

DÁIL ÉIREANN

AN COMHCHOISTE UM NITHE A BHAINNEANN LE MÍCHUMAS

JOINT COMMITTEE ON DISABILITY MATTERS

Déardaoin, 30 Meán Fómhair 2021

Thursday, 30 September 2021

Tháinig an Comhchoiste le chéile ag 9.30 a.m.

The Joint Committee met at 9.30 a.m.

Comhaltaí a bhí i láthair/Members present:

Teachtaí Dála/Deputies	Seanadóirí/Senators
Holly Cairns,	Alice-Mary Higgins,
Seán Canney,	Mary Seery Kearney.
Emer Higgins,	
Jennifer Murnane O'Connor,	
Violet-Anne Wynne.	

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

Business of Joint Committee

Chairman: Apologies have been received from Senators McGreehan and O’Loughlin. Before we begin, I want to address recent media coverage regarding the cancellation of a private meeting on 16 September. I firmly believe the media coverage misrepresented the commitment and work of the committee and members individually and as a group in respect of the issues we are charged with discussing. This caused hurt to members but more importantly to the relationship between the disability community and the committee and the community’s trust in the sincerity of the committee over the past 12 months. Since its establishment, the committee has focused on issues and on ensuring that the lived experience and analysis of those with a disability, their carers and disabled people’s organisations inform its work. This is a hugely important committee. We believe the voice that people with disabilities have actively taken under the UN Convention on the Rights of People with Disabilities must continue to influence and inform policy and be heard by all sectors of society. This is crucial work for the committee in a society that has marginalised and excluded people with disabilities over time and its history. There is transformative power behind the motto “nothing about us without us” and our committee takes this very much to heart. The implementation of the UNCRPD, which this committee is focused on, must be at the forefront of what we do.

I cannot say how proud I am to have worked with the committee and all of its members over the past 12 months. It has been a privilege to watch the commitment and sincerity of each member of the committee as we discussed issues and witnessed powerful testimonies brought before us. With each committee member from Dáil Éireann and Seanad Éireann, together with the disability community, I want to work to build a consensus between all so we can deliver for people with disabilities, their families, their communities and their carers as they go forward.

Participation of People with Disabilities in Political, Cultural, Community and Public Life: Discussion (Resumed)

Chairman: The purpose of today’s meeting is to discuss the participation of people with disabilities in political, cultural, community and public life. I extend on behalf of the committee a céad míle fáilte to Mr. Joe McGrath, vice chairman of the National Platform of Self Advocates. From the Irish Deaf Society, I welcome Ms Elaine Grehan, advocacy manager, Ms Lianne Quigley, chairperson, and Mr. John Sherwin, CEO. From LEAP, I welcome Ms Rachel Cassen, co-founder, and Ms Deirdre Fitzgerald-Graham, board member.

I remind members they are only allowed to participate in the meeting if they are physically within the precincts of Leinster House. In this regard if members are joining the meeting remotely I ask them to confirm they are on the grounds of the Leinster House campus prior to making a contribution to the meeting. As witnesses are accessing the meeting remotely due to the unprecedented circumstances, I ask anybody watching the meeting online to bear with us should any technical issue arise. I now invite Mr Joe McGrath to make his opening address.

Mr. Joe McGrath: I thank the Cathaoirleach very much for the invitation to speak today. I am the vice chair of the National Platform of Self Advocates. We are Ireland’s first independent disabled person organisation, DPO, run for and by people with an intellectual disability. We have more than 350 members all over Ireland advocating for their rights in forums such as this.

When we talk about participation in public and political life we do not just mean voting and being elected. We mean all activities and decision making that affect the public. The UN Convention on the Rights of Persons with Disabilities, UNCRPD, is very clear that states have to guarantee the rights of disabled people as voters, candidates and officeholders at all levels of government. Participation means more than coming along one day to a meeting and telling our stories. Participation for us means we should be involved in running events, chairing consultations, writing up reports and deciding what the solutions are.

People with an intellectual disability are not involved at every level of government. We are not employed as experts in the Civil Service. We are not elected to public office. We are not even represented on all the departmental consultative committees. The State does not seem to understand that many of us are not readers, do not write or do not have access to technology. We are excluded from participation when we are not given the time or the supports we need to communicate. We feel we are only allowed to participate in story-telling and not in decision-making.

The UNCRPD says that states have to encourage the participation of disabled people through their own DPOs. This includes funding. When we are fully funded we can bring the voices of people with an intellectual disability into different forums. We have taken part in personalised budgets and Make Work Pay. We deliver training on the Assisted Decision-Making (Capacity) Act. We are empowered advocates but without funding we still have very little power. When funding stops, all our time goes towards finding money and our advocacy work stops.

If we want to be heard we cannot join bigger disability groups. We need to keep our own independent voice. We have lots of evidence that when we merge with other groups our voices are silenced. Other disabled people do not always understand the extra barriers we face and they do not always advocate for accessibility or include us in how decisions are made. We want the State to give funding for a wide range of DPOs so that unique groups can have their voices heard. If there is competition for funding for advocacy activities, prioritise DPOs. This may mean taking money away from service organisations and giving it to DPOs instead. The State needs to communicate with people with intellectual disabilities in accessible ways or we cannot participate. This means providing information in accessible formats such as easy-to-read English and videos, and giving us time to respond to information. Calls for submissions should be published long in advance of deadlines. Many of us rely on supporters to give us information and to assist us in telling our stories. This takes much more time than is usual.

The best way to engage with the National Platform is to invite its members to a meeting of only people with intellectual disabilities. This gives us space to talk about issues that affect us. We find that when we are mixed with other groups, people do not give us a chance to speak.

We want the State to include us in policymaking from setting the agenda to implementation and evaluation; make sure the public process is accessible in how it is organised, scheduled and run, and include people with intellectual disabilities in the design and chairing of events; guarantee that our unique voice will be heard and heeded; and require that all official information is provided in accessible formats from every Department, not just information about disability issues. People with intellectual disabilities have the right to be included in every part of life. We want the State to train public servants on the Convention on the Rights of Persons with Disabilities, CRPD, and the public sector duty; and employ people with intellectual disabilities in the public service as advisers and access champions.

Chairman: I thank Mr. McGrath for his contribution. Ms Grehan will now give her open-

ing statement.

Ms Elaine Grehan: I will stand as I make my opening statement so that the interpreter can see me clearly. I thank the members for inviting us here today. I am here with my colleagues Ms Lianne Quigley, chairperson of the board of management, and Mr. John Sherwin, who is the chief executive officer. I am the advocacy manager in the Irish Deaf Society, IDS. The Irish Deaf Society is a national deaf-led organisation, a cultural and linguistic minority. Our aims are to serve the best interests of deaf people and their welfare. The IDS is a recognised disabled people's organisation, DPO, under the UN CRPD.

We have the Irish Sign Language Act 2017 which states that deaf people have a right to access public services in their first language, which is Irish Sign Language, but it does not always happen. I wish to talk about Articles 29 and 30, which specifically address the deaf community. In Article 29, there are seven points I wish to explain. There are no deaf Members in the Dáil or Seanad. Recently three deaf people put themselves forward for public representation but were unsuccessful. I hope the three deaf people who did that will be role models to deaf people who may in future consider doing the same. Their experience was very challenging, with many barriers when putting themselves forward as public representatives, particularly with the additional burden of seeking interpreters and translation in different Government meetings, and accessing funding. There was a negative bias towards deaf people putting themselves forward as deaf representatives.

In regard to education, language, training and resources, the IDS encourages and empowers deaf people to make representation to Government organisations at national, regional and local levels.

In regard to voting, deaf people understand voting and elections but do not have Irish Sign Language access to watch political debates which happen during election time. Leaflets, information, posters and so forth are not accessible as they are all in English. When candidates go door to door canvassing, there is also the communication barrier at the front door. Many deaf people have a basic education due to the provision of education they received, so literacy levels can be low, which impedes access to information. In regard to the news and what is happening at election time, information about candidates or political parties, their manifestos, what policies they are promoting and so forth, there is much lengthy discussion on such matters. However, deaf people get only limited conversation and dialogue in the social arena on these. For example, they get limited information on the RTÉ News, they get just five minutes of information about what is happening rather than the longer dialogue other people receive. Deaf people therefore feel left out and excluded. They are language deprived from the information. They do not have a full knowledge of candidates and who would be best for them to vote for.

Local deaf clubs have invited Deputies to come to the clubs or to where deaf people gather. They would like to hear their political manifestos and their campaign but they do not always get access to that.

A recent survey for the DPO Coalition, of which IDS is one of the founding members, found that 24% of people with disability have difficulty in accessing their right to vote and that 55% have difficulty in contacting their local representative. The survey proves that the best way to improve the lives of deaf people is in one of two ways. Government should provide core funding to DPOs, for example, to do research to show the experience of deaf people, and fund the IDS to enable deaf people become more involved in political life. This survey will be published in the near future.

The IDS, as a DPO, has representation for the deaf community. However, it does not receive enough funding to link in with local government or on a local or national level. The Government has asked DPOs to consult different organisations, but we do not have the funding or the resources to enable us to do this. IDS recommends that the Department of Children, Equality, Disability, Integration and Youth should take an active role in facilitating this consultation process with DPOs to get the information across to Government.

The IDS would like to see Government use and promote a social model of disability, as is recommended in the UNCRPD. How do we make this social structure? We need to ask people with disabilities, not the other way around. It is not a disability issue; it is an equality issue. It is not a charity model or welfare we are looking for.

As for other points under Article 30, the Citizens Information Board, CIB, and sign language interpreting services are running a pilot project at the moment in terms of access to interpreting services for cultural, sporting and other such events. This is what was enacted in the ISL Act, so we expect to see the results of this and the deaf community's participation using this pilot project. We very much want to see it become a permanent structure within sign language interpreting services in order that we will have this model of providing interpretation. At the moment we are very much lacking in information on ISL and there not being enough interpreters. That creates additional barriers for deaf people in their cultural lives, attending museums and suchlike. Deaf people's choices in life are very limited. They have to plan long in advance of an event if they want to go to it and they have to have a lot of patience. They have to wait and then see what the choices they can access are. They are significantly disenfranchised compared with other hearing people. Grants are available to cultural organisations, but what we need to see in those grants is a stipulation that interpreter access must be provided because deaf people need to access services through ISL.

Oftentimes the media are not accessible to deaf people. There is a bigger focus on subtitling than on ISL. Subtitling is in English, and English is not the first language of the deaf community. As I mentioned earlier, many deaf people have literacy skills. Some are able to read subtitling really well and some are not, but the majority of deaf people would prefer ISL access. Sometimes you think subtitling will be there and you turn on the TV and it is not there. Subtitling is not reliable, and there is very sparse ISL programming provided. The Broadcasting Authority of Ireland, BAI, insists on targets for broadcasters to meet, and subtitling is included in the provision for deaf people, but very often the subtitled programmes are just repeated at unsociable hours, meaning that the target is met in a distorted way. We know the quality of subtitling is unreliable and we may report this, yet it still goes ahead and the poor subtitled programmes are still included within the targets. There was a TV programme that was on called "Hands On". It was produced by Mind the Gap Films and RTÉ. It ran from 1985 right up until 2014. It had 18 seasons and then it stopped. IDS has pleaded with RTÉ that we would really like to see this specific deaf programme back on the air. Many of our people who are deaf were presenters who worked on that programme, on either the technical side or the presenting side. They ended up going abroad to pursue their careers because the programme ended.

I thank the committee for having me.

Chairman: I thank the IDS for its presentation. I now call Ms Rachel Cassen to make her opening remarks.

Ms Rachel Cassen: Thank you, Chairman. Actually, our opening statement will be read by my colleague, Ms Deirdre Graham, and I will contribute to the proceedings later if that is okay.

Chairman: Okay.

Ms Deirdre Fitzgerald-Graham: I thank the Chairman and the members of the committee. My name is Deirdre Fitzgerald-Graham. I am a parent of three young children, one of whom has a disability, living in Galway. I am a board member of LEAP. I am a PhD scholar and lecturer in children's studies at NUIG. The committee has already met my colleague, Ms Rachel Cassen, who is the co-founder and director of LEAP. She is also a parent of two sons, one of whom has a disability, living in Westmeath. Our opening statement relates to community participation.

LEAP is a family-based, non-profit organisation that assists families of children with disabilities to take action for an inclusive life. We work with families, people with disabilities and their supporters and allies. We focus our efforts on increasing expectations of what is possible in the lives of people with disabilities. We work with families with children with intellectual disabilities. We believe the ordinary life is the most precious of all and the term "special" does people very few favours. We know an ordinary life, a typical life, produces better outcomes for people than segregated pathways.

We believe much of what is good in life is not in the currency of money, that we can lose years, decades even, in the struggle to obtain more services and more resources and that, ultimately, our children's lives are here and now. Many families of children with disabilities and their representative groups are clear on what they are against and what is not working but less clear on what they are for and what is working. We believe families who have a family member with a disability need support not only to survive but to thrive. To achieve this, we explore the idea of what a good life looks like with families through visioning and planning. We assist families to develop and articulate a strong and compelling vision of a good life. We do this to counter the culturally held low expectations of people with disabilities. We assist families to plan in order that the elements of a typical life are more likely to be present as a child grows to adulthood. We encourage families to aim high and to focus on an ordinary life with valued roles.

This work involves ongoing conversations with families typically held around the kitchen table. Since the start of the pandemic, however, these conversations have moved online and happen through our family leadership webinar series or our online visioning and planning sessions. The seminars we deliver include topics such as developing a vision of an ordinary life for your family member; an introduction to inclusive education; celebrating families through sharing stories; supported decision-making for children and young people with disabilities; safeguarding the future; family advocacy; planning for life after school; creating community in the street where you live; and getting a life, not a service - how to utilise individualised funding.

As a family-based organisation, we assist families to figure out what we can do for ourselves, then what we can do with others and then when we need outside help. We focus on belonging, relationships and valued social roles. Many families have found that this approach has a better track record than relying on services to figure it all out. This is important not only at crucial life stages such as starting a new school or leaving school but also when considering leisure and lifestyle options for our children, such as joining clubs and other groups. We believe it is essential to connect with other families and to work with people who are positive, have high hopes and are creative and who have managed to create good lives for their own family members.

We encourage families only to dip their children's toes in special or segregated services and

not to immerse them in those services. We know the earlier a child deviates from the ordinary life path, the more difficult it will be for him or her to return to it. For example, if you attend a special school, the opportunity to partake in typical milestones such as work experience or having a part-time job are often lost. This makes it extremely difficult for a young person to rejoin the typical life path on leaving school.

Why does this matter? As we can see from the OECD report from 2021, Disability, Work and Inclusion in Ireland, Government interventions in Ireland aimed at increasing the employment rates of disabled people are well intentioned but failing strategies. Data up to 2018 show that only 34% of people with disability are employed, with much lower rates of people with intellectual disability and people with autism in employment.

One example of a successful employment project is RISE. It is located in Washington, USA, where 70% of people with developmental disability are in open employment. Research from RISE shows that the younger people with disability enter the labour market, the more likely they are to stay in open employment for the rest of their working lives. RISE has also established that the optimal age for people with disability to commence paid employment is 13 years. Embedding young people with disabilities in ordinary valued roles in the community, such as part-time work, is one of the most powerful ways to ensure that they do not live their lives on benefits, living in the shadows and experiencing loneliness and profound social exclusion, as is the case for many people with intellectual disability today.

Creating a positive and hopeful vision for the future, a vision that is supported by others, is vital to moving in the right direction.

In our work with families, much of what people say makes a good life, is not provided by services. LEAP believes that children's and adults' fundamental needs are for inclusion, participation, relationships, value and respect. These needs are best met in the community when the person is embedded in a network of positive relationships.

We have a number of recommendations for the committee today. These recommendations contain many of the enablers of good lives, typical lives, valued lives. Our recommendations centre on resourcing children and families to stay on the inclusive life path, personal budgets, promoting innovation and the creation of inclusive neighbourhoods.

When the majority of the voices in this space are service providers lobbying for more funding, what gets lost is the simple truth: that the majority of people with intellectual disabilities are supported throughout their lives by their families.

Thank you for listening to us today, we are happy to take any questions now from the members of the committee.

Chairman: I thank all of our witnesses for their presentations and for the thoughtfulness of what is in front of us today. The evidence has been very thought provoking and will certainly generate further discussion. Before we start I have received apologies from Deputies Tully, Hourigan and Phelan. Our first speaker from the committee is Deputy Wynne who may direct her questions to any of the groups before us.

Deputy Violet-Anne Wynne: Gabhaim buíochas leis an gCathaoirleach and I welcome all of the witnesses to today's meeting. I thank them very much for their contributions and time today also. I am also very glad to welcome such a broad variety of representatives here today carrying the voices of allies, advocates and activists with direct lived experience. That is very

important to us as a committee. I thank the speakers from LEAP, from the National Platform of Self Advocates, the Irish Deaf Society and the Disability Federation of Ireland. Even from their diverse areas of expertise and focus, they are all united in their commitment to equal access and participation in public and political life.

Based on their very engaging contributions I have a few questions. Mr. McGrath made a very compelling argument around the blatant discrimination towards people with intellectual disabilities in the Electoral Act of 1992. I am curious to hear what the situation is or has he any knowledge of what happens in other European countries? Is Ireland, for example, an outlier in this regard and who should we be looking to for best international practice? I will stop there, Chairman, if Mr. McGrath perhaps wishes to reply but I also have two other points to make. Will I make them now, Chairman?

Chairman: Yes, please do, Deputy.

Deputy Violet-Anne Wynne: Following on from that, the UN Convention on the Rights of Persons with Disabilities, CRPD, is generally hailed as championing the rights of people with intellectual disabilities explicitly and equally with other categories of impairments such as physical or sensory ones. Due to the overrepresentation of people with intellectual disabilities in unemployment figures, can our witnesses share their expertise on what job support schemes have worked well? What support do our witnesses feel that our committee should be lobbying for?

I also have a question for the Irish Deaf Society. We note that the society is a founding member of the Disabled Peoples Organisation Coalition, DPO Coalition. Can the society please elaborate on this coalition and its involvement with the State's Disability Participation and Consultation Network? Are people with disabilities sufficiently reflected on the State's network?

My last question to the LEAP advocates is that they called for a normal and ordinary life for all children. This is something that has been raised with me through my work on this committee but also in a personal capacity as a mother of a child with additional needs. I know that some parents feel more secure by their children attending a special school as they may feel that their needs are definitely going to be met where others would have a different opinion in that their child would be best placed in a mainstream school and integrated, as referred to by Ms Fitzgerald-Graham, into an ordinary school. Can Ms Fitzgerald-Graham shed some light on that divergence and on her experience of the community and if there is a general preference for mainstream schools?

Chairman: I thank Deputy Wynne. Who would like to respond to the Deputy's comments and questions?

Mr. Joe McGrath: The Deputy asked me whether I know of any other political models in other countries, the answer is "No", not at the moment.

Deputy Violet-Anne Wynne: I thank Mr. McGrath. That is something that we can possibly look into.

Chairman: Absolutely.

Mr. Joe McGrath: It is something that perhaps the platform can do some research on to see if there is anything out there that could be used in this country.

Chairman: That is a very good and important point. Does anybody else wish to respond to the Deputy?

Ms Rachel Cassen: I thank the Chairman and Deputy Wynne. We have various comments on the recommendations from the committee's report which was published in July and we watched with interest the committee's public meeting which the committee has uploaded live on the website.

I will directly address both the Deputy's question and recommendation No. 23. Recommendation No. 23 in the committee's first report: Aligning Disability Funding with the United Nations Convention on the Rights of Persons with Disabilities states:

Children with special educational needs have the same rights to appropriate education as children without special educational needs. Accordingly, [you recommend] ... that the [EPSEN Act] Education for Persons with Special Educational Needs Act 2004 ... is [fully] commenced and ... implemented to ensure that children with special educational needs are educated, where possible, in an inclusive environment.

LEAP has a proven track record in asserting the importance of inclusive education in line with Article 24 of the CRPD. Inclusive education is the foundation for social inclusion and participation of all citizens in ordinary community life. We know that the majority of children with disabilities attend their local neighbourhood school. However, there are very few resources available to families to support the full inclusion of their child. That is not just inclusion in the ordinary school building but inclusion in the whole curriculum and the full life of the school, such as the playground - to break it down - and inclusion on school trips.

We understand that many children, as the Deputy has described, feel "more comfortable" placing their child in a special school setting. Within that, we would include the autism spectrum disorder, ASD units, more commonly or typically known as classrooms. I would like to make a comment on those in a moment, if I may. In 2019, LEAP hosted a joint conference with the school of education in Trinity College Dublin called "Belonging in School: The What, Why and How of Inclusive Education". This conference resulted in the formation of LEAP's families for inclusive education subcommittee, whose purpose is to provide a platform for families to share knowledge and experience of pursuing an inclusive education for their child. During the pandemic, we had a meeting with Deputy Madigan at which we spoke about the issue of inclusion and the push at that time to return children with special educational needs to school ahead of their non-disabled peers. We gave powerful testimony from families who are members of LEAP who did not want that. They only wanted their children to return when all their children were returning. They felt this proposal did not support their inclusion and that it othered them. There was a lot of othering during the pandemic. Imagine one child in a family going back while the others did not when, for years, the family had worked really hard to allow all of their children to go the same school, the local or neighbourhood school, so that they could be involved in the life of that school and community with their brothers and sisters. Our families felt that this well-intentioned effort undid a lot of the careful work families had done with a view to full inclusion.

I will now comment on the National Council for Special Education, NCSE, increase in the number of special classes by more than 130%, from 548 in 2011 to 1,456 across the country now. Some 1,192 of these classes are so-called autism spectrum disorder special classes. Special units or classrooms are contrary to Article 24 of the UN Convention on the Rights of Persons with Disabilities, UNCRPD. LEAP is concerned about the normalisation of the seg-

regation of children with autism in special classrooms. We ask the committee to challenge the assumption that any child should be segregated and placed only with other children with the same or similar diagnostic labels. Testimony from actual autistic adults is beginning to emerge. These are adults who were segregated in these settings as children. One will particularly hear this testimony in the UK and other countries. It is not good. We need to listen to these voices.

Ms Lianne Quigley: I thank Deputy Wynne for her question. I will briefly explain what the DPO Coalition is. Two years ago, we had no national independent organisation here in Ireland and so the Irish Deaf Society and other disabled persons' organisations got together to set up the DPO Coalition, the aim of which, as we have discussed throughout the meeting, is to create a shadow report on the Government's performance on the UNCRPD. The Disability Participation and Consultation Network, DPCN, along with the disabled persons' organisations, was involved in these meetings and received funding to proceed with them. I am not sure if that answers the Deputy's question. I do not know if my colleagues from the Irish Deaf Society, IDS, would like to add anything.

Mr. John Sherwin: I will add a little bit to that answer. The DPO Coalition is made up of seven members: Independent Living Movement Ireland, National Platform of Self Advocates, Voice of Vision Impairment, Physical Impairment Ireland, AsIAm, the IDS and Disabled Women Ireland. Our involvement with the DPCN has been very positive. There is good representation from disabled people who can share their own lived experience. At the moment, the network is working to develop a strategy for how it will move forward. The disabled persons' organisations involved are happy to work with the network to ensure the voices of DPOs are prioritised.

Deputy Jennifer Murnane O'Connor: I apologise; I am just after coming in. We had questions in the Dáil. I thank everyone for coming. It is very important for us, as a committee, to listen and to make sure we represent the witnesses' organisations and that our voices are their voices. Last week was international week of deaf people. We also marked the international day of sign languages here, as the witnesses are probably aware. That was really important.

I have two questions. What are the witnesses' experiences of early access to sign language and services in sign language in the Irish education system? What access do people have? Can they share ways they have felt included in political culture and community and public life so that we can learn from their experiences?

Ms Elaine Grehan: I thank the Deputy for her question. When it comes to access, I will have to try to select just one example. When people are going to the cinema, they have plenty of different choices as to what to see. However, a deaf person can only choose what has been subtitled. Much of the time, that is just one film. It very much depends on the cinema. That is a general example of access. When it comes to going to a restaurant or trying to order a sandwich, communication barriers can arise. Even basic things such as devices being controlled by voice or having sounds but no visual representation when accessing physical buildings can cause issues. Even with speakers, much of the time things are operated only through spoken language with no access through sign language. I hope those examples are enough. Ms Quigley will add to that response.

Ms Lianne Quigley: With regard to political life, Ms Grehan noted in her opening statement that three deaf candidates have stood for election at county council level. I was involved in canvassing for one of those candidates. We relied on voluntary interpreters to provide access. We were constantly in search of interpreters who were willing to work voluntarily so that we

could interact and discuss matters when canvassing in the community. As the Deputy herself will know, going to local meetings of housing associations, public meetings and different local events and so on is a regular occurrence for those involved in political life. Whether there is access through Irish Sign Language, ISL, very much varies. That is a very negative aspect of being involved in political life.

In respect of cultural life, art and design, I have been involved with the deaf artists in our community and our deaf culture and deaf arts for many years. It is very limited here in Ireland. We very much depend on the funding that is available. Opportunities to get involved and take part are very limited. We have to apply for grants for monitoring programmes, development programmes and so on. Even if we do receive those grants, they can be very limited and very small. Of course, we always have to factor in the cost of interpreting. A great responsibility is put on us rather than on the public arts institutions, theatres and the like, to provide interpretation and to make people aware that ISL access needs to be provided. Really, it should be the opposite way around. I could stay here all day and provide plenty of examples, but there are just two to answer the Deputy's questions.

Deputy Jennifer Murnane O'Connor: We are talking about funding here as well. As Ms Quigley just said, those are just two examples. We need to make sure these are considered. That is what this Joint Committee on Disability Matters is going to do. It is our objective to make sure that funding is available. As the witnesses have said, their organisation needs more funding as it is always applying for grants and so on. There should be funding there. It is important that those of us on the committee fight to get funding in the budget which can be easily accessed. That is important for everyone. My other question is for Mr. McGrath. I heard recently from adults with intellectual disabilities in County Carlow about how, during the Covid-19 pandemic, the Government did not publish information on Covid-19 in a more accessible format. I appreciate Mr. McGrath raising the issues of accessible public communication. He has spoken about information being available in accessible formats. Can he tell me more about what that would mean? It is important. As I said, I spoke to people in my own area recently. Perhaps Mr. McGrath could provide more information on the issue.

Mr. Joe McGrath: What I mean by that is that everyone can read printed language, but some are struggling to read it, so they need it put into simple plain English that they can understand. Sometimes they do not get the support to do the things they need to do because the support is going home at 5 p.m. It could be the case that material arrives at the house in the evening when the person concerned comes home and they may not be able to understand what it is. I am one of the lucky ones. I can read and understand printed material fairly well, but there are many others out there who do not have the same understanding as I do.

Deputy Jennifer Murnane O'Connor: I thank Mr. McGrath for his response. It is an issue that we need to look at. Communication and information are key here. I would like us, as a committee, to take this on board and ensure that we make it a priority on our agenda and for us going forward. I thank the witnesses for answering my questions today.

Senator Mary Seery Kearney: I apologise for the noise. I am in my office and the bells for the Seanad are going off in the background. I wish to thank the witnesses sincerely for their contributions and submissions, as well as the opening statements. They are very impactful. I wish to raise a few points.

I found Mr. McGrath's statement most striking. What he described is not a one-day only event; it is not storytelling. It is about the real lived experience and how we can ensure that

everyone is included and that we are not making assumptions. I read Mr. McGrath's opening statement and came away feeling that we should have invited him to attend the Joint Oireachtas Committee on Housing, Local Government and Heritage during the pre-legislative scrutiny of the Electoral Reform Bill 2020. He would have been a very powerful witness there too. I will follow up with a letter to that committee voicing my support for all that I have heard from Mr. McGrath today. Perhaps, with his permission, I will include his opening statement. We need to take on the challenge of accessibility of information and ensuring manifestos and other such documents are available. I would welcome and appreciate any further comments Mr. McGrath may have on that.

To our friends representing the Irish Deaf Society, I would say that one of the very few positive things to come out of Covid was that every day, in the context of the delivery of information on Covid, we saw an ISL interpreter in front of us. That normalised for the presence of ISL interpreters for everybody. In fact, I miss them when they are not there now. I think we should be building on that. We have gotten used to it and have an expectation now. We have an expectation of things being translated into Irish; we should have an expectation of always having an ISL interpreter there. The representatives of the Irish Deaf Society have made very important points. I am also a member of the Joint Oireachtas Committee on Children, Equality, Disability, Integration and Youth. In that context, I would like to raise the point made by representatives of the Irish Deaf Society regarding co-ordination. I suggest that, as a committee, we should write to the Joint Oireachtas Committee on Children, Equality, Disability, Integration and Youth to emphasise the points that have been raised by the Irish Deaf Society today. I would like the witnesses to contribute to that letter by telling us what they would like us to include in it, highlighting the points they made to us in their opening statement. Similarly, we should write to the Joint Oireachtas Committee on Media, Tourism, Arts, Culture, Sport and the Gaeltacht to emphasise the need to look at the BAI. We should be using the voice of this committee. We should be listening to the witnesses and ensuring we do their bidding. They have given us an opening statement and a submission. We should act on that and write, accordingly. We should emphasise what the witnesses would like to say so that we are performing our duty of service to them.

In respect of the representatives of LEAP, I support the call for an "ordinary life" that was emphasised by Deputy Wynne. Othering is something that was best understood in the conversations around, and the reaction to, the opening, or not, of classes in the context of Covid. We saw it in recent weeks with NPHEI information on self-isolation. The advice came out and I was very glad to see that the Minister of State, Deputy Madigan, held meetings the next day from which clarifications arose and are continuing to arise. Another clarification was issued yesterday. Therefore, we must keep front and centre at all times the idea that we are not othering. I ask the witnesses to outline what they would like us to do to support that and to ensure we are doing that.

I noted that Ms Cassen initially referred to ASD units, then stated that the preferred terminology is now "classes". That highlighted an issue for me. I was hammered on social media when I used the term "ASD units" when I was beginning my advocacy work, particularly with the Minister of State, Deputy Madigan, on this issue. There is a fear of using the wrong terminology in a way that results in othering. How might we overcome that, provide a good service in listening to the witnesses and do what they tell us so that we are doing what we are supposed to be doing?

Ms Rachel Cassen: May we address four of the recommendations in the committee's first

report, on aligning disability funding with the UNCRPD, or would the Chairman like us to do that at a later juncture?

Chairman: It is important that we hear it, but perhaps Ms Cassen can address the points raised by Senator Seery Kearney and respond to them directly first. However, it is also important that we hear the witness' opinions on our submissions.

Ms Rachel Cassen: Okay. I would say that it is a difficult and nuanced point and position to make. When we speak, we often speak from different roles in our lives and in different settings. When my colleague, Ms Fitzgerald-Graham, speaks today, she will sometimes speak as a professional in her own field, but more often, she will speak as a mother. The same applies to me. However, when we speak as mothers, something funny happens and we risk becoming like a bad smell in the room. I do not know how else to say it. We are aware that we have to walk mindfully when we speak as mothers. We want to draw the attention of committee again to our opening statement. I hope it is apparent that from our inception nearly ten years ago, we have worked very hard to align all of our work with children and families with the UNCRPD. Our work is about assisting families to stay on the typical, normative and valued life path.

I will get to my comments. Frequently, government and services deal with individuals. They deal with individuals just as individuals, as if they are not connected to families. There is none of us living a good life that is not connected to other people. Whatever government and services do, they must not seek to separate or alienate people from their family and friends, for it is they who constitute the enduring sources of love and support, however flawed at times, in people's lives.

If the goal of the UNCRPD is inclusion, I ask the committee how that is then achieved and why some people enjoy a rich and meaningful life when many others do not. The disability advocate ally of LEAP, Jeremy Ward, stated:

The reality is that the full and positive lives of people with disabilities that we hear and read about do not happen by accident. These inspirational stories can be told because someone had a vision and belief in what is possible, sometimes against considerable opposition, and planned to make it happen.

That someone is frequently a family member and yet we ask the committee why family-based organisations such as LEAP struggle for funding and to be recognised under general comment No. 7 of the UNCRPD as a DPO? We do not represent our children; we raise them. We are not disability representative organisations but neither are we fully welcome or acknowledged in the DPO camp yet. That is where the committee can help us.

Senator Mary Seery Kearney: Very powerfully said.

Ms Elaine Grehan: I thank the Senator for her question and for her comment about seeing interpreters on the screen. Sadly, there is no interpreter for the 9 p.m. news, the 1 p.m. news or the 6 p.m. news. I know it is a positive start and hopefully it will lead to full access and better inclusion in society so that when one watches TV or the news there is access for the deaf community, similar to the Irish language news which is on at the moment. Sometimes when there is an interpreter it is not put on the main RTÉ news channel but it is on RTÉ News Now. We would like to see that on the mainstream channel, rather than being moved to a separate channel and almost hidden.

When children's schools were being closed due to the coronavirus, that was big news on the TV and it meant that so many children were home-schooled. RTÉ's "Home School Hub" was set up and we had to ask RTÉ to provide an ISL interpreter for that show, which it agreed to. It was important that families educating at home could include all their children in watching the same programme, whether they were hearing or deaf. That is another example of how we can encourage inclusion. Rather than segregating ISL provision to a separate channel, it should be mainstreamed.

We work with the BAI and the representative there and I am constantly advocating. I would love it if there was someone who worked in the BAI who fully understood everything because sometimes one can feel as though one is going around in circles. It would be useful to have a deaf representative within the BAI.

Ms Lianne Quigley: I would like to talk about the example of the coronavirus when there were interpreters on television every day. During previous emergencies in Ireland, ISL interpreters were not present or provided and we had to advocate for them to be provided. It should be automatic that ISL interpreters are provided but previous to that there was a lot of advocacy on the part of the IDS to campaign and lobby for them to be provided. It should be the public sector's responsibility to provide those interpreters.

When it comes to children and deaf children in school, there is nothing mandatory in place for teachers of the deaf to have learned full ISL. It is encouraged but it is not a mandatory requirement. When it comes to political manifestos and information during election campaigns, as we mentioned previously, the IDS had to repeatedly ask for translation and ISL interpretation. It is not automatically provided. Hopefully there will be greater awareness in the future and continued ISL access will be provided.

Mr. John Sherwin: The IDS would welcome the opportunity to support the committee in its letters to the Department of Children, Equality, Disability, Integration and Youth and to the BAI. Perhaps we can send in some information after this meeting but I will quickly summarise a few points related to both. In terms of the Department of Children, Equality, Disability, Integration and Youth, IDS and other DPOs need champions in government and we would hope that the Department could become a champion for DPO status for us. Following up from Mr. McGrath's point about the time needed for DPOs, the Department could hopefully champion time, budget and universal design in the planning of all government processes, activities and plans. These matters need to be checked early. Our work with the HSE during Covid, when we tried to update existing processes to include universal design after they were put in place, was difficult. It is much more possible if it is included from the outset.

We would also love the Department to champion the efficient use of our limited resources. For example, we engage with one organisation in respect of services on six different committees. It is an unsustainable use of our resources. There must be easier structural ways for us to engage with Government.

We would ask the BAI to update and consult us on how it forms its targets. We have a number of other points that we would be happy to share with members after this meeting.

Mr. Joe McGrath: The Senator can use the opening statement and send it out with her information if she so wishes. I ask her to send the letter to myvoiceireland@gmail.com requesting that as well just so I have a copy of it for my members.

Senator Alice-Mary Higgins: I thank the witnesses. So much has been brought up and I will focus on two or three aspects. I was struck by the importance of time and space being allocated. It is not just about the technical right to participate but it is about the time and space that make participation possible, enjoyable and meaningful. I would like to hear more comment on that issue of time, especially in terms of public participation, meetings and discussions. When I worked with the National Women's Council of Ireland, we found that women often went on to say what happened to them and then some man would explain what happened. Mr. McGrath said that it is not just storytelling but it is about decision-making. In this committee we always say we want to hear the experiences and analyses of people with disabilities because that is so important. I ask the witnesses to talk more about the issue of time and participation and what could be done.

Points were made earlier about making sure that cultural venues, playgrounds and sports amenities are accessible. I was happy to co-sponsor a Bill on playgrounds in the past. I want to highlight something around that which also relates to the deaf community. We will hear a lot about the national development plan in the next week or two and the committee made a detailed submission on it. Something that was important to us in that submission was insisting that new State public spaces and buildings have universal design and accessibility because there will be a lot of capital expenditure on same in the NDP. Could the witnesses comment on the importance of that? We insisted specifically that the provisions of the Irish Sign Language recognition legislation, which I was proud to see passed by the last Seanad, be reflected in the design of buildings where there are to be public meetings or public performances. Could the delegates comment on this? Regarding the spatial aspect, it is not a matter of being *ad hoc* but of having the appropriate design from the beginning in any new public buildings or public spaces.

I would appreciate it if the delegates commented on the EU's Web accessibility directive. There is now an obligation to have greater accessibility online in terms of participation. In particular, there is an onus on public departments and bodies. Could I have the delegates' sense of how this is going, how the measure is being implemented and what should be improved? In the Oireachtas, for example, we should be able to do better at captioning debates. While I am aware that we have the transcript and video, we should be able to follow up with subtitled debates. People do not just want the summary; they want to engage and see where the political nuance is. Where are the key gaps regarding participation and the implementation of the measures in the Irish sign language legislation?

Indirectly related to the new EU Web accessibility directive is the new legislation on online safety that is to be introduced in the Oireachtas in the autumn. It is called the Online Safety and Media Regulation Bill but it is transposing the audiovisual directive from Europe. The directive is not just about protecting or avoiding harm; there is a duty to have inclusive cultural participation. I am referring to *l'exception culturelle* and the right to cultural participation, expression and diversity. Could the delegates comment on that? With the central focus on the protection aspects, which are important, proactively ensuring diversity in our media, including online media, and culture might get dropped. Are there any comments on that?

My last point relates to special classes in schools and even to employment opportunities. We have seen in Ireland a failure to avail of some of the opportunities that exist in terms of sheltered workspaces and so forth under EU law, but we have also seen, in other parts of Europe, the overuse of such spaces, whereby they become the only places where people access employment. I am referring to ensuring access not only to employment, in respect of which Ireland is woefully behind the rest of Europe, but also to a fully diverse range of employment

opportunities.

What are the steps to ensure education and employment, which are normally points of connectivity for people, do not become culs-de-sac for people with a disability, whereby the places or jobs found for them are not regarded as steppingstones? What can we do to ensure we are building progression opportunities into employment and educational spaces?

Ms Rachel Cassen: I thank Senator Higgins. She raised a lot of points. On time and space, it is not just a question of the technical aspect; it is also about process. It is a question of ensuring families with children with disabilities can undertake a process as a family, because families are not always on the same page on all these issues related to living a good and inclusive life. In an attempt to get families on the same page, or even reading the same chapter of the same book, we bring families away each year to a live-in residential event, a weekend retreat. We work with them on the question of what a good life looks like rather than on what constitutes a good service. Asking the right questions is really important. It is not really possible to work with families with children under the age of three, or children in arms. There is too much going on in such families and they need to settle and get to a point where they can focus on major needs beyond the daily routine of an infant. At that point, we introduce the notion of the good life, the ordinary life and the inclusive life, which links to all this good stuff and the thinking that if a child is not nursed and threaded into his or her local community from a very young age, it will be much harder for him or her to come back from a place of segregation and rejoin the normative life path. That is why we work with children in the context of their families from the age of three years.

We give families a process, a piece of time in which they are all welcome. There is a big welcome on the mat at all our events for them because many of them get used to being hidden in plain sight. They are excluded from the point of the child's diagnosis. The day they bring the child home from the hospital, they are excluded from many ordinary life events in their communities and become hidden in plain sight. Therefore, time is critical. Over years, we have conversations with families. They are welcome and they are invited out of their isolation to our events. We place great emphasis on hospitality, welcome, reciprocity and belonging. The process that the Senator described, beyond just a technical process, is important. The warm, human welcome is important.

That brings me on to the issue of design. Design is critical. In this regard, the Senator mentioned playgrounds but it is often the case that what we do in the name of inclusive design, while well intentioned, fails. For example, a swing surrounded by a fence for children with physical disabilities, which may be funded by the Lions club or another such charity, may be very well intentioned but it puts a physical barrier between the child using it and all the other children in the playground. While it is not the intention, it others them. Similarly, I see a rise in the installation of hubs on university campuses for neurodiverse students. We believe in LEAP that those hubs, although very well intentioned, are othering. I do not know whether it is positive to be seen to climb into one of those hubs. Does it, in fact, other people? We have to be very careful when we consider design for inclusion. We must consider whether what we are doing is clumsy. We need to kick the tyres of inclusion. If we call something inclusive, it is very often not, based on our experience in LEAP. It does not matter if we call autism spectrum disorder, ASD, classrooms units or classrooms; changing the label, or the plaque on the door of the building, does not really change what goes on inside. Many try to claim that autism units and classrooms are inclusive. By our definition, they are not. By our definition, inclusion is what people your age are doing and what people from your culture are doing. It is what is typi-

cal, optimal and normative.

I will move on to discuss work. Sheltered work has no place in modern society. It is not compatible with the UN Convention on the Rights of Persons with Disabilities, UNCRPD. Work enclaves have no place in modern society either. There were well-intentioned efforts at inclusion that put people with the same diagnostic label to work in a cafe. That was a feel-good thing. Such a person may get a wage and feel great. It is, in many ways, a valued role better than what those people had before. However, it is not good enough and we can do better. I challenge this committee to think carefully about the issues with placing people in work enclaves. It is a step forward from sheltered work but it is not yet good enough. It is not yet full inclusion in open employment.

Senator Alice-Mary Higgins: I will go to our other guests because there were a number of questions about sign language. I will come to Mr. McGrath, too. I will note that spaces have been provided in universities. If different needs are being accommodated within a shared space, I do not believe that needs to be othering. The othering aspect of that comes more from a societal attitude to people using spaces in different ways and for different needs. I think it is coming back to the design point. Having design that includes, if necessary, spaces allowing for sensory reduction creates an inclusion whereby it is okay that it is visible that people in this space have different needs and that the spaces have been designed to accommodate them. That is a slight query I have in that regard. I am conscious we have limited time so I am going to go to Mr. McGrath.

Mr. Joe McGrath: On the issue of employment and getting people to work, it is important that the committee looks at ways of getting employers to give people work experience that will, hopefully, lead to a meaningful job after work experience. We should not go back to workshops or place like that because they have no value and do not get people ready for the outside world.

Ms Elaine Grehan: When we talk about access to public buildings, the Senator is right that it is very important we have inclusion. In doing that, we need to consult Article 4.3 of the UNCRPD, which states that we must ask deaf people what we can do to make a building more accessible. It is a waste of time and expenditure if we do not do that in the first instance.

We must talk about universal design for deaf children and older people. Special supports are made available to deaf children in schools. Is that enough support or full support? It is not. Many deaf children within mainstream schools do not have enough support from the Government. I would recommend that schools should have a curriculum from primary through to post-primary for sign language for everyone, not only for deaf people. When sign language is taught in schools, deaf children are better able to socialise with their peers out in the playground when they go out to play. When they go out to the playground at the moment, they do not have the same access. Irish sign language, ISL, needs to be on the curriculum in primary and post-primary schools.

Likewise, opportunities should exist for older people. We had a facility at St. Joseph's House for Adult Deaf and Deafblind in Stillorgan, which has now closed due to HIQA recommendations and older deaf people have gone out to live in the community. They may feel isolated, even within nursing homes and nursing home care. We need and must provide sign language access in order for them to feel included within the newer communities to which they have gone. I think Ms Quigley would like to come in now and add to my comments.

Ms Lianne Quigley: I have a couple of comments. When we talk about websites being

technologically accessible, Government websites, in general, provide very little ISL. I would recommend straightforward planning. The deaf community have ISL translation providers and through the Irish Deaf Society, IDS, we can consult and translate documentation on Government websites. Not all deaf people within the deaf community are able to read English at a higher register. Most deaf people would prefer the information in their first language of ISL on the page. It is a straightforward issue and is not expensive to add onto a website.

When we talk about the ISL Act, it was fantastic that it was passed in 2017, as the Senator said. That was a momentous occasion for us and I remember it well. In 2020, a register of ISL interpreters was established. That is a positive. Last June, a pilot project was established for a social inclusion voucher scheme whereby funding has been made available to deaf people to allow them to access interpreters of their own choice in attending cultural, religious, social and other events. It started in June but they have extended it by an extra month. From the pilot project, we will be able to ascertain whether it should continue, and the IDS will be lobbying for its continuation. Deaf people can book interpreters for themselves without having to worry about the money because the funding is there. That could be to go to the theatre, to attend a one-to-one meeting with a solicitor to make a will and so on. Deaf people do not have to rely on and seek grants and funding but can instead access a social inclusion voucher scheme to go to these events. Those are the examples I wanted to give for the moment. I thank the Senator.

Mr. John Sherwin: I have a few points to make in response to the Senator's questions. She mentioned the attitude of the general public to universal design and spaces. That could translate to mean culture change within Government organisations. One of the biggest culture changes needed is coming back to the idea of universal design and including that at the start of every single process. To offer an example from my experience today, and this is in no way a criticism of the Oireachtas, but I was struck by the circular nature of this room. When I started working with the Irish Deaf Society, I learned very quickly that theatre-style seating is no good because deaf people need to be able to see each other signing. Looking at someone's back does not work.

We have also noticed here today that both Ms Grehan and Ms Quigley have to stand up in order to be seen while they are signing. If universal design is included at the start of a design process for a room such as this one, the small physical barriers that do not affect me as a hearing person giving testimony would have been designed in a slightly different way.

In terms of the European Accessibility Act, we have some very good information from our partners the European Union of the Deaf. We would love to have the opportunity to share with the committee its research work on how that can the Act can be implemented. Perhaps that is something on which we can follow up afterwards.

There was also a question about barriers to the implementation of the ISL Act. The IDS is producing its own shadow report on the UNCRPD and we are including some information about the implementation of the ISL Act in that report. We would love to be able to send that on to the committee. The need for deaf awareness training throughout Government is key because that awareness leads to action. We would like to promote deaf awareness training throughout Government and the State provided by deaf people who give their first-hand experience and support to organisations that want to make their engagements more accessible. Capacity is a huge barrier. The number of interpreters employed in Ireland is limited and it creates huge problems in timing. The number of people who are teaching ISL is also very limited. Until these professions become more supported and more viable we will continue to have a capacity challenge in responding to the needs of the Government as it tries to respond to the Irish Sign

Language Act. There is a need for capacity building and a focus on it.

Senator Alice-Mary Higgins: I know I do not have more time because others wish to speak. Does Mr. McGrath from the National Platform of Self Advocates have further comments or a written submission he wants to make on the issue of time? He put it in my head when he spoke about better planning for time in terms of inclusive processes. He spoke very strongly on it. If he has further comments or submissions he wants to send on how processes could be better I would appreciate it.

Ms Deirdre Fitzgerald-Graham: I want to respond to something the Senator said. It struck a chord with me when she spoke about people with disabilities facing cul-de-sacs in their lives. It brings me back to the notion of where we come from in LEAP whereby the role of the families is poorly understood. If we want the people we love to be connected to others and to be part of society as adults we have to think about the relationships they form when they are children. Their classmates and the neighbours they grow up with will become their co-workers and friends later in life and they are less likely to meet this cul-de-sac the Senator described so eloquently. It is about the role of families in supporting the full inclusion of their child with a disability.

We need to think about various roles now if we are serious about implementation of the UNCRPD. We speak about roles such as inclusion facilitators and community animators. Our vision is to move beyond the approach of employing only therapists, commissioning only separate or segregated services or having only one pathway for people with a disability towards segregated sheltered workshops. We ask the committee to consider this point in its final write-up.

Deputy Seán Canney: I apologise because I must go to another committee meeting. Earlier we spoke about trying to do two things at one time. I heard some of the presentations and I have listened to what the witnesses said. I thank everybody for participating. My first question is on the issue of employment. There are employability services trying to assist people with disabilities to get work. How do the witnesses see these services working? What improvements can be made to them? Are they effective?

Ms Elaine Grehan: I thank the Deputy for his question. When it comes to employability we really need improvement when it comes to communication. The barriers lie within communication. There are the Intreo offices and services and employment to support people with disabilities. Unfortunately, those who work in the service do not have the communication skills to communicate with the deaf community. They are not interpreters. In real life it is impossible to provide this type of support for interpreter provision all of the time. Of course there are limitations. When it comes to the deaf community the barriers lie in communication.

There is also an attitude that a deaf person is not able to work or to do certain roles. There is a real barrier when it comes to attitude. Deaf people are able to work and they definitely can. Sometimes health and safety is used as an excuse to say a deaf person is not able to be involved and that it would break health and safety regulations. This is something we often face when it comes to employment.

Ms Lianne Quigley: I was unemployed for a few months just before Covid-19 hit. I went to the Intreo service. I realised that when it comes to access for deaf people it is terrible. Luckily, I have the ability to communicate. I was able to have ISL interpreters provided and I was able to send emails. When it comes to public websites it can be quite difficult to find email addresses. Often people have to either phone a number or send a letter. The Irish remote in-

terpreting service can relay and interpret phone calls but something that needs to be included when it comes to providing feedback is that there needs to be a clear email address that can be used. At present, there is not 100% access to employment services for deaf people who sign.

Chairman: If Deputy Canney has finished I will move on to the other speakers because I am conscious of time.

Deputy Seán Canney: I have one more question. I was also struck by the proposal that ISL be taught as part of the curriculum in national school. We forget that unless we have sign language we cannot communicate with people who are deaf. It is important that we do so. This is something I am taking from today. We should pursue it through the Department of Education as something positive in what we have spoken about today.

Chairman: I could not agree more.

Deputy Holly Cairns: I have a question for each group. If they want to take all of the questions together I do not mind. To follow from what the Irish Deaf Society representatives said in response to Senator Higgins, they highlighted the forthcoming DPO coalition report, which will highlight that 24% of disabled people have difficulty using their right to vote and 55% have difficulty contacting local representatives. This is concerning. Will the witnesses outline concrete actions we can take individually as public representatives and that we can push for as a committee? The witnesses also mentioned the under-resourcing of ISL supports. I have been seeking updates from public bodies on their compliance with the ISL Act. Will the witnesses elaborate on areas where ISL needs are not being met?

I thank Mr. McGrath of the National Platform of Self Advocates for his opening statement and for taking a stand on participation in all forms of decision-making. He highlighted the need for all public processes to be accessible in how they are organised. Like others, I was taken by his point that people are only allowed to participate in storytelling and not in decision-making. Will Mr. McGrath discuss further how we can meaningfully include people with intellectual disabilities?

My next question is for LEAP. I thank the witnesses for their contributions and for working to highlight the vital role that families play. Their points on increasing employment rates among people with intellectual disabilities is incredibly important. The witnesses mentioned international examples. There is Project RISE in the US. Will the witnesses expand on what was involved in this project and the type of structures and programmes we can put in place here? As one of their recommendations they mentioned the importance of creating inclusive neighbourhoods. Will they outline the significance of this and how we can foster these types of supportive communities? The witnesses also spoke about the optimal age for employment being 13. Will they elaborate on the reason for this as I am curious?

Chairman: I am anxious to get everybody in so I invite Deputy Higgins to ask her questions after which we will go back to the witnesses to respond to the points made.

Deputy Emer Higgins: I thank the Chair. I was panicking because I could see the clock ticking and I very much wanted to contribute to this discussion. I was in the committee room earlier to hear the witnesses. It was great to be able to be there to see how ISL worked in a practical way. We have heard contributions on exactly that. If rooms were set up with that in mind, that would all happen a little more naturally and would be a little easier for everybody involved.

I enjoyed today's discussion. I particularly commend Mr. McGrath, Ms Fitzgerald-Graham

and Ms Grehan on the points they made. I was struck by what Mr. McGrath spoke about regarding the focus on full participation. It is not just about consultation but full participation when it comes to decision-making on how things are run and how they are done. I heard loud and clear his point about the funding that will be necessary to make that happen.

There has been a lot of discussion, especially in the second half of this meeting, on work experience and the need for meaningful professional positions to be made available to people of all abilities. I was involved in such a scheme in my previous role when I worked for PayPal, which collaborated with the Trinity Centre for People with Intellectual Disabilities. As Mr. McGrath said, it was a work experience programme that turned into meaningful jobs at the end. We need to see more of that.

I was quite struck by what Ms Fitzgerald-Graham spoke about in respect of the Washington experience, RISE and what had happened there. That is something we should strive to achieve. In my constituency, Stewarts, where I was over the summer, do a fantastic job in supporting people when it comes to inclusion. It was great to hear so many stories about their clients who are in the working world and who are making meaningful contributions in the professional world, as well as in every other walk of life. We need more of that. Ms Fitzgerald-Graham's contribution was particularly positive. She talked about everything from a possibility, as opposed to a barrier, perspective. We need more of that kind of language because that is what we want to do. We want to enable people to thrive and to fulfil their full potential.

Ms Grehan spoke about an issue relating to the deaf community in particular. I was struck by one thing that would never have occurred to me, which were the expenses and additional expenditure involved for a member of the deaf community to run for election. What can we do to support them? The situation does not seem fair or right. I was also struck by the figure of 55%. Ms Grehan spoke about 55% of people from the deaf community having difficulty contacting local representatives. I would love to learn a little more about that. She spoke about literacy sometimes being an issue within the community. Is that why people are not able to email local representatives? What are the barriers and how can we break them down? It is important that we do so.

I was also struck by what Ms Grehan said about the television show, which was such a success for so many years. I intend to write to RTÉ to ask why it is not being aired any more and what plans there are to bring in a replacement that would engage with people from the Irish deaf community.

Chairman: In the few minutes we have left, I ask each group to respond, as briefly as possible, to the points made by Deputies Cairns and Higgins, in addition to the outstanding point made by Deputy Canney.

Mr. Joe McGrath: It is very important that people with disabilities are trained at an early stage to work in the community. Organisations involved in this area are very important. Their representatives should go into schools to talk about the service they provide for people who are leaving school, so they can start at a young age.

Ms Elaine Grehan: I would like to respond to Deputy Cairns's question on what the Government can do to help things improve in the next 12 months. We need core funding to be provided to the Irish Deaf Society in order for us to carry out research on deaf people's lived experience. ISL support can mean supporting people who would like to be involved in political life and campaigning. There needs to be funding for that. Those are the two areas I would

comment on.

Mr. John Sherwin: There were so many questions from the last three representatives that it is difficult to capture them all. I apologise if we do not reply. We can possibly follow-up.

Chairman: I would appreciate that.

Mr. John Sherwin: In response to Deputy Canney's point on employment, we have started a significant deaf career project with funding from the Dormant Accounts Fund. It became very clear that there was no exact sign for "career". There is one for "job" and that in its own right explains quite a lot. The project is going very well but one UK precedent I would like the committee to focus on is the access to work scheme. In the UK, interpreters are provided for working people for their entire working life. There is a net return to the Exchequer for that expense. It elevates deaf people into management positions in the UK. We would love to see a scheme like that investigated and implemented in Ireland.

Ms Rachel Cassen: : I would like to answer some of Deputy Cairns's questions on RISE, specifically, and I will also touch on Deputy Canney's previous questions. RISE is an organisation that has a great history. Its members have presented to the National Disability Authority. What they and other supported employment organisations such as Inclusion Alberta in Alberta, Canada, have found is that supported employment is the way to go. The type of employment support projects or initiatives we have traditionally had for people with intellectual disabilities and autism, more commonly known as developmental disabilities in North America, do not necessarily provide the right types of support on the job. Supported employment can assist an employer, for example, to look at a job that is not already being done in an organisation and to create a new job that does not exist. Employers might go into a plant, factory or warehouse and see there is a particular task that is not being done. They would then carve out a new role for a person to go in and take on, for full payment and with full terms and conditions provided.

We also want to mention Inclusion Alberta, to which LEAP has taken families. We have undertaken study tours around the world and we have taken families to countries and organisations that are doing extraordinary work towards the full inclusion of people with disabilities. Many of them are family-based organisations. The committee might want to look at Inclusion Alberta. It has a Rotary employment partnership whereby it works with Rotarians, business-people and the like in communities. It does not use job coaches but places people with intellectual disabilities in open employment using the Rotary Club as its main partner. There is no job coach but support is provided by an inclusion facilitator. It is extraordinarily successful. It leverages the support of the community and business partners in that community to place people in jobs. The workers, as we know, are extremely loyal and extremely good at timekeeping. We know this because LEAP has spent time there. We have been to Alberta on three occasions. We have spent time with these projects to learn what is best in employment practice for people with intellectual disabilities. We use 13 as the base age because that is the typical and normative age at which all of us in this meeting probably got our first part-time job. I know I had mine when I was 11. Back in England all those years ago, I had a paper round. Many of us started work at 11, 12, 13 or 14. If we are parents, hopefully our own children started work around that time. It has got a little later with the pandemic. It has probably not happened at all. If it has, it has probably not happened in the same way. As always with everything in LEAP, we recommend that young people and children with disabilities do what their peers are doing at the same age and stage. When we say "peers", we do not mean other people with the same diagnosis.

Chairman: Unfortunately, we must bring the session to a close. I thank the National Plat-

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form of Self Advocates, the Irish Deaf Society and LEAP for coming before us and for the profound and thought-provoking discussion we have had. We must reflect on it. A few issues were raised during the morning that we must feed into our deliberations as a committee. One of the most immediate issues is core funding as we head into the last two weeks before the budget. It behoves all of us, as committee members, to advocate at every level to make sure there is awareness of the need for an increase in funding across the disability community. We will be advocating for that. Perhaps it is something we might look at external to the committee's meeting next week. I thank our witnesses and our hardworking and dedicated committee members for their work. We will continue our work in the same vein.

The joint committee adjourned at 11.32 a.m. until 9 a.m. on Thursday, 7 October 2021.