people are coming out without any kind of qualification. It is assumed they will go into a day service. It is not right to assume they will go in there at 18 and remain there for the rest of their lives. The rest of us do not come out of school and assume we will do one thing for the rest of our lives, so we should not assume it about anyone else.

Professor Mary McCarron: Exactly. There is an opportunity to provide lifelong learning, especially for the older population. We have highlighted that as an area that needs to be addressed, what lifelong learning and access to third level education look like. It is critical and affects multiple domains in people's lives. How do we build in the structures to ensure that happens?

Dr. Martin McMahon: On the interventions to support people with an intellectual disability, a point was made about medication. People may present with behaviours that challenge or behaviours of concern. Much of the time, the interventions are longitudinal, with support from the therapists Professor McCarron spoke about. However, when services have a risk they are trying to manage, the use of medicine is innocent. They have the difficulty of trying to balance the health and welfare of the person with those of people providing support, knowing the intervention - for example long-term positive behavioural support, PBS - takes time and resources. Many times medicine and such interventions are used for a reason, for safety, and that creates lots of problems. We have retention and access issues, which augment these problems. That is why, as Professor McCarron described, the problems of psychotropic drug use and hyperpolypharmacy manifest on a practical level, when people are trying to support people with an intellectual disability because the interventions take time to have an impact. Within that, people are trying to manage risk and situations. It is a difficult situation for services to manage with the workforce. The Deputy hit the nail on the head. It is about projections and how many people there are with disabilities. On the front of an interesting report from the UK about children transitioning to adult services, one mother is reported as saying that she never thought her child would grow up. It says it is out of the pond into the sea. We have excellent data in IDS-TILDA. We know the problems and challenges and we should be able to address them.

Professor Mary McCarron: We also need to backstream. We are looking at people aged 40 and over and many of the health issues this population presents with are due to how they have lived their earlier years. It is the same as for the rest of us. We need to follow a younger cohort to see the transition into old age. Very often, especially for young adults with Down's syndrome, there are good services until they reach 18 years of age and then they simply fall off a cliff. They leave children's services and there is nothing for them. That is a major concern.

Deputy Jennifer Murnane O'Connor: Many of my questions have been asked and answered. I thank the witnesses for their excellent presentation. We all know someone who is looking for support or have family members looking for support. I will ask about mental health supports available for people with intellectual disabilities living in the community, independently or semi-independently. What additional supports would be helpful? Funding is a huge issue and we are all aware of that, but we really need to look at it.

From our meetings with all the different groups that have appeared before the committee, I know about the experience of people with disabilities, but there are no data on groups. What are the data on the different groups people attend? Do the witnesses work with the different groups?

There are challenges. I work with families all the time in which a mother might have had to give up work to stay at home with a child who might have an intellectual disability. They do not qualify for carer's allowance because of an income that is over the means-test threshold. We should not be doing that. That has affected many families in recent years. I talk to families every day. We need to do something about that. Through no fault of their own, they need to stay at home with a child, an elderly person or other family member. They might apply for carer's allowance, but if they are in any way over the threshold, they will not qualify. It does not make sense. Many of the families tell me they have mortgages and other bills to pay and they do not know how they will cope.

We need to look at what the system can do to support families, people with disabilities and the different agencies that need support. All the families I work with in County Carlow are excellent. We have all the different groups including Carlow Special Olympics Club and Down Syndrome Carlow. The families are very involved in the different areas and give up their time two or three nights a week. Social outlets are important for people with disabilities. They have their friends they want to meet. It is all about interacting and meeting their friends. People are good, but there is a lack of funding, awareness and education. What do we need to do to support the families who need that support? When people come to me, especially about trying to get carer's allowance, it is hard.

Something important was said here today. I hope we have learned from our past when people with intellectual disabilities were segregated from their communities. We have to move on. It is great that people are living longer. However, while we have done great work - I am aware of the work the Ministers of State, Deputies Butler and Rabbitte, have done - the system is not able to cope as well as it should with the different areas.

I thank the witnesses. We are all passionate. My nephew has Down's syndrome. I am his godmother and he is the apple of my eye, as he is of his family. Every family has a story and we need to support them.

Professor Mary McCarron: I thank the Deputy for her comments. I know families who have a small child with severe medical and healthcare needs and they have that issue. They cannot get the carer's allowance, yet one of the parents has to give up work to look after that person. We should not be dependent on organisations such as the Jack and Jill Foundation for essential care. The funding the Jack and Jill Foundation can give should be the icing on the cake. It should not be providing the package so the family can get away for a night to get a break. That must be State funded. We must understand the package that needs to be put together and the system. Often, the bureaucracy in getting critical resources overwhelms families when they are dealing with such complexity and providing loving and essential care, which they want to provide. It is not that they do not want to provide it. They have enduring love for the family member, but they need help and we need to understand how the system can give that help.

An Cathaoirleach: I sincerely thank the witnesses for their contributions. The important thing is the amount of information encapsulated in such a small number of words about the challenges people face. The challenges being faced by the disability community include attitudes and culture, but also involve funding. There are many voluntary bodies. We have had

many attacks on the State from its foundation when it devolved education and health to the churches. In the 1950s and 1960s, it was community organisations that came together to found various organisation like St. Michael's House, St. Joseph's Foundation and Cope Foundation. It was the goodwill of people in the communities who came together to form them. It is from the communities that best practice is coming within those section 38 or section 39 organisations. We have so far to travel.

This is the final meeting of this committee, but we hope that, over the past four years or so, we have shone a light into a huge challenge that is facing society, not just now, but into the future. The presentation this evening certainly challenges us, as public representatives, and the system to the extent that we cannot even say we have much done. We have only scratched the surface of what is really needed to make sure people with disabilities reach their full potential and have the best possible life. It is more than 80 years since Maslow wrote the theory of the hierarchy of needs. We may have achieved a lot of that for the majority of society, particularly in the western world, but we have a long way to go in terms of disabilities.

I wish the witnesses continued success and thank them for the work. I hope there will be a disability matters committee in the Thirty-fourth Dáil because it is hugely important that we continue to shine a light on the challenges being faced to try to advance the lives and expected lives of people with disabilities.

Professor Mary McCarron: I thank the Chair, and I thank the committee for the important work it does and for the opportunity to present today.

An Cathaoirleach: Before I wrap up, I thank all members, and our Vice Chair, Deputy Tully, who has stepped in on numerous occasions. She has been excellent to work with. All members of the committee have been excellent to work with. Those of us who attended regularly applied ourselves to the job at hand to improve the lives of people with disabilities, their families, carers and communities. Of course, I also thank our team. I know Brenda has left, but Mairead and the whole team were superb people to work with. I wish them continued success in the roles they have.

The joint committee adjourned at 6.43 p.m. *sine die*.