

# DÁIL ÉIREANN

## AN COMHCHOISTE UM NITHE A BHAINNEANN LE MÍCHUMAS

### JOINT COMMITTEE ON DISABILITY MATTERS

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*Dé Máirt, 20 Aibreán 2021*

*Tuesday, 20 April 2021*

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Tháinig an Comhchoiste le chéile ag 9.30 a.m.

The Joint Committee met at 9.30 a.m.

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Comhaltaí a bhí i láthair / Members present:

Teachtaí Dála / Deputies	Seanadóirí / Senators
Holly Cairns,	Ivana Bacik,
Seán Canney,	Alice-Mary Higgins,
Emer Higgins,	Erin McGreehan,
Neasa Hourigan,	Mary Seery Kearney.
Jennifer Murnane O'Connor,	
Pauline Tully,	
Violet-Anne Wynne.	

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

## **National Disability Inclusion Strategy: Discussion (Resumed)**

**Chairman:** I welcome everyone to our meeting. We have received apologies from Senator O'Loughlin.

The purpose of today's meeting is to discuss the progress of the national disability inclusion strategy. To that end, I welcome our witnesses. We are almost six months behind schedule with Covid and everything else. This meeting was due to take place earlier. I extend a very warm welcome on my behalf and on behalf of the committee to Ms Lorraine Dempsey, interim CEO of Inclusion Ireland, and Ms Jacqui Browne, chairperson of the Disabled Persons Organisations Coalition, who is here on behalf of Inclusion Ireland. I also welcome Mr. John Dolan, chief executive officer, and Dr. Joanne McCarthy, head of policy, advocacy and engagement with the Disability Federation Ireland.

I must remind members that they are allowed to participate in this meeting only if they are physically located in the Leinster House complex. In this regard, if members are joining remotely, I ask them to confirm that they are on the grounds of the Leinster House complex prior to making a contribution to the meeting. I ask anyone watching the meeting online and witnesses accessing the meeting remotely, due to the unprecedented circumstances, to bear with us should any technical issues arise.

Before we commence the formal proceedings, I will begin with some formalities. First is the note on privilege. Witnesses are directed that only evidence connected with the subject matter of these proceedings is to be given and are asked to respect the long-standing parliamentary practice to the effect that where possible they should not criticise or make charges against any person or entity by name or in such a way as to make him, her or it identifiable. I advise the witnesses giving evidence from a location outside of the parliamentary precincts to note that the constitutional protections afforded to witnesses attending to give evidence before committees may not extend to them. No clear guidance can be given as to whether or not or to what extent their evidence is covered by absolute privilege of a statutory nature. Persons giving evidence from other jurisdictions should be mindful of their domestic statutory regimes. If they are directed by the Chairman of the committee to cease giving evidence relating to a particular matter, they must respect that direction.

I will go straight into the business of the committee. I call Ms Dempsey, interim CEO of Inclusion Ireland, to make her opening remarks.

**Ms Lorraine Dempsey:** Inclusion Ireland welcomes the opportunity to be here. Since the beginning of the Covid-19 period, in March 2020, we have seen many health and social care services, including disability day services, closed to people with intellectual disabilities. Thankfully, day supports have remained open during the second and third lockdowns, albeit on a limited basis for many and a little or not at all for a few. Inclusion Ireland has previously addressed Oireachtas committees on the multiple suspensions of children's disability services and the lack of educational supports during school closures, which parents report has affected the development of their children, many of whom were regressing. This cessation and then reopening of these services has had a significant negative impact on people, affecting their well-being and independence and the mental health of people with disabilities and their families. Prior to Covid, many people with an intellectual disability told us they felt invisible and poorly treated by mental health services and that they were struggling to access them. Now, given the impact of the pandemic on the mental health of people with an intellectual disability, there is expected

to be an increased need for mental health services as a result of Covid-19. It is vital that the mental health intellectual disability programme is rolled out, funded and established in communities across the country.

More than three years on from the ratification of the United Nations Convention on the Rights of Persons with Disabilities in 2018, Ireland is at an important juncture at which the Government must show leadership in its implementation. The new Department of Children, Equality, Disability, Integration and Youth must show leadership and actively promote the implementation of the convention across all Departments. One crucial element of the convention's implementation is the ratification at the earliest opportunity of the optional protocol. Another important aspect of ratifying the convention is the full commencement of the Assisted Decision-Making (Capacity) Act 2015. The Act was enacted several years ago but is yet to be fully commenced. We need to see action on swift commencement of the decision support service and to ensure that the issue of those being made wards of court as a result of the Act not being fully commenced is redressed as soon as possible. Full commencement of the Act is essential to ensuring that individuals with disabilities have the support to exercise decision-making and choice in their own lives. It also plays a key role in the State's compliance with the UN convention.

The Government's Time to Move On from Congregated Settings policy was clear in recommending that all congregated settings be closed by 2018. This simply has not happened. In total, 8,300 people currently live in residential services, with an additional 1,500 people with a disability under the age of 65 living in nursing homes. According to HIQA, these figures include approximately 2,900 people living in congregated settings. We know the consequences and risks of this arising from Covid-19 over the past year. The convention is clear in its opposition to institutionalised living and on the right of people with disabilities to live a life in the community. It is, therefore, imperative that the Irish State ceases the continued use of institutions that are in clear breach of domestic and international rights and increases funding to accelerate the deinstitutionalisation process.

One of the biggest barriers facing people with an intellectual disability in accessing social housing is the clear lack of available support services that are required for them to live in their own homes. People who need supports in their homes have no clear pathway to apply for these supports. Through our advocacy work we have found that many people report being placed high on social housing waiting lists due to their disability but then not being able to access social housing through their local authorities due to the support services not being readily available at the right time. This must be addressed.

I will now hand over to Ms Browne, my colleague, who will speak on the work of the Disability Participation and Consultation Network.

**Chairman:** I thank Ms Dempsey. I now call on Ms Browne to give her presentation.

**Ms Jacqui Browne:** It is a pleasure to be here. I thank the Chairman, Deputies and Senators for the opportunity to have an input at this sitting of the committee. I am chairperson of the Disabled Persons Organisations Coalition, or DPO Coalition. We are one of the member organisations of the Disability Participation and Consultation Network, and I present this statement on behalf of the entire DPCN. This is a very young group and I will tell the committee a little more about it. We see the development of the DPCN as a very important milestone for the disability community and we welcome the Government's commitment towards its establishment. The overall purpose of the DPCN is to ensure that disabled people and their representa-

tive organisations will be heard directly by the Government in making decisions on disability policy and law. There are four grant-funded members of the DPCN: AsIAM; the coalition of the six national organisations of disabled people, of which I am chair, and which is known as the DPO Coalition; the Disability Federation of Ireland; and Mental Health Reform. As the committee can see, the membership is a very broad church. The membership of the DPCN is also and very importantly includes more than 100 non-funded members, individuals and disability organisations. Representatives from the four grant-funded members, along with Inclusion Ireland, as the network organiser, are involved in establishing the network.

Our immediate task has been the network's response to the State's draft report under the Convention on the Rights of Persons with Disabilities. That consultation process closed very recently, on 9 April. The DCPN organised six consultations, which included anyone and everyone from around the country. In these Covid times everything was online and more than 190 people participated across all six of those consultation sessions. This presented a very good opportunity for the DCPN to connect with the wider membership. Following the consultations, a response to the State's draft report was formally submitted on 9 April.

It has been a very challenging start for the network. It is new; it was established in December 2020. In reality we only began meeting in January, with the timeline of 9 April to be met for submission. The five organisations have been working together for the first time, consulting at the same time with more than 100 members on the State's report. All this has happened within a very short timeframe. Our next priority is to explore how we can formally establish the network and to focus on governance, organisational structures and planning. However, given the substantial increase in the network's membership, with many members being volunteer-led, additional resources are essential to ensure that our participation is genuine, active and meaningful and that the direct voice of disabled people is prioritised at all times.

**Chairman:** I thank Ms Browne for her contribution. I now call on Mr. John Dolan, chief executive officer of the Disability Federation of Ireland, DFI, to make his opening remarks.

**Mr. John Dolan:** I thank the Chairman and members of the committee for this opportunity. We welcome our colleagues, Ms Lorraine Dempsey and Ms Jacqui Browne, who have introduced themselves.

The Joint Committee on Disability Matters requires a complementary mechanism through the Department of An Taoiseach, namely, the operation of a project management function to ensure effective and efficient implementation across the Civil Service and public service area. This is urgently needed.

There are over 640,000 people with disabilities in Ireland and they have a shared reality of poverty and exclusion from many things that others rightly take for granted. The United Nations Convention on the Rights of Persons with Disabilities, UNCRPD, requires nothing less than the will and preference of people with disabilities to be front and centre and, equally, that all organisations, be they State, voluntary, community or private, work together. They all have an obligation to work together to make this great project work.

The DFI has been involved in the implementation of a number of national disability strategies. This is our learning from that. If Ireland uses the same approach for implementing the UNCRPD it will not succeed. The programme for Government commitments to the implementation of the UNCRPD came after the arrival of the Covid pandemic. We now need, and expect to have, to have a strong implementation programme for the remainder of this Dáil. We look

forward to what the budget might bring us in a number of months' time as a start to that.

I will now discuss progress on implementing the UNCRPD, the optional protocol and the State's response. In our opening remarks I laid out a number of important foundations to progress implementation, namely, the new Department and a full Cabinet Minister with disability as part of the remit, along with equality and other related organisations.

Ms Dempsey and Ms Browne mentioned December, when the State published its first initial draft report on the UN convention. This was a very positive move. DFI, as one of the funded members of the DPCN, consulted within our own disability family, people with disabilities and organisations. I want to make some points that came out of that consultation.

Ireland is rich in policy and relevant legislation. We are constantly and consistently weak on implementation. There are notable parts of Education for Persons with Special Needs, EPSEN, Act, the Disability Act 2005, the Citizens Information Act 2007 and the more recent Assisted Decision-Making (Capacity) Act. They are all pillars of disability inclusion legislation, with significant elements of them not having been implemented. That is not a bad place to start catching up.

Ireland continues to have the highest rate of poverty among people with disabilities in the EU. We still have a big problem in terms of having reliable and relevant data on people with disabilities to better target our initiatives and work.

Ireland still has to ratify the UN optional protocol. When the convention was ratified in March 2018 there was a sting of disappointment that the protocol was not ratified at the same time. For God's sake, let the Oireachtas get on with it now and encourage it to happen. There is no substantive reason that cannot be done now.

To conclude before I hand over to Dr. Joanne McCarthy, I wish to state that the DFI position on how well we are doing in compliance can be best characterised as being policy-strong but lacking overall project management. We are not getting on with doing the job effectively. That is the key point.

**Chairman:** I thank Mr. Dolan.

**Dr. Joanne McCarthy:** I thank the Deputies and Senators here today for giving us the opportunity to contribute. I want to welcome my colleagues from the DPCN, Ms Dempsey and Ms Browne. One of the points the committee asked us to cover was amply addressed by Ms Browne, in terms of the role of the establishment of the DPCN. I want to reiterate a number of points the committee has heard from Ms Browne, but they are important and we hope the committee takes some time to consider them.

If we are to truly ensure that our consultation processes hear from the voices and experiences of people with disabilities, our consultation process has to be genuine. Unfortunately, once we were appointed as the four funded members of the DPCN there was a very quick turnaround to gather the input from people with disabilities for the State's draft report. There are over 640,000 people with disabilities in Ireland. They are not all the same and there are many different spaces and locations. If we really want to hear from those most marginalised or those most distant from the political process, we need to be genuine in how we carry out that level of engagement. There is learning from the first round of engagement that we hope to build back into the network.

The methodology employed to identify members of the DPCN has to be commended. One unanticipated outcome was the identification of over 1,000 additional members who were eager to be involved in this process. Again, because of the quick turnaround required of us for our response to the State's report, that level of engagement has yet to be fully realised. We encourage the committee to provide the necessary resources and timelines to enable us to hear from and exercise the expertise in that broader network.

As Ms Browne said, we comprise five organisations, four funded and one co-ordinating member. Some of us have a history of working together on measures such as the Oireachtas disability group. Others do not have that experience, therefore there is a period of time where we have to figure out how to work together in terms of achieving the best possible outcomes for the people with disability we represent. I reiterate the point that there is definitely a need to examine investing appropriately to make sure that the best possible outcomes can be achieved from across the membership.

I want to move on to the impact of Covid. In some ways, it is a bit like Groundhog Day. DFI and others have been before the committee a number of times over the lifetime of this pandemic to talk about the issues. We are all acutely aware of the impact Covid has had on individuals and families, and that has not changed. I want to take this opportunity to commend individuals, families and organisations on their innovation and commitment, which has ensured that people have been protected from the impact of Covid, especially those in residential and day services.

We are, however, concerned that we do not have reliable data to understand how prevalent Covid was among people with disabilities who are not availing of those services. Unlike other countries, we did not gather data on the presentation of people with disabilities to acute and hospital services. That is alarming because international evidence suggests that there would have been a high prevalence of those cases, outside of day and residential services, who may have been affected.

I also want to take this opportunity to remind the committee that the organisations that have played such a critical role in providing, as best they can, some sort of shield to individuals and families during the lifetime of the pandemic are the same organisations that in 2019 came before the Oireachtas to explain the crippling deficits they were carrying. Between them they are carrying a deficit of more than €40 million. Despite the challenges they have faced they have turned into the pandemic, and that is something that should be commended.

There are a number of learnings from the experience of Covid within disability services, something that committee members need to reflect on. The first is that Covid exacerbated what we already knew were some of the big challenges in disability services and, outside of those, within services to disability generally. We know the 3,000 people in congregated settings and the 1,400 plus people under the age of 65 who are in day services are inappropriately placed and were in the eye of the pandemic storm due to the unacceptable nature of their current locations. When the pandemic hit and we had to look at how we safely deliver services, in particular day services, we also began to identify how we are not yet in the position to provide appropriate individualised services and supports. It has been a difficult period both for the 27,000 people who use day services and for their families. We now know from the last tally that there has been a return to day services of between 40% and 50%, and we acknowledge the extra investment in those to try to help them to reopen. There is still a service gap for people with disabilities, and without planning and the resources to deliver much more person-centred services in future, we will always have this challenge in adverse situations.

We must acknowledge the significant investment in budget 2021. For the second time successively for a long time we have seen investment in personal assistants and home supports. What this pandemic has also shown us is that these are the critical services that enable the best responses to be developed to people's individual needs and family needs. It is incumbent on all of us to consider how best we can resource and invest in these models of service as we go forward. They are, after all, in keeping with Article 19 of the United Nations Convention on the Rights of Persons with Disabilities, UNCRPD. They are the baseline for Article 19.

We often lose sight of the fact there are 640,000 people with disabilities in Ireland. A very small number of that population access day and residential and other core national disability services. Most people are users of general health services and these have been crippled during the pandemic. The impact of the pandemic will be carried by these services for a very long time and will inadvertently impact on people with disabilities as they work to have good quality health and well-being. We know from the recent tally there are almost 27,000 people waiting for neurological outpatient services, more than half of whom have been waiting longer than 12 months. We have to address this issue as a matter of urgency. We welcome the acknowledgement in the recent HSE operational plan of the need to invest in disability services. One of the main things from today we are looking for the committee to think about is how best it can support the HSE and others to ensure investment best suits the necessary outcomes for people with disabilities.

I do not know whether I have a minute to talk about the vaccination roll-out. I am sure it is high on all of the members' agendas and they are probably getting many queries in their constituencies around it. It is merely to acknowledge the fact we will pass a milestone at the end of this week or next week whereby all people in day and residential services within disability services will have been vaccinated. Our colleagues within the HSE and within the services must be commended on this heroic effort. I would encourage Oireachtas Members, however, to ensure they complete this programme to people within disability services. There are many people who receive personal assistant, PA, supports and home supports who have yet to receive vaccines. Many of these are vulnerable because of the comorbidities they have to the impact of Covid and we would encourage members to ensure the Oireachtas pushes through and finalises the vaccination of all those within disability services. Equally, we are conscious of the role GPs will play in vaccinating most people with disabilities, and we would encourage members to ensure GPs are receiving the most up-to-date information they can to help in prioritisation.

We are lending weight to our colleagues from Inclusion Ireland, the Carers Association and the Care Alliance on the need to vaccinate carers as a matter of urgency. The symbiotic relationship between individuals and carers is well appreciated. If people with disabilities are vaccinated but their carers are still exposed to the impact of Covid, should they contract it, it puts extra pressure both on families and on the services that provide the added support. Do not forget that carers are the unfunded service providers, and once the State has put the hand out to support those who are funded to deliver day and residential services, we are now asking Oireachtas Members to do the same for the families who provide most of the care within these settings.

I will hand back over to Mr. Dolan for some final comments and I thank the committee for taking the time to listen to our concerns today.

**Mr. John Dolan:** If the way we have implemented the disability strategy so far continues, it will be a failure. The Department of the Taoiseach needs to be leading and drawing in all the other Departments and public bodies with a master plan to do this. The programme for

Government, as I said, after we knew we were in Covid and long before we had any hope of a vaccine, made specific commitments to deliver on the strategy. The budget is now the next obvious place we can see and people with disabilities can see, in their pockets - or not in their pockets - and in their services, what is happening and where we can move on those pieces of legislation and whatever.

People with disabilities must be front and centre, and every other entity and organisation in the State has to come in around that to do the problem solving and to work with people. I cannot emphasise enough that poverty and exclusion are the twin parts of life for everyone with a disability.

Over the past year, thousands of new people entered the world of disability during Covid. Covid will wane but living with a disability will not. That is the challenge. I wish the committee the best of luck. It is brilliant to have this committee in place to draw on a whole range of things. I was excited to see the work the committee did on International Women's Day when it had women with disabilities giving witness to their lived experience.

**Chairman:** I thank Mr. Dolan. We will now go to members. I ask members to be concise because we are just about to the clock.

**Senator Mary Seery Kearney:** I thank the witnesses for their considerable contributions and opening statements. I also thank them for recognising what is positive as well as articulating extremely well what the challenges are. They have my ongoing commitment, as a member of this committee and as a Government party Senator, to advocate, push, lobby and ensure the programme for Government commitments are adhered to.

I come from a privacy background as a privacy lawyer and it is ingrained in me to have privacy by design. One of the things that came out of the meeting on International Women's Day of this Committee on Disability Matters was the idea of ability by design, that everything across Government needs to have that. One of the main outcomes of that for me was to pursue the commencement of the Assisted Decision-Making (Capacity) Act 2015 and to speak about that, and the following Friday I had a Commencement matter with the Minister of State, Deputy Rabbitte, to discuss that very matter. In my previous life, I dealt with how that Act, coupled with the general data protection regulation, GDPR, could empower people with disabilities, when it came to decision-making, in having access to all of their information, so I came to it with a little bit of background in how to deal with that. While I have no doubt the rest of the committee will deal with all of the other serious matters the witnesses discussed, I want to devote my time to the assisted decision-making aspect, if that is all right.

In the Commencement matter, when the Minister of State, Deputy Rabbitte, was replying, she stated the Act is expected to be commenced in full by June of next year but that there are two impediments or delays, the first of which is the setting up of the decision support service, although recruitment on that is under way, and the second of which is amendments to the Act are now needed before it is commenced. Could the witnesses elaborate, for the benefit of the general public and everybody else, on the difference that having the Act in place will make? What amendments would they encourage us to support and advocate in advance of the Minister publishing amendments?

**Ms Lorraine Dempsey:** The public at large do not realise how considerable the legislation is and the impact it will have on lives because they do not understand what the ward of court system means, particularly for an adult with a disability. Imagine not being able to travel out-

side Ireland without asking permission of the courts. Imagine not being able to make medical decisions about yourself and your own bodily autonomy without going through the ward of court system. Imagine someone with an intellectual disability wanting to enter a sexual relationship and get married but not being able to do so unless he or she goes through the ward of court system. These are decisions that, as a community, we take for granted, but certain people, particularly those with intellectual disabilities or mental health difficulties who are made wards of court, are stripped of any power over their bodily autonomy and decision-making. We view wards with intellectual disabilities or mental health difficulties as being incapacitated and they must prove their right to understand anything big in their lives on which they wish to make a decision. The fundamental change under the legislation and through the setting up of the decision support service will be that we will assume they have the capacity to make decisions, and it will be up to the State to prove otherwise. In that, they will be supported with co-decision-making practices. For those who do not wish their families to be part of their decision-making, if issues arise in that regard, there will be an independent support service to help them make decisions that are right for them without the interference from the courts.

**Senator Mary Seery Kearney:** I reinforce that. The whole thing is to move away from the idea of best interests to a place where there is a reverse onus. Once the legislation is commenced, the onus will be on the State and not on the individual to prove his or her capacity. In fact, the presumption will be that there is capacity. This is really powerful and good. It is really important that we get this in place as quickly as possible.

If there were a blank slate and the delegates could make amendments at this stage to add to what is already in the legislation, what amendments would they make?

**Ms Jacqui Browne:** As alluded to by Ms Dempsey, one of the factors impeding the full commencements of the Assisted Decision-Making (Capacity) Act 2015 concerns the mental health legislation. There needs to be a revoking of the lunacy Act and a few other Acts, but issues also arise over detention in the mental health service. It is quite intricate. It is too intricate to be discussed today at a meeting of the committee. On the decision support service, Ms Áine Flynn is very much on top of the matter. Let me outline one of the main things that it would be great to see the committee pushing for in order for the decision-making support service to truly work for us, disabled people, especially those who are very marginalised and excluded and often in coercive or controlled settings or relationships that are unhealthy. The decision support service really and truly must be properly resourced with sufficient staff, expertise and everything else to hit the ground running; otherwise we are going to fail.

**Deputy Pauline Tully:** Good morning to all our guests. It is great to hear from all of them. Since the time is limited, I have some questions I would like to ask. Every member of this committee is very anxious to do what he or she can to implement the UNCRPD but I do not want to see this committee consigned to history as being full of good intentions while having no teeth to get things done. In this regard, reference was made to many reviews, reports and strategies that were prepared but whose recommendations were not, or not fully, implemented. Could Mr. Dolan expand on his proposal to have the Department of the Taoiseach operate a project management function? How can this committee make that happen, and what should we be doing to make something of that nature happen to ensure we achieve what we set out to do? We have had a number of meetings with Ministers and have raised issues with them. I acknowledge that our work has been hampered by the Covid restrictions and that we should have a lot more done than we have but it is difficult when trying to talk to Ministers on a media platform rather than face to face. I find we do not get the answers we want to many of the questions we ask. The

lack of independent supported living, which I see as a cornerstone of the UNCRPD, is raised with me constantly. What we are seeing is a lack of co-ordination between local authorities and the HSE. How can we do something about that and move it on?

What are the delegates' thoughts on how we could address and perhaps reverse the regression the closure of schools has resulted in for many students with additional educational needs? Is there something that could be put in place, such as enhanced July provision and other supports, in schools? The waiting lists for intervention and therapy seem to grow longer all the time. The withdrawing of therapists to do contact tracing has had a negative impact in this regard. We keep getting assured that the therapists are back in place but that is not what I am hearing from many parents. The waiting lists seem to be getting longer. Children who get an assessment of need often have to wait years for any sort of intervention.

**Mr. John Dolan:** I will pick up on the first question and let colleagues pick up on the issue of school closures etc. It is as simple as this: one of the roles of the Taoiseach's Department is co-ordination. It is the Department that supports the Taoiseach of the country. It is our absolute experience that the efforts to achieve implementation to date have fallen down because there was not what I would call a ward boss, or somebody with authority who can ring up any Department and say, "Come on, lads, you need to think this through a bit more and work with other Departments." All the problems people with disabilities have are exacerbated because they have to go back out the door of one Department, go down the street and queue up to go into another Department, local authority or other organisation to actually get things moving. The Oireachtas disability group and the voluntary members, the Disability Federation of Ireland, National Disability Services Association, Inclusion Ireland and Independent Living Movement Ireland — I believe I have mentioned them all but I may be corrected if I have not — looked for two critical infrastructural things in the run-up to the last general election. One was a committee, this committee. We did not come up with the phrase "disability matters"; some other genius came up with that lovely name. It is all about the disability matters in people's lives. We also looked for a Minister of State in the Department of the Taoiseach who would have responsibility for disability matters and who could, in effect, pick up the phone, pull Departments together and go back to the Taoiseach and say we need more in a certain area. It is that leverage that is needed at the centre. We did not solve the unemployment problem of ten, 11 or 12 years ago without a whole-of-government approach to it. It was the job of every Minister and Department every day of the week. The response to Covid has been at a whole-of-government level. It is not just been regarded as a health issue for the Department of Health to solve. If disability and implementing the UNCRPD involve a lived commitment, the Taoiseach's Department has to find a way to put in what I describe as a project management system to help and support and to test that things are happening efficiently and effectively. Public service reform is supposed to be about efficiency and effectiveness in carrying out the commitments the State has already made.

**Chairman:** While I am aware that several members want to contribute on Deputy Tully's points, I am conscious of the time. We are trying to stick rigidly to the timetable so I ask just one of the witnesses to answer on the important points the Deputy raised.

**Ms Lorraine Dempsey:** To respond to the point on therapists being directed towards testing and contact tracing, as far as I am aware this is no longer the case but what we are left with are services that are being delivered predominantly remotely. Instead of being diverted towards testing and contact tracing, therapists are being directed towards assessments of needs and reducing the State's breaching of the statutory obligations to complete assessments within the statutory timeframe. This means any children on intervention waiting lists, or in intervention

but not receiving intervention, have to wait because of the State's obligation to meet the assessment of needs deadline. I understand the Minister of State, Deputy Rabbitte, has invested more than €7 million towards reducing the assessment of needs waiting lists but while children are in a constant loop of assessments they do not get what they really need, which are the actual interventions to make a difference.

Inclusion Ireland came before several Oireachtas committees to speak about the impact of Covid on children in schools through school closures and remote education not working. What we would like to see is a massively expanded summer programme, even larger than last year. This means incentives for more schools to engage in school-based summer programmes because for the most part this is what children really need. What we do not need are parents having to struggle to find tutors or special needs assistants themselves with no centralised database operated by the Department of Education. I understand the spokesperson for education in Deputy Tully's party has raised this issue with the Department. Inclusion Ireland, Down Syndrome Ireland, AsIAM and Family Carers Ireland requested, and received approval from the Minister of State, Deputy Madigan, and the Minister, Deputy Foley, that the Department should set up a regular consultation forum for our organisations in order that we can input collaboratively to the development of measures such as the summer programme. Instead of something that will not be effective being announced, we can be part of designing something that will be effective from the outset. We have written to the Department to establish this group.

With regard to services, Covid has only exacerbated waiting lists. It did not create the waiting lists. What we need is investment. When we do have investment the HSE has a problem with recruitment. I understand it is looking at how we get over this. I cannot see any difference being made in the coming years if we do not produce the required therapists in third level and entice them into children's disability services. Otherwise, we will always have unfilled yet funded posts. This is the direction we are going in. We are at risk of not being able to deliver for children's needs because we simply cannot fill posts when funds are available.

Every other day we hear parents on the radio, in the media and on "Prime Time" expressing how distressing it is to see their children not developing and not meeting their potential because the parents are not been given the right resources to support them. This also goes for schools. We know that allocation of special educational teachers and special needs assistants are based on whole school profiles. Re-examining these school profiles has been stalled. We understand the reasons for this, given the pandemic, but schools will be trying to provide an additional teaching allocation for children with special educational needs based on the same numbers they had four years ago. This is particularly the case for developing schools, such as those with Educate Together as a patron body. We need to see an increase in supports for special education teacher allocations and special needs assistant allocations to wrap around schools, as well as additional therapy supports to ensure children are delivered therapy in the right place at the right time for what they need. If it is school-based so be it. If it is home-based or community based, depending on what the goals are for that child, we need to develop the systems and resources to deliver them effectively for children.

**Deputy Jennifer Murnane O'Connor:** I confirm I am in Leinster House. I thank all of the witnesses. Their presentations were excellent. Ms Dempsey spoke about people with intellectual disabilities being prioritised on housing lists. They should be prioritised, and it is something on which we need to work because we need a lot more support and help in this regard. There are issues with support services. Does Ms Dempsey know of a local authority that she feels is doing it right? Is there a model version? Do we need to look at other jurisdictions? This

is very important. I am conscious that the closing date for the first round of the consultation for the new national housing strategy for people with disabilities closes on 23 April. Have many submissions been made? Is Ms Dempsey happy that it is to close on 23 April?

I thank Ms Browne for her presentation. She spoke about the challenging start for the network, with five organisations within a very short timeframe consulting more than 100 members on the State's report. We need to look at the timeframe. We also need to look at supports. During Covid we have virtual meetings. Does Ms Browne believe that if the timeframe was extended, the network would be able to meet when everyone is vaccinated? I understand we have to get the vaccinations right. Does Ms Browne think this would be the long-term goal? Is the network looking at setting up various teams, such as for transport or social welfare? We see people with disabilities and intellectual disabilities in poverty. Is the network looking at adults or children? Is there a bigger plan for this on which Ms Browne could give us information?

I thank Mr. Dolan for his presentation. It is important that responsibility for disability is being moved from the Department of Health to the Department of Children, Equality, Disability, Integration and Youth. I understand it is progressing very slowly. Perhaps this is something we need to address. I have had several meetings with the Minister of State, Deputy Rabbitte, and it is important that the transition happens very quickly. From working with the Minister of State, and from this meeting where we have spoken about primary care and occupational therapy, I know there are many issues we need to address very quickly. Funding is another issue. We need to make sure there is proper funding.

I also want to speak about the summer programme. We need to get the summer programme right. Various organisations need to be able to input to it, to make sure we deliver a proper summer programme. The closure of schools and home education has been very hard on families and children. This is important.

I agree with Dr. McCarthy that the database is important. It worries me that we do not have a database and it is something we should also look at. To go back to Mr. Dolan, we have to implement our policies. This is something we in the Oireachtas must focus on. It is something we need to make sure that we do.

I thank all of the witnesses. There is so much information that we need to work on and we can play a part.

**Chairman:** Dr. McCarthy has indicated she wishes to speak, as has Ms Browne. I ask them to be brief because we are running against the clock.

**Dr. Joanne McCarthy:** I thank Deputy Murnane O'Connor because the question of data is an issue I wanted to raise. Deputy Tully asked how we would know we were successful at the end of this term. The most important thing to remember is that we do not have the baseline data to understand how we will know. We have it on some things within the disabilities services programme but there is no knowledge of the number of people who require a personal assistant or home support. We do not have these data. One of the key successes that would give a foundation in the world of UNCRPD is having the right data and understanding them.

This is also linked to the question on housing. Often people may get a house but have difficulty accessing the personal supports to enable them to live independently in the house. How do we marry data from various Departments to ensure the most comprehensive person-centred responses can be delivered? We need to tease out some of the challenges on what data we have

and what data we need. The census has been very important but it has gaps. We use data from the survey on income and living conditions, SILC, but sometimes it is very difficult to disaggregate it. We really need to think about what are the data we need. If we look at what is in the draft State's report on the UNCRPD we will see this. Without baseline data it will be very hard to track success or otherwise over the coming years. I encourage the committee to think about the data deficit because it is very important.

The housing issue is critical. Consultation has been quite good. Housing advisory groups have been established in most local authorities. Sometimes they work very well and sometimes they do not.

In terms of very good models, it is almost like a systemic change within local authorities. There are different models. We in the Disability Federation of Ireland are supporting a model in Wicklow, which is powerful. We would welcome the opportunity to come back and talk to the members about that. It is where we work with local authorities to consider how we plan in an inclusive and mainstream way for the inclusion of the needs of people with disabilities within that county in the services we plan. There is a definite need to consider the role that local authorities play because when we think about health we are almost pulled by the nose in terms of the €2.2 billion that is in disability services. However, while that is a lot of money it funds 9,000 places within residential services, allows 27,000 people to access day services, as well as providing a small amount of respite and a few other services. Most people with disabilities never get near that. The role and the importance of local authority planning for their population, which might include 13.5% of people with a disability, is critical. We need to think that through and bring that over to other Oireachtas committees to ensure they also ask those questions in a mainstream way.

**Chairman:** We are running over time. We are hampered by the two-hour rule in terms of Covid-19 and I am trying to allow everybody to get in. I will come back to the witnesses again. Powerful information is being given here and I would love this meeting to go on for three, four or five hours. We need to give the topic that much time but, unfortunately, we are restricted in that regard. I call Deputy Hourigan. I will call Ms Jacqui Browne immediately after Deputy Hourigan's contribution. Ms Lorraine Dempsey and Mr. John Dolan want to come in also so I will do that as best I can.

**Deputy Neasa Hourigan:** I second all of that so I will speak briefly to allow our excellent contributors to give us all the information. I have a couple of short questions. I am very mindful that Mr. Dolan said we have a great deal of policy but not enough implementation. The contributors might unpack that a little for me because I believe we fall down in many sectors in Ireland around the issue of implementation. We talked briefly about data gathering and setting benchmarks to allow us know how we are doing. We may need to address issues around data gathering in light of developments like the "RTÉ Investigates" programme. I would be interested in the witnesses' views on that. That has had an impact on the disability community in the past month or two.

Is the issue about training? Is it about restructuring particular Departments or the way we operate? I want to understand the witnesses' vision for effective implementation across every Department.

In terms of 2021 and being right in the middle of the Covid pandemic, lockdown and so on, hopefully the position will be slightly different in the months ahead. What we experienced during the highest point of the pandemic will be different from what we will experience in the

next 18 months in terms of the road back. If the witnesses have thoughts on that I would like to hear those also.

**Chairman:** I thank Deputy Hourigan for being so brief. I appreciate it. Does Ms Browne want to respond to those questions?

**Ms Jacqui Browne:** Yes. I will try to be brief. There is so much I could say and offer, in addition to the other members and colleagues from Inclusion Ireland and the DFI. I want to remind people of something that has been forgotten about, especially in today's discussions where we talked a good deal about the service provision. We are losing sight of disabled people as individuals and their direct participation in life but also in the implementation of policies and strategies. For too long in this country we have operated in silos. That is one of our core barriers generally. We saw some very good examples of how we broke down silos when it came to resolving many issues around homelessness during the Covid pandemic. For example, very few people who were homeless died because of Covid. That was as a result of partnership in terms of breaking down silos. I urge the members of this Joint Committee on Disability Matters to not forget to take the Convention on the Rights of Persons with Disabilities, CRPD, as their mapping and overarching policy tool. There are only 50 articles in the convention. I urge the members to lead and not impede. In particular, I urge them to look at Article 1, the opening article, which speaks about how disabled people are at the heart of the convention. We should be doing nothing without the direct involvement and representative voice of disabled people and not have others speaking on their behalf. That is very important.

Equally, Article 4 talks not only about the participation of disabled people but also the prioritisation of the voice and the lived experience of disabled people in decision-making and in planning, implementation and strategy. Those are two critical points for the committee to take on board when it is discussing the future and championing the rights of disabled people under the Convention on the Rights of Persons with Disabilities. I hope that helps.

**Chairman:** I thank Ms Browne. We will go to Deputy Cairns, who will be followed by Mr. John Dolan.

**Deputy Holly Cairns:** My questions are for Mr. Dolan but I thank all the witnesses for their contributions. I will be brief also. Mr. Dolan highlighted the disappointment in respect of the ratification of the optional protocol. That would mean the State would be held to account for not allowing people to exercise their own rights under the UNCRPD, for example.

Mr. Dolan also spoke about the lack of housing and supports for independent supportive living. I have two brief questions. First, does he fear that the reason the optional protocol has not been ratified is because there is not the required political will across all Departments, for example, the Department of Housing, Local Government and Heritage, to implement the UN convention? Second, if he has time to answer, what do we need to do to accelerate supportive living and to move away from congregated settings? Is the policy articulated in the Time to Move on from Congregated Settings strategy document a good approach if resourced and implemented properly, or would Mr. Dolan be looking at different models also?

**Chairman:** I appreciate Deputy Cairns being so brief. I call Mr. Dolan to answer those questions and other issues raised by members earlier.

**Mr. John Dolan:** I will do my best. Members might remind me if I miss out on something. I will start with Deputy Cairns' questions because they are most easily remembered. On the

optional protocol, there was a commitment to implement the CRPD in the 2011 programme for Government. It was not done in that one and it was re-ignited for the next programme for Government. There seemed to be a sense that the line that was always being put out was that Ireland is not ready to do this until we have all this other legislation lined up. I thought that was ridiculous in the sense that it is progressive implementation. It is about implementing the convention bit by bit, year by year and module by module. It starts on the basis that many things in one's state are not the way they should be in terms of legislation, funding, services, participation and so on. Am I being cynical in saying that they held that piece back? I cannot see any reason it cannot be done, particularly when a state says it is up for it. We were the last country in the EU to ratify the convention. We then moved very quickly and did something that was ground-breaking, namely, the establishment of this committee. Why do we spoil that by not signing up to the protocol and saying that we will do our damndest to make sure that people have their day in court, if they need it? All other mechanisms have to be dealt with also in terms of that process.

On the Time to Move On from Congregated Settings report, as Ms Dempsey said at the start, it should be history by now; it should have been done. We are talking about approximately 2,900 people. The undertakers of Ireland will solve that problem if it is not taken by the scruff of the neck.

Ms Dempsey referred to 1,400 people. Those are people under the age of 65. While it was right to focus on people in congregated settings and the delivery of that policy, at the same time the State was putting young disabled people into nursing homes across the State, and that number has been increasing every year. There is a small commitment in this programme for Government to start moving people out of those nursing homes. It is down to political will and the confidence of the State to get on and do what needs to be done.

In response to Deputy Hourigan's questions, I totally agree with Ms Browne's points. People with disabilities are the front and centre, as I have said already. Anyone and everyone else comes in to support that, not to speak on behalf of that. Otherwise, the Assisted Decision Making (Capacity) Act 2015 is a joke.

On Deputy Hourigan's point, I mentioned four items of legislation in my opening remarks. There might be others, but those I mentioned are key. It would be great to get the relevant Oireachtas committees to consider them and to actually start pushing them. I will mention one more, namely, the Public Transport Regulation Act 2009. It gave the National Transport Authority, NTA, the right to require private operators providing public transport, for example, buses, to make the vehicles more accessible. It has never chosen to do that, even though it is in the legislation. Therefore, there are many issues across the system, including cultural issues, lethargy and all sorts of other things.

Deputy Murnane O'Connor asked some questions in respect of responsibilities transferring from the Department of Health to the new Department. Let us be clear about it. It concerns the transfer of the disability services programme. There is a whole range of services and supports that fall under the remit of the Department of Health and which should rightly remain under the remit of that Department. People may be in congregated settings, day programmes or residential supported living. They equally and strongly need access to a whole range of other health services, whether they are dental, neurological or whatever. I warn against thinking that responsibility has been transferred elsewhere. It is one of the responsibilities that will have to remain. I do not have a view. It is important that focus is placed on getting the move done right rather than just getting it done. However, it does need to happen sooner rather than later.

Going back to a point made by Deputy Murnane O'Connor on whether there is a model local authority in respect of housing, generally, Wicklow County Council was the first local authority in the State to set up a committee that is almost akin to this joint committee. That county council is the first local authority to start to look at disability in the round. That is something worth looking at. I hope I have not detained members for too long.

**Chairman:** Mr. Dolan has not. The information is hugely important. It is just that we are under time constraints. Deputy Higgins is the next speaker.

**Deputy Emer Higgins:** I thank the witnesses for coming in or logging on virtually today. It has been a most important discussion and it has been great to get a sense of where the witnesses are coming from.

The points Mr. Dolan just made in respect of Wicklow County Council are most interesting because if there is best practice, it is important that we learn from it on a national scale and build to roll it out nationally where it is appropriate to do so.

Another point he made, and indeed other contributors have touched on it already, concerns the Department of the Taoiseach taking a more proactive lead in effectively project managing not just the work of this committee but the implementation of the UNCRPD across different Departments. It is something we have discussed previously at this committee. We have spoken about the potential benefits of setting up a steering group that would have on it a representative from each Department that would set out its own objectives in terms of delivering on the UNCRPD commitments and objectives and report to us on a quarterly basis. If we had something like that, that was cross-departmental in nature, with the backing of the Taoiseach, and most importantly, with goals and targets and a structure whereby it did not necessarily set deadlines but reported on a quarterly basis, as everybody would want to deliver a good update. If we had that, we could create more impetus around ensuring that each of the different Departments is bringing this to its top table and is always considering whether policies are inclusive and how they will work from a disability perspective. We should be encouraging them to always ask those questions and to strive to achieve their objectives under the UNCRPD.

Ms Dempsey spoke well about congregated settings and where we are - or indeed, where we are not - when it comes to progress in that area. I was interested to hear her remarks about the Assisted Decision-Making (Capacity) Act 2015. I know that my colleague, Senator Seery Kearney has touched upon that issue and on what amendments to the legislation might be required. It is something on which all of us here from the different parties must work on a cross-party basis to ensure that when the laws come in, they are as strong and practical as possible and can be implemented.

The discussion has been most welcome. Ms Browne and Dr. McCarthy have made really interesting points. It has been hugely welcome to have this level of discussion around the issues. I know that from Ms Browne's perspective, the network that she is hoping will make a significant difference to the sector requires resourcing and will require funding. That message was heard by me loud and clear - that is for sure. I thank her for all of her work. I would like to hear some more about what is happening in Wicklow County Council to enable us to encourage our local authorities to take a leaf out of its book.

**Chairman:** Does Ms Dempsey wish to respond?

**Ms Lorraine Dempsey:** I can come back to the Deputy's point and tie in with remarks

made by some of the other members.

As Mr. Dolan said, our undertakers are partially responsible for sorting out the Time to Move on from Congregated Settings strategy. They always have been. In the period since 2012, when the strategy was launched, over 1,000 people have passed on rather than moving out to live within the community. The issues with this are as follows. We are both under-resourcing and under-prioritising this as a policy. According to the HSE's service plan for 2021 - and consistently in its service plan every year - the number of people set to move out into community-based settings is under 200. That does not mean those people are moving out to live on their own, isolated from supports; it involves moving the supports out with them.

In relation to housing, one issue is that in cases where people choose to move from a residential setting under the care of a service provider out into social housing, quite often they find it impossible to decouple their funding from the disability service provider, which gets substantial funding for each person that is in a residential setting. While those people might be able to acquire the social housing, they simply cannot avail of it because of that. Under the national housing strategy for people with disabilities, there is an obligation to develop national protocols and frameworks for interagency co-operation, right down to local authority level. The best practices that exist need to be shared, but it must be consistent across the country.

In response to the Chairman, Deputy Moynihan's point, when the Covid restrictions are lifted, I would love to invite the whole committee to visit Inclusion Ireland's offices. In our boardroom, there hangs a picture that was painted by Ms Frieda Finlay, a former chair of the organisation, called Gathering Dust. I have repeatedly mentioned this. It is a painting of probably 300 different documents, papers, legislation, steering group and departmental reports related to disability on the shelves that have never been implemented or have been partially implemented. Mr. Dolan has mentioned four key items of legislation. There is a significant deficit in funding implementation. We provide the legislation and the framework, but we do not actually provide the funds. For example, in respect of the Time to Move on from Congregated Settings strategy, which is part of the HSE transforming lives programme, without exception, it was requested that most of those streams be implemented on a cost-neutral basis for the HSE. That was impossible from the get-go. Project management came in late in the process, three or four years into some of those programmes.

There are good examples of cases within Departments where either legislation or a policy has been agreed in the programme for Government, and from the start a budget has been allocated to implement it, a strong project management team put in place, along with interdepartmental communication, co-operation and, more so, accountability. These are the types of model that we need to see in other areas of disability. A good example is the access and inclusion model under the remit of the former Department of Children and Youth Affairs. It is one of the few policies under the programme for Government and the national disability inclusion strategy that has actually been fully implemented and year on year, it is about improving it and developing its capacity. Therefore, there are good examples of where this works. However, we do suffer from what some refer to as "implementitis". It is significant across Departments. When the new national disability and inclusion strategy is launched and cross-departmental strategies and steering groups are established, we will face the same challenge again. The implementation is poor because they are not funded to be rolled out in any significant or meaningful way.

Deputy Hourigan also mentioned the effects of Covid over 2021 and 2022. Aside from the roll-out of the vaccine programme, we really do not know what is ahead of us in terms of variants and everything else, but what we know is that there has been a significant impact on people

with disabilities both in services but more so in the community. These are people who are not connected to services. They are people who are living independently, albeit with support. We keep talking about services in the context of the HSE, but there are people who can no longer go into their employment because of the risk to their personal health and people are isolated within their communities. I hope that when the restrictions reduce and we look at developing inclusive communities in 2022 and 2023 that we build back better. When we identify people who are isolated by Covid, we must identify those who were isolated long before Covid and ensure we do not leave them behind in the country's recovery.

Deputy Cairns mentioned the optional protocol. Again, it comes down to accountability at an international level for the State. All too often we shy away from accountability, whether it is at a Civil Service level or a political level. We have to wait until we get to the ballot box. This was going to make the State accountable at an international level, where we as individuals have the right to call our country into question. We have the draft report on the UNCRPD. For some, reading that report does not reflect their lived experience. It is a description of the State's systems, with a shine on some of them, but certainly for individuals looking at them, they will say that this is not about them and their lived experience.

Part of the network is being able to capture that.

Regarding intellectual disabilities specifically, Inclusion Ireland works very hard to try to create a platform for individuals to be able to have their say, but that takes time. If there are consultations and submissions to be made, it takes time to work with people with intellectual disabilities to develop their capacity to speak for themselves. Following this meeting, Inclusion Ireland is before the Joint Committee on Education, Further and Higher Education, Research, Innovation and Science where we have a person with intellectual disabilities speaking on the Education for Persons with Special Educational Needs, EPSEN, Act and their experience of special education in mainstream education. It takes time to enable people to be able to speak for themselves. In any Government process, whether it is consultation, input into committees, accommodation or time, it requires us to put in the time and to create a space for people who have the quietest voices in all of this. Whether it is a voice, an augmentative and alternative communication, AAC, device or other means of communication, we need to create that space for them.

Regarding housing submissions, I am not sure of the numbers, but Inclusion Ireland created an easy-to-read survey for people with intellectual disabilities to be able to submit their thoughts into the national housing strategy for people with disabilities. Departments are more open to that, as part of the new standard to involve people with all types of disabilities to be able to communicate their thoughts on the formulation of Government policy, but we need to do more and better.

**Deputy Violet-Anne Wynne:** This is an excellent discussion. I thank the witnesses for their contributions so far and the information they provided prior to the meeting. A wealth of areas could be mentioned, but I specifically want to touch on the optional protocol. I know it was discussed earlier, but I had a recent communication with the Minister of State, Deputy Rabbitte, where she committed to the ratification of the optional protocol once the UN has responded to the State report on the UNCRPD. What is the response of the witnesses to that? We are aware that the Irish Human Rights and Equality Commission, IHREC, recommended its ratification on the same day as the UNCRPD was ratified. I ask the witnesses to comment on that.

I also note that the DFI has discussed its involvement with the vulnerable people subgroup of the National Public Health Emergency Team, NPHE, and the need for the group to continue. Along with other committee members, I called for the reinstatement of the group. I want to raise the matter at today's meeting to get a response in that regard.

Much of the information that has been discussed so far shows the frustration on the part of people with disabilities given the lack of implementation, in addition to the stark figures on the rate of poverty and social exclusion for people with disabilities, which is one of the highest in the EU at 38.1%. Inclusion Ireland mentioned in its submission that targeted interventions are needed in households where there is a disabled person, as highlighted by the ESRI. Could Ms Dempsey touch on that and indicate what interventions are needed to change this trend?

I wish to move on to housing before I finish. It would be great if we saw Wicklow County Council's idea of setting up the committee replicated across all local authorities. That is something the committee could seek to progress in the near future. In the interim, how do we ensure collaboration between local authorities and the HSE? Could we, as public representatives, facilitate that in any way?

Could the committee do anything to address the lack of data or could we work with the witnesses on an ongoing basis to identify where we could fill the gaps and how we could apply pressure in that regard?

**Dr. Joanne McCarthy:** I will respond to a few questions. I was the person who sat on NPHE representing disability. We were hugely disappointed when NPHE's vulnerable subgroup was stood down, because there are so many issues that are so specific to disability and the nuancing that is required. I will give an example. By just vaccinating those in residential and day-care facilities and not extending the programme to include those who receive other disability services such as key home supports, many of those have very complex disabilities and it makes them very susceptible to Covid. It is difficult not having a space to escalate this or to be able to find a space to have it discussed appropriately. I think we are still suffering the ill effects of that. We did and would appreciate that ongoing push because we are not through it yet. We are all talking in a positive way as we are rolling out the vaccine, but we are not out the other side yet. I think it was my colleague, Ms Dempsey, who said we do not know what Covid will look like this time next year, so it is really important that we plan to make sure that we have the best wraparound response to all people with disabilities.

DFI would really welcome the opportunity to come back and to talk about the pilot project in operation in Wicklow and to demonstrate the impact that has had in terms of decision-making and hearing the voice of and the experience of people with disabilities and their families in how they plan their services.

I do not want to take up too much time but if I can, I will make some other quick points on which I did not get a chance to respond. Somebody talked about bringing in each Department once every quarter and that Departments would be answerable to the committee. That is really interesting. We did that under the national disability inclusion strategy so I think there is learning there. If the committee is doing that, the most important thing is to look at what it is asking them to measure against. Everybody in the disability sector is very busy, but are we busy tracking the impact that this busyness is having on the lives of people with disabilities. If the committee is bringing people together and asking them to come in, the types of information they are asked to talk about or give evidence against is really important. We must examine what is being achieved through all this busyness, and how that is impacting on people with disabilities

We must be commended as a country. We have been on a long journey for disability since the commencement of the Disability Act. We have a lot of history and a lot of knowledge around that. One of the key things on which we are consistently challenged is interdepartmental work. Things fall down when two Departments are asked to work together. Someone talked about housing. That has been one of the biggest challenges. Most people with disabilities are not in disability services, they acquire them at working age. If their housing needs adapting and the housing adaptation grant is not sufficient, all of a sudden they are on the social housing list. Their needs can change or escalate, for example, in the case of a neurological condition. They need a home support package in order to sustain their ability to live independently. They need access to a limited number of personal assistant, PA, hours. Less than 0.3% of the disability budget goes into PA hours. Someone else asked what is needed going forward. We do not need more of the same. We are asking members to think about how we invest in day services and decongregation. That is just sorting out where we are currently. We do not need more of that. People want to live ordinary lives in ordinary places so do that one needs one's own home and front door, and access and to be secure in the knowledge that one will get personal assistant and home support hours, which will follow one into one's employment so that one can have a job.

Earlier, people talked about poverty. Almost 15 years later, Indecon is doing another round of research on the extra cost. As we know there is an extra cost associated with having a disability, we do not have to wait for the report to tell us that. We also know that the 120,000 people in receipt of the disability allowance are bearing the brunt of poverty or risk of poverty. We urge the committee to start with them and it does not need Indecon to provide more information.

We have learning, so if the committee brings in representatives of Departments then I urge it to pay particular attention to the measures and find what works, as well as what interim measures does it want reported on. It must assess how Departments work together and should make that a valued measure in its own right. When two Departments need to work on something to deliver a service, the committee must find ways to track that. The committee must remember that it is not about doing the same. It is about how we track things such as the investment in new models, personalised budgets, personal assistance hours and the number of people who own their own homes or live in social housing. They are the most important things to think about.

**Senator Erin McGreehan:** I thank all of the witnesses for coming in today. The debate has been an incredible experience. Every time we have public meetings I am left completely frustrated because there is a relentless need to do so much. A few things have been raised today, including funding and resources, a consistent implementation and an attitude. Wicklow County Council has shown a great attitude towards its disability pilot programme. When I was a councillor, I tried to get disability awareness training to all staff who worked in Louth County Council, and a few of my county councillor colleagues around the country passed that motion as well. Yet, the staff still have not received the training over a year later but it is compulsory for council staff to receive training on climate change. That shows there is an attitude. Disabilities are considered to be separate and something to be tackled at some stage, which is wrong because these people are our brothers, sisters, fathers, mothers and friends. Disability is relentlessly boxed off. While climate change training has been made compulsory, we do not have compulsory disability awareness or access and auditing training for technical staff in county councils. It is all down to personalities and not looking from the ground up, and looking and listening adequately.

The last contribution made by Dr. McCarthy touched on inclusion and some of what I wanted to ask her about. Inclusion and participation in society is down to poverty and exclusion.

Obviously poverty comes from services and supports but not being able to work. Dr. McCarthy mentioned exactly what I was going to ask about the cost of disability. I have seen at first hand that the extra cost of a disability is huge.

Today, many other issues were well covered but I have a few problems with the wage subsidy schemes. There is so much more that we can do to assist people in waiting for wage subsidy schemes, and to encourage and help people. I recognise that yesterday it was announced that €5 million would be available for employment schemes for people with disabilities. Dr. McCarthy has long experience. Can she recommend ways that we can implement a more positive change in trying to get more people actively engaged in working and fulfilling their lives to the best of their abilities?

**Ms Jacqui Browne:** Senator McGreehan has made some very interesting points. I will outline one thing that can be very helpful to the committee to be aware of and which can be of assistance to Members of the Dáil and of the county councils. They have available to them the backbone and support of the public sector duty, which is a position in law under section 42 of the Irish Human Rights and Equality Commission Act. That legislation is available in order that members can encourage and have mandated all of the issues around awareness and training and regarding the implementation of the delivery of accessible public sector services. It would be hugely beneficial for the committee to find out more about the legislation and participate in some of the training or at least increase members' background knowledge on it. We should not forget that option is available. Some county councils around the country and in urban areas are implementing the training very well.

On some of the other points, one thing struck me today, and I mean this with the best will in the world. There is a lot of frustration, we all feel frustrated and sometimes we see a solution in calling for another committee to be established. To be perfectly frank, in my opinion and that of an awful lot of disabled people to whom I talk and with whom I work all of the time, we have too many committees. The problem is we will have too many committees and then there will be no time left to do the work to implement what we want implemented. Sometimes one needs to say stop, step back and undertake a scoping or mapping exercise on how many and what type of disability-related committees exist, on whether there an overlap and whether we are duplicating efforts and thus wasting resources. One will often see the same players and actors sitting on several committees. They are getting no work done other than spending their lives attending committee meetings and saying the same thing in different places. Sometimes we need to take a step back in order that we can come back with a simple, realistic and implementable strategy right across Irish society. We must consider it as spanning the time from the cradle to the grave. We must consider the lived experience of the person and, indeed, the family and parents of children with disability. When we talk about people with disabilities, we talk about them in an inclusive way in terms of parents and partners as well. We do not want four more committees and groups but we need to take a step back. We must analyse everything and refine things. Sometimes we are loath to let go of things for fear of losing something that we think is valuable.

**Senator Ivana Bacik:** I join with others in thanking all of the witnesses for giving their time this morning. The debate has been really interesting and instructive for all of us to listen to their comments and hear about their experiences and views. I appreciate that along with all of my colleagues. It is very nice to see Mr. John Dolan back here, as he is a former Seanad colleague.

I am conscious that a great deal of issues have been covered already and all of us are conscious of the immense impact that Covid has and is having on persons with disabilities. My first

question is on the closure of congregated settings. The issue has been covered extensively and I hear the chilling point that was made about the number of people who died in congregated settings. I am conscious that there is still quite a number of people in congregated settings despite the commitment to close them by 2018. Was that not the original commitment?

I take the point about the difficulty with decoupling funding from service providers where people move out of congregated settings into supported living arrangements. A charity closed a residential service that operated in St. Mary's Centre Telford, which is located in my own area. The closure had an immensely hard and difficult impact on the lives of the people, mostly women, who had been resident for so long and it was their only home. There was no clear alternative in place. I do not know if there is anything we can do, as legislators, so that there are proper step-down and other supports in place where congregated settings are closed, especially for people who have been resident in them for many years and who may be very vulnerable and really open to terrible trauma through closure.

My second point is a very different one, which is to pick up on the creation and establishment of the new coalition, the disability, participation and consultation network. I very much welcome that. At an earlier meeting of this committee I asked the Minister of State, Deputy Anne Rabbitte, about her experience on coming into this sector and about the very many groups that currently represent so many different people and interests within the broad community of persons with disabilities. The Minister of State said that there is a huge number of such groups. Any co-ordination is very welcome and it is good to see. It will only strengthen the advocacy. How can we as legislators support the new network? What is the best way for us to engage with the network to ensure that the voices of those with a disability are heard at policy-making level?

**Chairman:** I thank Senator Bacik. Perhaps Mr. Dolan will take those points and address any of the issues that other members raised.

**Mr. John Dolan:** Senators McGreehan and Bacik and Deputies Wynne and Higgins have raised a number of points and we are short on time. Deputy Higgins spoke of meetings with different Departments and steering groups. I ask the Deputy to think of this committee as pulling together the Oireachtas voice and the Oireachtas questioning about moving on the disability strategy. If the committee has what I would describe as the "project management" function, working from the Taoiseach's office down, one also has the executive side of what the committee wants to do. The committee is on the legislative side and there is also the executive side. Flowing from that would be some kind of consistency of reporting and development of the strategy. Ms Browne, interestingly, referred to the public sector duty. Every Department must do a statement of strategy. I do not believe there is any statement of strategy in this Government that should not be referencing the public sector duty, and no strategy should not reference the commitment to the Convention on the Rights of Persons with Disabilities. On the optional protocol, it was interesting to hear the point made about the Minister of State, Deputy Rabbitte. That sounds to me a bit like the old speak: "We were waiting for somebody else to do it." I absolutely do not see any reason it cannot be ratified now.

Senator McGreehan spoke about the frustration around needing to do so much more consistent implementation. I go back to the point that we need the two pillars. We have one pillar. As I said earlier, in the run up to the general election the Oireachtas disability group looked for two infrastructural pieces, one of which was there would be a committee such as this, which is brilliant to have. The committee is handicapped and frustrated by the circumstances that we are currently in. I know that members are mad to get out and get at it, and to be able to have more people with disabilities, and organisations and groups in to the committee. To be really effec-

tive, are the committee members going to be able to go around and quiz every Department? Not really. This is why the committee needs the Taoiseach's office to put that project management in place. It must be remembered that there is a National Disability Authority that is funded by the State, which could do a lot of the workshops element and the backroom work on that.

Senator Bacik referred to the huge numbers of groups, the congregated settings and decoupling funding. These are big issues. I would also add the other issue of people. Youngsters, people our age and much younger than us, are being given an absolute life sentence of going into a nursing home. The first thing we must do is ask if we can stop one person going in this month and another next month. This needs community-based funding for personal assistants, home help and other supports to wrap around people, and for us to sit down to listen to those people and what they want from their lives exactly. The rest of us come into it in trying to make that happen.

With regard to the huge number of groups, there are two things going on. There is the fundamental right in the Constitution to form associations and unions. The point about there being too many groups keeps coming up. Are there too many political parties? Are there too many independent schools around? There are 1,500 or 1,700 schools that are all independent. Yet, they can work in a unified way. This can also happen with the organisations and groups. Everyone now has to face into being an implementer, a minder and an owner of the convention. We have the script, we have the road that everyone must go down, we have the Charities Act, we have HIQA, and we have a lot of State-funded regulatory authorities to put smacht on organisations and groups. I believe we can move through these but the critical point for the committee members is to get that pillar sponsored by the Taoiseach's office, which is the project management piece. It will make it manageable and it will be the executive part of what the committee is trying to do with the Oireachtas.

**Senator Alice-Mary Higgins:** I thank the witnesses for the great presentations. Many issues were raised. I will put aside the congregated settings. I was very interested to hear what Ms Dempsey had to say around digital empowerment, the web accessibility directive and assistive technology. I would be very interested if Ms Dempsey had something in writing on that, as my time is limited.

I want to talk about the big picture. We have talked about the pieces that need to be done and about the legislation already in play. I will address two other pieces that I feel we need if we are to take leaps forward: the statutory entitlement to home care and the regulation of home care. How quickly and how massively can we scale that up? Has it in fact now moved to the point where we have delayed in delivering these, and the level of ambition has to actually increase to look not just at a statutory entitlement to regulated home care but a statutory entitlement to personal assistance so a person could have that political, cultural and full participation in life? Should we raise the ambition of that as well as delivering it? That is from the individual perspective.

From a societal perspective, reference was made to the public sector duty. I know Mr. Dolan. I co-sponsored legislation with him around how we could put community participation into effect. In this context, I turn to the national development plan and local development plans. The national development plan is a huge amount of capital expenditure. I want both plans trained in on climate change and the UN convention, both of which demand new thinking from local authorities in a really big way. What would a huge leap forward look like on the national development plan and in local development plans?

The Community Participation (Disability) (Miscellaneous Provisions) Bill has been hanging around forever and has never moved forward. If the witnesses were to pick one unexpected or other element, something that is missing from the Bill, what would they add to it? I am looking to what is coming through. I thank Mr. Dolan, and again, I thank Deputy Canney, who has facilitated me jumping his place in the conversation.

**Chairman:** I thank Senator Higgins. Will Ms Dempsey respond to Senator Higgins and perhaps to other points that have been raised in the conversation?

**Ms Lorraine Dempsey:** Yes; if I cannot cover all of them some of my colleagues might jump in. Regarding digital empowerment, Inclusion Ireland ran a right to connect conference last December on International Day of People with Disabilities, which looked at people's access, particularly because of Covid-19, to both the web and the infrastructure, for instance, smartphones and iPads. We take for granted that everybody hits their teenage years and gets access to a smartphone once they go to post-primary school. Some adults with intellectual disabilities, however, do not have any connectivity and have been extremely isolated both when living at home with ageing parents or in services. What we would like to see installed is that people have a right to connect and again, looking a couple of years ahead and at potential future restrictions, that people are supported with the infrastructure, which incorporates things like the national broadband plan, as well as in terms of financing.

The interrelationship between poverty and employment stretches back to education. What education path does a person therefore take? If one looks at a special education pathway from the point of a three-year-old, we know that by the time that person is 18 or 19, he or she will probably still be in a special educational setting. We have to look at the outcomes of that, which is quite often young people going into day services that are more special all the time. That leads us into poverty.

There are two reports the committee should be seeking. One is the cost of disability report that is sitting in the Department of Social Protection. As Dr. McCarthy said, we know the cost of disability and the level of poverty right across the strata of people with disabilities and family carers. We need the Government's report to be able to evidence that in figures that the Government itself will accept, however. The other is the capacity review of disability services. It is extremely hard to plan ahead if we do not have sight of what the unmet need is going to be over the next 20 or 30 years. We know it is significant because the report was there and available to the previous Minister for Health, who passed it on to the current Minister for Health and said it was a decision for the new Government to publish that plan. Again, I ask the committee to chase up the capacity review and have it published formally in order that we actually know what we are dealing with as regards disability services and the unmet needs of people with disabilities in the community.

Regarding the right to home care and the statutory scheme, a person does not have the right to stay in his or her own home and be provided with State support to do so. A person can, however, have the right to go into a nursing home and have the care he or she requires. That is not even suitable for many elderly people, let alone those under 65. Parents must therefore make decisions with their young persons with disabilities. I am a parent and I have aspirations for all my children. For some of my children, however, my choices are extremely limited if I cannot get the funding in order that they can live independently. And again, living independently does not mean living alone without supports. It means being given the supports so that one can live independently of one's family members.

If we look to ageing parents, Senator Bacik referenced St. Mary's Centre Telford. In the HSE's service plan for 2021, outside of emergency residential placements there is only provision for double-digit figures for planned transitional residential placements. That means significantly fewer than 100 people will be able to plan where they are going to live in the community with the required supports and everybody else will be pushed into emergency placements. At this stage, emergency placements are what we are talking about when parents die. That is a traumatic time for anybody with a disability but to be removed from one's family home and put into an emergency placement, quite often respite, which then means those who would normally have respite in that centre cannot have it there, especially during the time of Covid-19, is no way for future planning for anybody. That is what we are resorting to, however. For the first time in the HSE service plan, therefore, there is provision for planned transitions, that is, incorporating the voice of the person with disability into what they want, for example, who they want to live with, where they would like to live and what life they want to lead. It is led by them. Out of a country of 5.5 million people, however, we have provision for a double-digit number of people to engage in that process. That is scandalous. And when one adds in the 2,900 in congregated settings, I am talking about individuals who are currently living at home. There is very little focus on that cohort. We really need to readdress this in terms of actual transition planning with the voices. That is part of what would be required for the State to meet its obligation in terms of the right to statutory home care

I mentioned broadband with regard to the national development plan. Senator McGreehan mentioned disability awareness training versus having awareness training around environmental issues. If we had both, the Senator would realise that, for example, straws were developed for people with disabilities. They were not developed to put into a cocktail along with an umbrella. The removal of things that contain plastic, such as straws, removes something that is fundamental to some people's ability to drink independently. If, therefore, we have awareness training, which like everything else is siloed, we will miss the impact on certain cohorts within our communities.

**Deputy Seán Canney:** I have been listening and taking notes as both our members and guests spoke. I thank the guests for their input. I have written down a few key words but one thing that is becoming abundantly clear and is most important is the fact that we need an implementation programme for everything we talk about. I will go back to what Mr. Dolan said about the role of the Taoiseach's office in all this. We have enough reviews, committees, working groups and all these types of gatherings. A huge amount of people have brought forward parts of the problem within this area of disabilities. I have come across some of it myself. I do not know where to jump when I want to find out something because there are so many places one can go. Usually, one goes to five places before finding the place one needs to get the structure right.

Mr. Dolan alluded to the fact that when we had a jobs crisis, it was a cross-departmental issue. It was also targeted, however, by which I mean a plan was set out for five years with a target every year. There was a review every three months, however. The Minister in charge of it and probably one or two people in his Department, therefore, monitored what was happening on a quarterly basis. If something was not happening, they asked why it was not happening. It was flagged up with colours where red meant something had not moved and green meant it had moved and been achieved.

As my background is in project management, I like the term "project management approach". We need to set out a five-year implementation plan, not a strategy; we have enough

strategies. There have been remonstrations. People said they spoke to the Minister of State, Deputy Rabbitte, about the optional protocol. That can be done when something else is done. The question is who is doing that other thing to make sure the protocols are put in place.

From listening to the debate, the expression I would use is we have a fragmented approach at the moment. Too many organs within the State are doing bits and pieces. Somebody mentioned that a €5 million fund was announced this week for employment for people with disabilities. I did not know about it until I heard it today. Things are happening that we do not know about. We also need a co-ordinated approach to this in order that we know what to expect and when it will happen. Then, we as a committee can challenge why something is not happening if it does not happen on time. It goes back to that.

We have seen today, no more than any other time we meet witnesses, that we are learning more and more. I am, however, more drawn to the conclusion that we need to do what Mr. Dolan said and put pressure on the Taoiseach to put in place an implementation team with somebody at its head who will call the shots and ask why this and that is not being done. We need to bring together all the departmental officials to say this is our plan, this is how and when we will do it and then put the funding in place in order that it is achieved. The legislation that is required to change things should be put in place in a proper timeframe rather than waiting for somebody else to do something.

It has been very interesting to hear what the witnesses had to say. I can sense the frustration in everybody around these issues. We need to be able to say when we will be getting on the train and starting to move towards getting things achieved and ticking the boxes that have not been ticked. I said at the first meeting of this committee that my aim is to work to remove some of the things that I personally, as a politician, am not very proud of when it comes to disability services. There are issues we need to address very quickly. I thank the witnesses for their input and look forward to working with them to achieve what we are all trying to achieve, namely, putting the plan in place, with somebody at the head of it who will call the shots and get it done. The funding must be provided by Government and looking to the Taoiseach's office is the way to do that. When the Taoiseach says at or before a Cabinet meeting that he wants a report on something, he will get that report. We need to have a person at the top who will make sure this is a national issue rather than being segregated off and spread all over the place, with nothing being achieved other than frustration.

**Dr. Joanne McCarthy:** I thank Deputy Canney and Senator Higgins. There is a kind of commonality in the issues they raised. I am delighted to see the integrity with which members have listened to us today. I can really hear it in the questions they have asked and that is very welcome. One of the key points to make is that there is a great deal of detail to consider because the area of disability is dense. We know that because we work in the field. Several times, members asked me questions and something popped into the back of my head but I still cannot give a simple answer. The whole subject is really dense.

One of the key points we are taking from this meeting is that we all would really welcome a role for the Taoiseach in the implementation plan. Looking to see where that stitch can be made is very important. Another point is that we need a plan that is not just around telling us how much is going on and the activity that is happening. It would be hugely welcome to have it built into the plan that there would be a consideration of the impact of that activity. We know there is a plethora of policy and legislation that is hanging around and has not been delivered. That needs to be front and centre of the plan in order that we can begin to tick through it systematically. The policy and legislation are there and they have to be implemented.

Senator Higgins spoke about the big things that need to be done. We too often think about disability services in terms of little boxes. We talk about the people who get day services, for example, and the people who get personal assistance hours. In fact, the convention asks us to think about what we have to do to ensure people can have ordinary but good-quality lives in ordinary places. Article 19, one of the core articles in the convention, deals with the right to live independently. We need to ask whether people have the right to personal assistance hours and whether the State is planning for the appropriate hours. We talk about a statutory right to home care services. That right will be a noose around the neck of many people with disabilities because, although it will give them the right to have someone come into their home to get them out of bed in the morning, they will then be trapped like a prisoner in their own home because they will not have the personal assistance supports to enable them to attend further education, go to work, do the shopping or meet friends. No single Department can answer the right of people to have a good-quality life that is worth living in the community.

When we think about the implementation plan, we must go through the Acts and policies that are yet to be delivered. Then we have to think about the fact that doing more of the same is not going to give us what we need. We need to think about our expectation and what is put into the system to invest in delivery. We have talked about the digital poverty experience of people with disabilities, an issue that the Disability Federation of Ireland and others have been talking about for some time. We highlighted that issue at an Oireachtas committee meeting we attended in 2017. It took a pandemic, when everything went online, for us to see the real lived evidence of that. People could not access any services because they did not have access to computers, were not trained to access them or were living in places with broadband blackouts. There is a reality we have to think about in terms of what is required for people and the fact the answer will not always be day services, residential care or nursing homes. We need to think about the other models we want to put in place.

Senator Higgins spoke about ambition and aiming high. In the context of an implementation plan, we should look at each convention article and name the multiple Departments that will have a responsibility to deliver on that article. There is also a need to name any challenges that arise between two Departments or agencies working together that are hampering the delivery of an article. An expectation should then be put in place, over two years, four years and six years, around where they need to get to in achieving that delivery, and that is what people will be brought before the committee to discuss.

**Chairman:** I thank the witnesses for attending, giving their insight and answering the questions as best they can. I thank members for attending the briefing this morning and tuning into the meeting. It is hugely important that we continue this engagement. The frustration of members is clear. The restrictions over the past six months mean we are finding it more difficult to do our work and continue the work that is in place.

A number of points came across this morning. One is the importance of a whole-of-government approach or a direction from the centre of government in terms of how we are going to implement change and ensure disability is kept to the forefront. I thank the witnesses for the invitation they issued to us. We would dearly love to meet with them in their places of work and see what is being done. We commit to doing that the very minute restrictions are lifted.

Another point that came across is that there is much work to be done to knit everything together. There is a sense in some arms of the State that there should be a centralised model or approach. Likewise, we get the sense from the various section 39 organisations with which we have engaged that the approach should be streamlined. I am not sure that is the right way to do

it, because differences can be useful. For instance, the point that was made about the different types of schools shows that things can all work under the one umbrella provided the policy is right.

In my view, the fundamental issue underpinning all of this is the question of resources. We have seen how the limited change there has been since the budget in reversing cuts and putting in further funding has somewhat eased the situation. Several members spoke about how the provision of therapies and assessments of need is in an absolutely shambolic state right now. We need to advocate on behalf of the people who need those services. The witnesses' evidence has shown us that there is a lot of work to do. The new word for my vocabulary is "implemētītis". It is a concept we need to take away from this meeting. We have had enough talk about what we need to do. Certain Parts of the Disability Act that was passed almost a generation ago have still not been enacted. These are issues we need to tackle as a committee. We must have a whole-of-government approach. Our hope is that we will have representatives from every Department before us to discuss how they are implementing the UNCRPD and making changes in how they deal with disability issues. That is our hope and ambition for the service.

I thank the witnesses for their engagement. We look forward to further engagement with them as we try to advance the lived experience of people with disabilities. We need to keep that at the forefront. On the point about the title of the committee, that was decided on by the committee itself. We will continue our work on disability matters and I thank witnesses sincerely for their help in this regard. I wish them well in their continued good work and look forward to further discussions with them. I would appreciate if members could remain online for a brief private discussion.

The joint committee went into private session at 11.29 a.m. and adjourned at 11.31 a.m. *sine die*.