DÁIL ÉIREANN

AN COMHCHOISTE UM NITHE A BHAINEANN LE MÍCHUMAS

JOINT COMMITTEE ON DISABILITY MATTERS

Déardaoin, 29 Meán Fómhair 2022

Thursday, 29 September 2022

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
Pat Buckley,	Catherine Ardagh,
Holly Cairns,	Micheál Carrigy,
Seán Canney,	Tom Clonan,
Joan Collins,	Róisín Garvey,
Marian Harkin,	Erin McGreehan,
Marc Ó Cathasaigh,	Mary Seery Kearney.
Pauline Tully.	

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

Joint Meeting with Joint Committee on Autism

Accessibility in the Built Environment, Information and Communication: Discussion

Deputy Michael Moynihan and Senator Micheál Carrigy co-chaired the meeting.

Co-ChairmanDeputy Michael Moynihan: Apologies have been received from Deputy Ellis and Senators O'Loughlin and Wall. Senator Flynn is not on the Leinster House campus.

In accordance with the current guidelines, all documentation has been circulated to members via the Microsoft Teams platform. This session will be a joint meeting of the Joint Committee on Disability Matters and the Joint Committee on Autism. We are joined by Senator Carrigy, Chairman of the Joint Committee on Autism, and members of his committee. I call on him to make his opening remarks.

Co-ChairmanSenator Micheál Carrigy: On behalf of the Joint Committee on Autism, I thank the Chairman and other members of the Joint Committee on Disability Matters for proposing today's joint session of our committees on this important topic. Accessibility is at the core of the work of both of our committees. In our first public meeting, my committee called for Leinster House to be made autism friendly, as is the case in the Northern Ireland Assembly's parliament buildings at Stormont, Belfast. The Houses of the Oireachtas Commission welcomed our request to make Leinster House autism friendly and I hope to see developments this autumn. We look forward to such initiatives as suitable lighting, noise reduction, a sensory room and, most importantly, staff training. This will ensure that there are fewer barriers to access for autistic people attending Leinster House. I hope that we will set a good example for all to follow.

Our committee's work in public session thus far has focused primarily on education. This is just one area where considerable improvements are needed if we are to make accessibility a core principle. Greater accessibility measures have been implemented in some schools but not others. We need to see such measures being implemented in every school, be it a specialist school or a mainstream one. The same must apply to publish buildings across the board.

I look forward to hearing from today's witnesses about how we can make our buildings and society more accessible for autistic and disabled people. One of our powers is to draft recommendations for legislative change and examine statutory instruments. We would welcome any idea that the witnesses may have in that regard.

Co-ChairmanDeputy Michael Moynihan: The purpose of today's meeting is to discuss accessibility in the built environment, information and communication. On behalf of both committees, I welcome Mr. Adam Harris, CEO of AsIAm. From Independent Living Movement Ireland, ILMI, I welcome Mr. Desmond Kenny, chairperson, Ms Catherine Gallagher and Mr. James Crawley. Also with us from the National Disability Authority, NDA, are Dr. Aideen Hartney, director, Dr. Gerald Craddock, chief officer at its Centre for Excellence in Universal Design, CEUD, and Dr. Dónal Fitzpatrick, senior design adviser of ICT within the CEUD.

Before beginning, I wish to read out a note on privilege. Witnesses are reminded of the long-standing parliamentary practice to the effect that they should not criticise, comment on or make charges against any person or entity by name or in such a way as to make him, her or it identifiable or otherwise engage in speech that might be regarded as damaging to the good name of a person or entity. Therefore, if their statements are potentially defamatory in respect of an identifiable person or entity, they will be directed to discontinue their remarks. For witnesses attending remotely from outside the Leinster House campus, there are some limitations to parliamentary privilege and, as such, they may not benefit from the same level of immunity from legal proceedings as witnesses physically present do.

Members are reminded of the long-standing parliamentary practice to the effect that they should not make charges against a person or entity either by name or in such a way as to make him or her identifiable. Members and witnesses have the option of being present in the committee room or joining the meeting via Microsoft Teams. I remind members of the constitutional requirement that they must be physically present within the confines of Leinster House to participate in public meetings. If members are partaking, will they confirm before speaking whether they are on the grounds of Leinster House?

Without further ado, I call on Mr. Harris to make his opening remarks.

Mr. Adam Harris: I thank the committee for the invitation to speak to it today on this important subject matter. AsIAm is Ireland's national autism charity. Our vision is an Ireland where all autistic persons are accepted as they are – equal, valued and respected. Our purpose is to advocate for an inclusive society for autistic people that is accessible, accepting and affirming. We work to support the autistic community and our families to fully engage in Irish life and build the capacity of society to facilitate true inclusion.

As members will be aware, autism is a unique neurotype. Autistic people communicate, interact and experience the environment in different way from those who are not autistic. While Ireland does not have a census question on autism, we know that increased awareness and understanding have led to more people being identified as being autistic in recent years. While 2016 data from the National Council for Special Education, NCSE, indicated that one in 65 students in school in Ireland is autistic, it is notable that the Department of Education has recently indicated that number is likely to be closer to 3.3% of the school-going population. It is reasonable to assume that prevalence is represented across Irish society when adults without a formal diagnosis are also considered.

Autistic people are neurodivergent and therefore share many experiences with people who have other neurotypes and diagnoses, such as attention deficit hyperactivity disorder, ADHD, dyslexia and dyspraxia. In the context of any discussion around accessibility and universal design, this is an important consideration, as many of the adjustments or reasonable accommodations that may support an autistic person will support many others too. For example, visual information improves accessibility for those with dementia, those who may be functionally illiterate or those for whom English is not their first language. Reductions in background noise would improve accessibility for those who use hearing aids or suffer from migraine. This is before we even consider the reality that when an autistic person is excluded by the environment, it often has a much broader implication. As a child, there were many places I found to be overwhelming, from restaurants to busy shopping centres. The reality was that if I could not go somewhere, very often our whole family simple did not go. This leads to many people missing out on important day-to-day activities and represents a lost opportunity for many services and businesses.

I welcome the opportunity to participate in today's discussion, as too often the invisible accessibility barriers that autistic people encounter are not widely understood or even considered as accessibility requirements, despite being a legal requirement. There can be a tendency to focus on how the person responds to an inaccessible experience instead of asking why that person is feeling overwhelmed in the first place. The UN Convention on the Rights of Persons with Disabilities, CRPD, calls us to recognise that disability is experienced by the interaction between the impairments an individual may have with the attitudinal and environmental barriers within society. Creating universally accessible environments and services is critical to this.

In AsIAm, we address autism primarily as an accessibility issue. Autistic people experience barriers in society that others do not and, as a result, are often deprived of the same chance to access critical public services, engage in leisure activities or even do mundane tasks such as going to the supermarket or visiting a doctor. Small changes can truly make a big difference. In AsIAm, we explore accessibility through four key lenses: communication; predictability and control; sensory processing; and judgment and attitude. How others respond to a person who is experiencing the world in a different way is, as the community consistently tells us, the single biggest barrier autistic people encounter within the community. Public education and engagement must be seen as a critical component of accessibility and, in our experience, the creation of accessibility supports not only improves the experiences members of our community have, but also serves to demystify and destigmatise autistic experiences.

When we talk about accessibility and autism, it is important to recognise that, just like the general population, every autistic person is different and the sorts of accommodations and adjustments a person may need can vary greatly. Indeed, at times they can even conflict. For example, one autistic person may be hypersensitive to the environment, while another may be hyposensitive. As a result, accessibility in autism cannot be codified in the way, for example, some physical accessibility adjustments can be. However, we can create lenses or frameworks in which we can think about autism accessibility. One such example is the ASPECTSS framework developed by the Egyptian architect, Dr. Magda Mostafa. ASPECTSS stands for acoustics, spatial sequencing, escape space, compartmentalisation, transitions, sensory zoning and safety. AsIAm was proud to work with Dr. Mostafa to develop design guidelines for university buildings based on our partnership with Dublin City University, DCU. This framework will now inform all future building projects in DCU and has a much wider applicability also. I will be delighted to share it with members if it is of interest.

In AsIAm, we run a wide range of training and accreditation programmes to support organisations to consider the accessibility requirements that autistic people may have and to put in place the appropriate adjustments. This includes the autism-friendly university award, which I referenced, alongside our autism-friendly towns award, which this year will work with 20 communities across Ireland, and our autism-friendly schools programme, which was recently successfully evaluated by a team of researchers in Mary Immaculate College.

While each accreditation process is different, there are a range of common considerations across all our work in this area, many of which we would like to see adopted more formally by the State as a means of enabling the participation of autistic people in society. Central to the consideration of accessibility must be autistic voices and experience. Autistic people should be involved in the development of guidelines and accommodations and our lived experience should inform every aspect of how accommodations or adjustments are provided and made.

There is a distinct lack of understanding of the sensory differences experienced by autistic people. The rise of multipurpose space and open plan have made many day-to-day environments, including new school buildings, very overwhelming for many members of our community. We believe all buildings should undertake a sensory audit to consider the experiences of autistic people and make adjustments accordingly.

For autistic people going new places or trying new things, especially in stressful situations such as healthcare settings, can be extremely stressful and challenging. We live in an information age and the appropriate use of websites, video and photography can go a long way towards easing this burden. Showing a person what to expect prior to visiting somewhere can empower an individual to make informed decisions.

Autistic people and neurotypical people can encounter a double empathy problem when interacting. Both communities need to learn to respect and understand the differences in communication, from the use of body language to the use of words. There are insufficient means by which a non-speaking autistic person can access public services independently and how communication is provided is too often imprecise and confusing. The most important accessibility change in this area would be universal training on autism for all public services, coupled with improvement in the ranges of modes of communication. For example, many autistic people find the telephone overwhelming, but too often this is the only way to access vital services, such as a GP when people are sick.

When we consider the accessibility requirements from a universal design perspective, there is much to consider. Moving forward, we should be ensuring all services and businesses are fully accessible by design. What about existing infrastructure? What about settings and services, for example, a busy health centre, which by its nature will pose some accessibility barriers for autistic people? We must remember that not every autistic person is diagnosed or aware that they are autistic and many people do not feel comfortable sharing their diagnosis. As a result, it is vital that as many accessibility measures as possible are applied universally and open to all. This not only destigmatises but, in many cases, makes for a better experience for everyone.

There may then be other accommodations that, to protect their integrity, it is important to have as a means of a person identifying why they need this support. An example is priority queueing. AsIAm issues an autism ID card to support this sort of access and we welcome the developments surrounding an EU disability card.

Finally, there may be some accommodations and adjustments that are unique to the individual, for example, avoiding a very particular sensory trigger. Where this is the case, it is vital that organisations provide neuro-affirmative information in advance, which supports and gives confidence to an individual to request these supports.

Autistic people adapt every day to a world that is not built with autistic people in mind. It is essential that society meets us halfway and we create more accessible environments, communication systems and information that empower and support everyone.

Co-ChairmanDeputy Michael Moynihan: I call Mr. Des Kenny and Ms Catherine Gallagher to make their opening statements.

Mr. Desmond Kenny: I am not on campus. I believe the Chair asked that we would indicate that. I hope I will not make any defamatory statements in the course of this presentation.

I am pleased to have been invited by the committee and to share the platform with AsIAm. It was interesting to hear Mr. Harris's presentation, which we will talk more about later on. It is important that our mutual complementarity and potentially conflicting approaches do not in any way conflict with the generality of improving the environment and making it accessible for all.

ILMI is an organisation comprised of disabled people. We see ourselves as a disabled person's organisation, DPO, working on the lived experiences of disabled people. We are not associated or affiliated with any service provider. We recognise the great work they do but we are here to talk as individuals who consult with individuals and we are bringing the committee that lived experience. I will talk to the committee about one element of accessibility and Ms Gallagher will amplify that. On hand we have Mr. James Cawley, our policy officer, who can answer questions on the accessible environment.

I want to talk to the committee in the context of accessibility in a visual world. As a blind person, I rely on my ears, hands and feet - yes, my feet - to give me clues to and replacements for what might usually be regarded as visual. At the edges of steps you will notice dimpled surfaces; this is to tell me that I am confronting steps going up or going down. You will see the same dimpled surfaces at pedestrian crossings and along the edge of platforms in stations to demark the line beyond which it is not safe for me to venture. Audio crossings are present in all of our cities and most of our towns, telling me when it is safe to cross the road, provided no cyclist is coming that is. They have been growing in numbers since the mid-1970s and it is a tremendous assistance to the number of people who are blind or with low vision. It is reckoned that there are 200,000 people in Ireland with low vision. When you take into account the elderly, going up to the age of 85 and 90, there are 240,000 people with low vision, while there may only be 17,000 people like me who are totally blind. The number of those audio crossings has grown over the years.

Announcements on our public transport fleets, buses and trains help identify where I might be at any given time, that is when the announcements are working, which cannot always be guaranteed. New audio supports moving into use are audio description, AD, on film and TV. Some 10% of our home-produced programmes on RTÉ are targeted to be produced with AD built-in. AD tells me what the scene is composed and comprised of and what the people are doing when action is not happening in a clear sense. It tells me what people are doing by way of crying, frowning or looking into the distance. I can anticipate what members might be wondering about. For example, an audio clip from "Pretty Woman" announces to me that the couple are gone to bed and the blankets are moving. Much of the movie stock on Sky Digital contains audio description which can be switched on and off as required. Even the remote controls can be told where to navigate the channel selections to, with the selections talking back to me.

The following is an important point for the committee. An EU regulation now requires that all new electric vehicles, EVs, from the summer of this year should emit an electronic sound when they are travelling below 20 km/h, telling me they are present. Travelling in excess of 20 km/h the tyres are reckoned to emit enough noise for it to be clear that there is an EV present. That regulation is not yet being enforced in Ireland and the same expectation might be applied to ebikes and escooters for the same reason.

Another directive from the EU relates to web accessibility, which was touched on in part by Mr. Harris. This directive relates to the content on Government and local authority websites being accessible to screen readers for someone like me who is blind, and is capable of magnification for somebody with low vision. The directive is being monitored and encouraged by the National Disability Authority, NDA, and it is good to see the officials from the NDA here to give more guidance on that. It is an important directive.

In terms of touch, how many members of the committee will have picked up a pack of Panadol for their headaches or Gaviscon for their indigestion in the supermarket and noticed strange dots on medicine packs? These will not be present on the drugs in your local pharmacy.

Those dots, which are Braille, also come from a European directive on medicines, obliging pharmaceutical companies to print in Braille the name of the medicine and its dose. All that I have described in brief, not unlike what Mr. Harris was talking about and in a similar context, is a web of assistance that exists to support me to know or to interrogate my environment or, in the case of medicines, to tell me what tablets I hold in my hand.

Publishers of books are obliged nowadays to have available digital copies of their publications which can be shared throughout the world to countries signed up to share print material and make it available to people who are blind or who may be suffering from dyslexia. Ireland has been signed up to this book share protocol since 2016. When I first started my college education in the 1970s, textbooks were not available as such. I had to have my books read onto cassette and I relied only on that and on lectures being spoken. There was no other means of having that available to me. Since then, in advancing my education in later years, I was able to do my course content and further education in digital form because of the availability of digital formats, which were available to me from the Open University. That format could be read by my computer, again using screen reader software.

I will move towards a conclusion. As the world evolves into more digital channels, I am told who is at my front door, how my thermostat is set and I can have Alexa or Google assistant at hand to tell me how I might need to spell something or to look it up. I can have it looked up and spoken back to me from Google. These are all part of the evolving new technologies of communication and contact. The committee can monitor these things passively as watchers of the evolution of it all or from time to time, as we are doing this morning, it can look at the failures of our planners to think about access when designing the environments which make up our interface with the world as an inclusive society where all disabled people, as Mr. Harris said, want to be and live in.

I call my colleague Ms. Catherine Gallagher to continue this presentation and to present how she finds the information gaps.

Co-ChairmanDeputy Michael Moynihan: I thank Mr. Kenny for his evidence.

Ms Catherine Gallagher: I thank Mr. Kenny and the committee for the invitation. In case it is necessary to say, like Mr. Kenny I am not physically on the premises and I am tuning in remotely.

I would like committee members to think about every milestone in their lives: starting primary school, secondary school, sitting the junior or leaving certificate, going to college, employment, or further training, moving out of the family home, and so on. Did they face significant barriers in getting information to hand to see through all of those milestones?

Every decision disabled people make can span across multiple Departments. Further to this, Departments and public bodies may attempt to redirect us around in circles. These queries can turn into fully fledged information-seeking expeditions. The burden of bureaucracy can be overwhelming, and we are no different from our non-disabled peers in that we have the same number of hours in the day. There are also issues in relation to physical access and the built environment, specifically Part M of the building regulations which my colleague Mr. James Cawley can address.

I have not had the privilege of always living with privacy, dignity and discretion. For every thing I turn my hand to, multiple Departments in several separate administrative offices need to be notified. One of the most recent examples of this was my debacle on being offered a scholarship to study to a PhD level in Dublin City University in early 2021. The modest stipend was a bone of contention regarding my disability allowance. I was going to lose everything. I instigated both a public and behind-the-scenes political communications campaign. While it is rather a long story of how Catherine's Law came to be, the crux of what I want to highlight today was the lengths to which I had to go to establish the lay of the land. When I received the first letter - in written format by the way, on paper - from the Department stating I was to lose everything, I was not given a reason. I set about establishing the who, what, when, where, why and how of the matter. I received incorrect information on several occasions, including the leading statutory body that supports the provision of information.

I eventually managed to piece together a case and, to be fair, when I presented it, I came across little resistance. There were organisations and politicians who may not even have been aware it was an issue. It was described in the Dáil by one of the Government party leaders as a "mistake". It certainly was not, but everyone got a fast education.

The physical toll this pressure put on me, even before it went public, is indescribable. There was nothing private, nothing dignifying and nothing discrete about those couple of months.

When we think of coalition-building, we often think of it as being external to us, or forming governments. Internal and cross-coalition building is just as important in how we talk and work with each other. We need to acknowledge that there are Departments and State bodies that would benefit from an overhaul of the ways they provide information to target groups so that individuals can make informed decisions about their own lives. There are disabled people who have the expertise to aid with this. Consult us or, better yet, hire us.

As it happens, I am in the middle of preparing an application regarding my research. I am asked to outline, in detail, how I will disseminate my knowledge, what impact it will have, who and where it will be useful for, and how it will add to the state of the art, as it were. These are questions we also need to consider in light of accessible information and communication.

Co-ChairmanDeputy Michael Moynihan: -

Dr. Aideen Hartney: The National Disability Authority, NDA, is delighted to be here to address both committees on this very important topic. Our role is to provide evidence-informed advice to Government on disability and we incorporate the Centre for Excellence in Universal Design, CEUD, which promotes universal design in the built environment, products, services and ICT. It is the only statutory centre of its kind in the world.

Universal design is the design and composition of an environment so that it can be accessed, understood and used to the greatest extent possible by all people, regardless of age, size, ability, disability or type of disability. Accessibility is encompassed within universal design. If a universal design approach is applied from the outset, then accessibility can become universal. This is reflected in Article 9 of the United Nations Convention on the Rights of Persons with Disabilities, UNCRPD, and the UN monitoring committee's general comment 2. Universal design has the capacity to handle the variation and experiences referred to by Mr. Harris in his opening statement.

An accessible built environment is one in which the barriers to access by disabled people are removed or mitigated as far as possible. A universal design approach at planning stage can reduce the need for costly renovations later. The CEUD at the NDA has developed guidance for universally designed homes, places and facilities; early years learning and care settings; and the retrofit of long-term residential care settings among others. However, to Senator Carrigy's point, we believe that incorporating a requirement for a universal design approach in relevant regulations is necessary in order for this guidance to be routinely adopted. For example, we have called for a revision of Part M of the building regulations to include universal design and to ensure houses built are fully liveable for disabled people rather than just visitable as is currently the case. We advise that all new housing projects progressed by the State should be universally designed and that 10% of any development should be designed to UD+ standards, so that any wheelchair user can live in them. We also recommend the development of a national standard on housing that clearly sets out technical requirements for universally designed housing in order that a consistent approach can be applied in all local authority areas.

The Disability Act 2005 and the UNCRPD require all information and communications provided by a public body to be accessible to everyone. The NDA has developed a code of practice for accessible public services and information that sets out the detail of these requirements. We have recently revised the code to include provisions to meet the needs of those with autism and users of Irish Sign Language and to reflect the shift to digital services that was accelerated during the Covid-19 pandemic. We look forward to this revised version being approved by the Minister in due course. As has been referred to by Mr. Kenny and Mr. Harris, the EU web accessibility directive has brought additional obligations for public bodies to ensure their websites are accessible, and the NDA is pleased to be the national monitoring body for that directive.

The European accessibility Act is due to be transposed into Irish law in 2022 and aims to ensure there are more accessible products and services in the market at more competitive prices and with fewer barriers. A universal design approach will be key to implementation of the directive in Ireland, and the NDA has advised that multiple parties will be involved to ensure implementation moves beyond the minimum required to avoid infringement to a proactive approach to ensure standardised accessibility across both public and private sectors.

A universal design approach requires the involvement of the widest possible range of users in the design phase and a co-production approach to projects. This approach is also in keeping with UNCRPD and its requirement for the close involvement of disabled people and their representative organisations in matters relevant to their lives. Consultation initiatives themselves should be universally designed to maximise the opportunities for engagement. Our recently launched participation matters guidelines on consultation and engagement can offer support to all state actors in taking an inclusive approach to the projects in their remit.

To promote awareness and take-up of universal design, the NDA advises the importance of including it in curricula at all levels of the education system, in particular continuing professional development for specific groups such as architects, engineers and IT professionals. A universal design approach should also be taken to promote learning for all, which includes provision of accommodations that anyone who needs to can avail of. We welcome the recent developments in this regard in the further and higher education sectors. The obligations and duties for public bodies are clear but the NDA's work to monitor progress across these areas shows there is still considerable work to be done to ensure accessibility is embedded as standard. Our 2021 report on the web accessibility directive, which we submitted to the EU, showed that of the websites and mobile apps we monitored, none was fully compliant with the directive. However, our report shows that the majority of issues identified were common and could be easily remedied if web providers gave greater focus to their obligations with regard to accessibility. We are currently exploring structured mechanisms for monitoring compliance with Part 3 of the

Disability Act and will be engaging with all Departments to remind them of their obligations and to guide on how to improve their performance where necessary as initial desk monitoring shows a number of basic steps that could be taken. The ability to monitor progress and present data to public bodies is critical to encourage and track performance over time and the NDA hopes to enhance further our monitoring capacity to help embed accessibility as standard in all public organisations.

We advise that, while universal design is recognised in legislation and several national policies and strategies, a structured and systematic approach is now required to embed it in practice. Making accessibility a consideration from design stage through to procurement and on to delivery should become part of the standard operating procedures for all State actors to ensure everyone can be included. I thank the committee. We would be delighted to answer any questions on this matter.

Co-ChairmanDeputy Michael Moynihan: I thank all of the witnesses for their opening remarks. We will now go to the members. It should be borne to mind that this is a joint meeting of two committees. We will try to get everybody in. Our first speaker is the Vice Chair of the Joint Committee on Disability Matters, Deputy Tully.

Deputy Pauline Tully: I thank everyone for their presentations. When we have talked about accessibility over the years, we have always thought more about the physical environment but it is about much more than that. Mr. Harris in particular referred to the need to create awareness across all public bodies, employers and services.

I will address a couple of the issues. Universal design and ensuring that housing projects were liveable for wheelchair users was mentioned. A couple of the witnesses mentioned Part M of the building regulations. They have asked for the regulations to be revised. Is that happening? Will they be revised to ensure that all buildings are liveable for wheelchair users? Do we have any idea of the costs of building something to universal design+ standards as against the cost of having to adapt a house or building, because that is often thrown up? Do we have a breakdown on that? Mr. Harris said that we do not really know the number of people who are autistic and that it is not a question on the census. Does he believe it should be?

Do planners and public bodies regularly consult with AsIAm, Independent Living Movement Ireland and their respective members with regard to accessibility issues? Does the NDA employ many people who have disabilities? To what extent does it consult with people who have disabilities? I have talked to people who have been consulted about issues because the body had to do so to tick a box and ensure it was fulfilling its obligations but the advice they gave was just ignored. I am particularly thinking about someone who was consulted on transport issues - I believe it was about cycling lanes or outdoor dining when that came in during the pandemic - but all of their suggestions were just ignored. It must be ensured that consultation is done properly, for the right reasons and not just as a box-ticking exercise. Will the witnesses speak about that?

The NDA has to oversee the directives that are being introduced. Is it properly resourced to do so or is it being asked to climb a mountain with very few resources? I am conscious of time. I thank the witnesses.

Co-ChairmanDeputy Michael Moynihan: Will we use the same rota we used for opening remarks? We will start with Mr. Harris and then move on to Independent Living Movement Ireland and then the NDA may comment on Deputy Tully's questions.

Mr. Adam Harris: The census question is absolutely critical. Just last summer, we saw the problems we have with regard to data on autism in the context of education. At the minute, we have different data sets. There are efforts under way to marry them but it is not a perfect science. One very simple example of this is that, if you are an autistic adult accessing a diagnosis privately, as we know you must, you will not be in any HSE or Department of Education data set. The census is the way to do it. To be clear, it could be an autism-specific question or a reform of the disability question on the census. At the moment, none of the fields within that question truly speaks to an autistic person's experience. As a result, I fear that people are going unseen and that this is affecting national planning.

On consultation, the picture is very mixed. There certainly is tokenistic consultation on many matters across the public sector and times when consultations are not accessible in and of themselves, which undermines the point. If we step away from the policy area and think more about making services accessible, we have seen many public bodies coming to us seeking support and training in this area. Key examples of this in recent years have involved libraries, public transport and universities. Schools are a priority area because the State is going to be investing heavily in new school buildings over the coming decade. In my view, the school buildings that are being built are, in many instances, less accessible for autistic people. To give one example, very often you have to go through very busy areas to get to a quiet space. Very vibrant and overwhelming colours are sometimes being used. We sometimes even see that in the design of autism classes themselves. More work needs to be done in that area.

Mr. Desmond Kenny: I will take the first part. In a sense, it would be good to see what Mr. Harris has described regarding the expansion of the question on disability in the census. It would be better if it were included in that general disability framework rather than being something outside of it. We must see how the growth in the population of people who name themselves as disabled people will impact on the perception of our service delivery.

As for tokenistic consultation, most of the time - organisations will experience this as they grow older and their contacts expand - relationships are built with people like the Co-Chairman and Deputy Tully who know that we are there to provide our voice. However, that voice is sometimes not called on often enough. There is less of the tokenism than there used to be. We are not there just because we must be to tick a box. That does happen and Ms Gallagher can share her experiences of it but I am looking at the issue over decades. I have looked at the origin of many things and sometimes nuance is lost and things do not happen correctly. This can be seen in the enthusiasm to encourage cycling as a form of recreation and active mobility and the extent to which this is threatening the safety of elderly and vision-impaired people. For example, planners are often told that lights should be in place to tell cyclists when to stop where there are bus islands and floating bus stops at which you have to cross a cycle lane physically to board or get off a bus, relying on those cyclists to stop. However, it is all about the cyclists not stopping. That is going to be a danger. It has happened in other countries, and will probably happen here, that a human rights difficulty will arise that will have to be processed by the Irish Human Rights and Equality Commission because people are being exposed to a danger. With regard to the physical built environment, Mr. Cawley is our policy officer and could enlighten the committee as to how we are consulted about the physical environment.

Dr. Aideen Hartney: I will answer a number of Deputy Tully's question and then hand over to my colleague, Dr. Craddock, who will talk about built environment matters. The Deputy asked whether the NDA employs people with disabilities. Yes, we do. In 2020, approximately 20% of our staff felt comfortable declaring that they have a disability. That is something we are always keen to focus on. As to whether we are resourced to do our job, what we have done very successfully, particularly Dr. Craddock's team, is built awareness of universal design over the last number of years and begun monitoring work on compliance with the various directives. The challenge is the capacity to support the variety of public bodies we interact with on implementation. We are not finding anyone who argues with universal design as a good idea but developing the guidance and toolkits they need to take it up is resource-intensive work. That is where a little bit of extra resourcing would be very welcome.

We work hard on consulting with people with disabilities and their representative organisations in our work. We take a varied approach to that. Sometimes for specific projects, we might have an advisory group with membership from DPOs on it and sometimes we go out wide with public consultation on specific projects. We take a varied approach but it is something we are working hard on improving over time. Our "Participation Matters" guidelines, which launched last week, will offer a blueprint for us and for all public actors to improve in that space.

I will make a final point about data. One of the challenges is getting accurate data from the census, not just about autism. This also came up in another committee hearing around not having accurate numbers for wheelchair users. The NDA would love to see a national disability survey carried out after the next census. Anyone declaring they have a disability on the next census could be followed up with and asked a range of more detailed questions so we could capture specific conditions, barriers and challenges. That was done back in 2006 but there has not been an opportunity to update that survey since then. It is something we have had preliminary discussions with the CSO on. We would welcome cross-Government support for a national disability survey after the next census.

Dr. Gerald Craddock: I thank the Deputy for her questions. Regarding Part M, at the present moment we are creating guidance to match the work being done by the Department on changing places and toilets. Part M is being revised to included those. However, we have been advocating and advising the Government, particularly the Department of Housing, Local Government and Heritage, that Part M needs to be revised specifically regarding domestic homes. At present, Part M refers to "visitability", an unusual word in itself, whereas we talk about livability, meaning the homes need to be liveable in. Visitability stipulates level access, an accessible toilet downstairs and access to one other room. That is what it is within Part M, which is a bit short on what we are looking for. ILMI is very exercised about this and is talking to the Department about getting Part M revised.

The Deputy asked about the cost of universal design. Going back to Mr. Harris's point, if it is done at the very start universal design is invisible. We go to the supermarket every weekend or whatever and walk through sliding doors. We never even think about it but there is level access, car spaces right at the entrance to the shopping mall and accessible toilets within the shopping mall. It is a negligible cost if designed at the start. We are working on two projects at the moment - a cost-benefit analysis of universal design for homes and a cost assessment that breaks down the individual elements. We have calculated that there are 659 different elements in the home that need to be designed or incorporated. Of that, over 600 have no cost so we are down to around 50 elements where there is a cost element. We are working through that at the moment. We are working with the Society of Chartered Surveyors Ireland SCSI and engaging with the Department. The other project, the cost-benefit analysis, looks at the other long-term benefits of designing well from the start, such as cutting down on the cost of care and reducing the cost of medical supervision but also the issue of falls. As we all know, particularly with the ageing population, people often fall in their own homes. The reason for that is that they are designed poorly. If we can get the design right at the start, there are huge savings. That has been shown internationally. We are in regular contact with the likes of the Norwegians, who are leaders in Europe on this. The Japanese have been designing this in for 40 years, mainly because they are seen as the most aged population in the world. We are making headway but, as everybody has said, we have some way yet to go.

Mr. James Cawley: I am coming in online from lovely Longford. I thank the committee for having me. The questions Deputy Tully raised are valid. ILMI has consulted its membership around accessibility in a number of areas, including the UNCRPD and Covid measures that were introduced into cities. We also have a planning group and we have developed a document that covers principles of inclusive planning. Before we look at Part M and the logistics of that, we need to look at planning issues. There was talk of consultation. In some cases, decisions are reached without any meaningful consultation with disabled people. Consultation should be done directly through disabled persons' organisations at all levels - local, regional and national. That is the simple answer to a very complex issue. We know the built environment is not accessible but quite often disabled people find out too late about plans, so rather than inputting into the design at concept stage, disabled activists are reacting to planning decisions. That is an issue as well.

In Ireland we seem to plan, design and build to minimum standards. Often regulating creates barriers to more universal design ways of thinking. Our members have highlighted that the Part M building regulations are weak and need to be reviewed. We should be looking at minimum standards, not maximum standards. They are simply not working for disabled people. ILMI recommends that local authorities fully monitor the implementation of Part M when it is reviewed and we call strongly for it to be reviewed. The other key element is that, as the representatives from the NDA have said, homes need to be wheelchair liveable. We are in a housing crisis. It is very difficult for disabled people to find houses that are accessible for us to actually live in. It is one thing to give us the four walls but we need to be able to be genuinely included in our communities. Accessibility plays a massive part in our lives. It impacts on our spontaneity as disabled people. That is important. When we keep accessibility in mind at the design stage, we are actually designing for diversity, which reflects the society we live in and our intersectionality.

Senator Catherine Ardagh: It is great to sit with the Joint Committee on Disability today. It is an honour to be here. The autistic community is probably a lot further behind the blind community. We take for granted all the advances with Braille, the beeping traffic lights and different advances in assistive technology. Members of the blind community are therefore somewhat more able to go about their lives, have a meaningful life and participate properly. For the autistic community, especially those who need a higher level of support, it is a lot more challenging. Much of the time, people can tell a building is going to be challenging when they step into the foyer. If they have a child, they will immediately know even from the acoustics coming back from inside that it is a no-go area.

It is great that we are having these discussions at this stage in terms of buildings being adapted. I do not believe there has been enough research on what types of buildings are appropriate for people with autism, although I know a lot of research is going on at the moment. Even the foyer of a building has to be a certain shape and size and has to have a certain acoustic standard for people to be comfortable enough to go into the building. For example, if a child was brought to a pool, the pool echo can be heard from the front door and it is the most horrible building to go into, so they cannot even go there, and other public buildings such as busy train stations also have that type of environment. As Mr. Harris said, there has to be a calm environment from the start and there has to be a channel to lead to another calm environment. It is a real challenge for those with autism.

We can see how this works from the perspective of the blind community. Who would have thought we would have braille, a system that people understand through a bump on a footpath that means something? It is such an amazing system. I can see Mr. Kenny is referring to his notes in braille. It is amazing how it works and how people are able to read information from little packages. It is also good how the EU has gotten behind the blind community and has supported them like this. We are looking for the same support for the autistic community from the EU and from organisations like those represented here today.

It is great that we are having these discussions. My colleague spoke about lack of consultation. This is a great forum for consultation and we are delighted to hear from the witnesses and to have them come in. I know Mr. Harris is probably sick of coming in here but it is great to have him. The witnesses have such a wealth of knowledge. Today, they are talking about something completely different from what they came in to talk to us about a few months ago, given we are talking today about building regulations. They must have so many strings to their bows. This is such an important conversation.

We are usually here talking about how, when people get into the building, the professional they are going to see has to have some sort of autism training. Some organisations are doing great on that. I have a friend who is a pilot and he said recently that all of his colleagues who work for Ryanair had to have autism training, which is great and would not have happened even five years ago. They have to be super-aware of adults or individuals wearing lanyards. He says that when he sees the lanyard, he is in a different mode and he is trained to be calmer and more facilitative of the person, which is great.

I have a question for Mr. Kenny. Does RTÉ have those audio description, AD, facilities which describe what is going on? He can answer that at the end.

On a question for Dr. Hartney, as the Committee on Autism, we are very keen to have the Houses of the Oireachtas improved in terms of Leinster House being a building that is autism-friendly. Has Dr. Hartney or, indeed, Mr. Harris, engaged with the Oireachtas or had any discussions with it?

We discussed a register. Strong autism advocates would like to see an autism register. They see how it worked for the cystic fibrosis, CF, community in that once there was a CF register, we were able to say there are X number of people with CF who need X amount of support. Once the register was created, there was a big push to say that we need services or we need drugs. I am not saying it is perfect for the CF community, as it is far from that, but it has given that community a lot more momentum by having a register. It is a difficult discussion. It is a hard question as to whether we should have an autism register or a general disability register, given they are very different. Obviously, the adaptations that a person who is blind needs are different from those a person in a wheelchair or an autistic person needs. That is a question that we need to answer.

I know the Co-Chairman's committee is doing a lot of work on the Changing Places toilets. We are a total disgrace when it comes to Changing Places toilets. We need to really up our game because it is so difficult for people with teenagers or young adults who need to be changed. It is not fair. It is just wrong.

I thank the witnesses for attending. It is been great listening to all of the speakers.

Co-ChairmanDeputy Michael Moynihan: I call Mr. Harris.

Mr. Adam Harris: Thank you. I spoke to the Co-Chairman, Senator Carrigy, last week and we are awaiting contact from the Houses of the Oireachtas Commission about that piece of work. Some of that is about design. It is important that the Committee on Autism hears directly from autistic people but, for many people, this could be quite an intimidating experience. It is about giving people as much information as possible in advance so they know what to expect, such as having a calmer place to wait in or, for example, having a specific person to do the meet and greet when the person arrives. We have a great template to work from. The first building on this island or in the UK was Stormont, which was accredited by our colleagues in the National Autistic Society over ten years ago. There is a very good template that we can bring here to ensure our Parliament building is autism-friendly. That is obviously important for the work of the committee and I hope it will send an important message to other public services.

On the point in regard to the autism register, anything that enables us to have better statistics is worth exploring. One of the concerns in the autism community around the concept of a register is, first, that it would need to be voluntary, but particularly the governance around any such register because, for most of the history of autism, it has been treated in a very medicalised way. We want to ensure that the information on that register would not be used in such a way by researchers who want to do things to autistic people, who want to cure autistic people, as opposed to actually making the lives of autistic people better as they are.

Co-ChairmanDeputy Michael Moynihan: I call Mr. Kenny.

Mr. Desmond Kenny: I can answer the question as a reassurance to Mr. Harris and Senator Ardagh. The evolution of benefits for blind people over the decades has been slow. It can be traced back to the Poor Law in 1840, when there were the blind, the deaf, the dumb and what were called the imbeciles. We evolved from that charity model. We have had decades of engagement with the community in the recent century to inculcate or have introduced systems and schemes that now look easy and seem to be easily achievable.

With regard to autism generally, I would say to Mr. Harris and the committee that we found, as a community of blind people, that for much of what we wanted to progress, we could better progress it through the European Blind Union, of which we were members, in the various consultative committees of the EU. The regulations regarding web accessibility, medicines, procurement and issues relating to that all came out of those particular committees. The autism community need to place themselves in the right place at the right time. We all know it is good to say "I spoke to the chairman" and let people know we were talking in a higher place when telling somebody what is happening. As they have spoken in Europe, and Europe is doing things, I believe we should use our MEPs more than we currently use them to prosecute potential legislation.

Blind people have advanced over the years and decades. What I would like to do in some way is to share the piggybacking of our success with AsIAm and with the autism community so we can share some of that around our sensory needs. I would be fearful that if we work in total isolation of our sensory requirements, I could go back some day and find the lift no longer talks to me, tells me what floor I am on or the doors are closing in order to meet a request that was made for a totally silent environment. We can learn and pass on our learning to AsIAm and to Mr. Harris in all that.

Dr. Aideen Hartney: I echo what Mr. Kenny said. It is more helpful to think about a collaborative and a shared approach than different groups pitting themselves against each other with their varying needs. The beauty of a universal design approach is that it can accommodate the full range of experience. On the question of a register, we would very much advocate that it should be for people to declare and decide whether they wished to declare they have a disability for themselves. Many people wish to keep it private or do not consider they have a disability if the barriers in society have been successfully removed for them. If we got to a universally designed world, we probably would not need these data-collection mechanisms.

We have not been approached to engage directly with the Oireachtas to make it an autism-friendly building, but we would be very open to doing so. Dr. Fitzpatrick and Dr. Craddock might have some points to make regarding guidance we would have in that regard. In our web accessibility directive monitoring nobody achieved compliance. The Oireachtas website was one of the strongest performers we found in that first report and I congratulate it on that. Does Dr. Fitzpatrick wish to make some points about acoustics?

Dr. Dónal Fitzpatrick: Several speakers raised this interesting point. Properly designed acoustics in a building very much benefit people with autism. I am a totally blind person. I navigate by using the cane. Well-designed buildings with well-designed acoustics along with some tactile markings are also very beneficial. Dr. Hartney made the point that what benefits one group of individuals often benefits a significant number of groups, which is why we go back to the whole notion of a universal design environment. I will give one quick concrete example. Airports can often be busy, especially over the summer. The acoustics in many airports throughout the world actually make navigation problematic particularly when there is no tactile paving whatsoever. As is clear from this morning's discussion, modifications to that space would clearly benefit me as a blind person and clearly benefit people with autism as well. We need to look at this very much holistically taking into account the use needs of multiple groups of people. Multiple different scenarios of use are very important.

Dr. Gerald Craddock: Our conference will take place in Croke Park on 20 October to which all the committee members are invited. There we will launch a CPD for architects. One of the winners of the Royal Institute of Architects of Ireland universal design award was the Central Bank, just across the river from here. We have been working very closely with it but also with many of its employees with different abilities. We will launch an interactive e-learning module on 20 October, which could be very useful for the Oireachtas in addressing issues such as acoustics, which has been mentioned here several times, and navigation across the building from the car park right through to the various floors in the building.

The 2014 public procurement directive is now covered by a statutory instrument in Ireland, SI 284 of 2016. All public procurement of parts and services that affect people need to include accessibility as mandatory. We would highly recommend that that statutory instrument be implemented across government. In America in 1991, President George Bush sr. signed the Americans with Disability Act into law. That legislation was a turning point in making products and services accessible in America. It is the reason many of the products developed by Microsoft, Google and others are much more accessible than any products designed in Europe. The committee should advocate that SI 284 be implemented across government and local authorities.

Deputy Joan Collins: I am very humbled, listening to the experiences of the speakers. As a person who has full faculties, I understand there are some issues but I do not have the lived experience of people. I had the pleasure of knowing Dermot Walsh who was an advocate for independent living. He worked full time with Dublin Bus advocating for disabled access for transport. Is there somebody there who took his place? Is there an advocate for disabled people in Dublin Bus and in the transport area?

I take on board the point that Mr. Kenny made about the structures that were put in place during the Covid pandemic, particularly for cycle lanes and traffic islands. I have heard Gary Kearney frequently mention how dangerous they are for disabled people. How important would it be that the ringing or noise levels would go up on buses as they slow down to 20 km/h and below? From the point of view of cyclists, e-scooters are causing major problems. They can put people with disabilities in a very difficult and potentially dangerous situation with the risk of getting seriously hurt.

Do local authorities consult with the National Disability Authority on planning regulations? Part M seems to be very loosely based on visitation rather than liveable accommodation. What does the National Disability Authority want us to do to get that revised to the extent that the NTA and other disability groups can have an impact?

Regarding AsIAm, autism is a relatively new disability that is being grasped in communities and nationally. Could AsIAm link in with the NDA? Different disability groups, such as those who are blind or disabled, have autism or use a wheelchair, all have certain specific needs relating to their disability. If everything is thrown in together, the voices of different groups can get lost. Having strong groups like AsIAm and other groups is really important from the point of view of getting their experiences across to the NDA.

The NDA has referred to the implementation in public buildings and public areas. Does it have the staffing levels to have an impact? What levels of staffing would it need? What experience and level of education would be needed for that sort of thing? We need not just guidelines but statutory instruments in the planning process. We know that builders will not adhere to many of the guidelines. I will leave it at that and ask the witnesses for their feedback. What do they want this committee to do and how can we work with them on these issues?

Mr. Desmond Kenny: Before I respond to the Deputy, I would like to refer back to something that was raised earlier with regard to accessibility within the Oireachtas. I want to compliment the Houses of the Oireachtas for moving quickly on representations made to it. The ILMI made a presentation in the audiovisual room two weeks ago but we found it inaccessible for speakers who use wheelchairs. This was brought to the attention of those in charge of the workings of the Oireachtas and it will be remedied immediately. Inaccessibility is often not discovered because we have not been to a place but as we go to more places, people realise that something needs to be done.

On the NTA and our good colleagues at Dublin Bus, the former Minister for Transport, Shane Ross, made it a requirement that a disabled person be on the boards of Dublin Bus, Bus Éireann, the NTA and CIÉ. I am a member of the board of Transport Infrastructure Ireland, TII and at the moment we are looking improving the toilet facilities at all motorway service stations so that there are accessible changing rooms in those service stations.

Being involved and engaged is the way forward. One thing this committee could do is to encourage local councillors and local authorities to engage. Members of this committee are committed to these issues but at local authority level, what one often sees is enthusiasm in pursuing things like cycling facilities, which is fair and right, but the enthusiasts want minimum regulation. On a pedestrianised street like Grafton Street, for example, those who want to bring a bicycle or a scooter should walk. There should be an insistence that what is pedestrianised is for pedestrians. Not all cyclists adhere to the rules. We would like to see the Oireachtas committee on transport, for example, give consideration to issues affecting people who are less mobile and that includes children. A more collaborative approach is needed. When we were working at European level, we looked at ease of mobility in the context of ramps for older people and people pushing prams and buggies. The focus was not solely on providing facilities for people with disabilities but on universal design, as was mentioned by Dr. Hartney, Dr. Craddock and Dr. Fitzpatrick. The aim is to include everybody.

Finally, on the Deputy's question about RTÉ, that organisation is living up to its commitment to provide a number of programmes with audio description, mostly on RTÉ Junior. I was delighted recently to get a copy of "Kiva Can Do" as my grandson voices some of the character parts in it. If the Deputy has 15 minutes to spare, she should look at "Kiva Can Do", which has audio description on it. That is a good way to introduce audio description to a younger population who are not disabled.

Dr. Aideen Hartney: I thank Deputy Collins for her questions. On local authorities and guidance on how to improve performance in public buildings, one of the projects we have under way at the moment is the development of a code of practice for accessible public buildings. In our process to develop that we are taking a very consultative approach, which speaks to some of the points the Deputy made about how to encompass the full range of experience without diminishing the needs of individual groups. The code of practice will talk about how to maximise accessibility and then it will be broken down into what might be necessary for people with autism or for people with visual impairment, for example, on making sure Irish Sign Language, ISL, interpreters are available for those who are deaf and so on. It will provide some guidance for the individual requirements but also talk about accessibility as a universal concept. That is just one example of how we approach it.

Local authorities do not tend to come directly to us but what we do is make submissions to, and offer advice on, the local development plans when they come up for consultation. We are always available to offer advice. In terms of the staffing competencies we need to deliver on that advice, when the Centre for Excellence in Universal Design was established 17 years ago, it was established with Dr. Craddock as the chief officer, with three advisers underneath him. It has not expanded since then. The centre has done significant work in promoting an awareness of the concept of universal design and the fact that we are talking about it here today is testament to that. What is needed to turn the concept into implementation is technical guidance on how to break that down in the various domain areas. We would need technical competency in architecture and built environment skills as well as in areas such as ICT, such as what Dr. Fitzpatrick brings to the table, communications and product design. The aim is to build that so we can work with more bodies to help them on their implementation journey. That is what is required but we are not an enforcement body. We are an advisory body and our key strength is offering guidance that is grounded in practical and evidence-based research.

Mr. Adam Harris: I thank the Deputy for her questions. We link quite regularly with the NDA through its various consultation processes. I want to compliment the authority on the new consultation guidelines that were published last week. A huge amount of time was spent engaging with our community, with autistic young people, around what those guidelines should look like. That bodes well for the future and the ongoing conversations we will be having around some of these topics.

Co-ChairmanDeputy Michael Moynihan: Senator Garvey is next.

Senator Róisín Garvey: I am happy to listen to our visitors because they have a lot more experience than me. The big issue for me is that every single parent I know who has a child with autism seems to have to run an individual campaign to fight for his or her child's rights. That is why I am a member of this committee but I want to listen to the people who have a lot more experience and hear from them what we need to do to help. At the end of the day, I do not have any personal experience in this area. I have friends who have children with autism but all of them seem to have to fight individual battles. It is just insane. We need to find a uniform way of helping and I am glad that we have this committee. I must commend the Chairman on creating this committee so that we can focus on finding some sort of system to support the people who need it. In that sense, I would rather listen to the experts we have here today.

Co-ChairmanDeputy Michael Moynihan: Deputy Cairns is next.

Deputy Holly Cairns: Today's discussion on accessibility in the built environment, information and communication is fundamental in terms of the capacity of individuals and whole groups to exercise their rights under the UN Convention on the Rights of People with Disabilities, UNCRPD. In this committee we have tried to foreground the social model understanding of disability. That is relevant to this discussion as we can see how poorly designed systems create barriers. While many of the issues we deal with come down to a lack of public services or personal assistance, today we are examining matters that could be resolved through good and inclusive design. I was struck by the numerous examples that Mr. Kenny gave of accessibility, which was very impactful.

My question is for the ILMI and AsIAm. As disabled persons' organisations, DPOs, what is their level of engagement with Government Departments and public bodies in the development of policies, practices and laws that impact their members? Article 4 of the UNCRPD requires engagement on legislation and policies relating to persons with disabilities, but from all I have heard, this is rarely adhered to. When it came to the Assisted Decision-Making (Capacity) Act 2015, the most alarming parts of the legislation arose from non-consultations with designated public officials, DPOs, and people directly affected. I understand Article 4 should extend to all areas, such as transport infrastructure, involving Transport Infrastructure Ireland working with our guests in developing requirements for public transport vehicles, or for all State bodies to seek input in making websites fully accessible. Are Departments and public bodies engaging with these groups? In relation to that, what is their capacity as organisations to carry out that kind of work and what type of no-strings-attached funding and support should the Government be giving these organisations to allow them to operate independently and to fulfil all those roles? So many of the issues discussed today could be avoided if the State complied with the Convention on the Rights of Persons with Disabilities.

Co-ChairmanDeputy Michael Moynihan: I thank Deputy Cairns. We will start with Ms Gallagher from Independent Living Movement Ireland. Mr. Kenny has his hand raised. Then I might come back to AsIAm.

Ms Catherine Gallagher: I will focus on what Senator Garvey was saying on what we would call the human interest-framed stories. This is something that ties in with my own academic background research. While I am a disabled person, my background is in journalism and political communication, which I have been able to bring into my voluntary work. To remind people, I am not a staff member. I am a volunteer activist who has other commitments on top of what I do in my spare time.

On the human interest stories and how often disabled people or autistic people are framed in the media, there has been a trajectory of human interest stories and emotively framed stories. As it happens, recently I published an open-source academic article. While it is not particularly relevant to what Senator Garvey is asking about, it is entitled, "How 'cocooning' as a public health measure was reported during the Covid-19 crisis" in Ireland throughout 2020. While I accept it is a niche study, I found some interesting trends, some of which were not surprising to me, in that cocooning, let us say, as a public health measure, was very much reported on as a human interest emotive feature. Of the sample of coverage that I analysed, I found that there was four times the number of human interest-framed stories than reports that I deemed to be particularly informative. Consequently, we have a trajectory of people feeling that they needed to share their private lives, as I did last year in relation PhD scholarships, to bring about some kind of awareness. It is not a sustainable model of advocacy, both in my personal and academic opinion.

It is not that I want to vilify newsmakers either but there is also research which was conducted in Ireland recently that shows that newsmakers, a term which includes editors, journalists and news executives, know that interviewing an autistic person, a parent of an autistic child or a disabled person and constructing a story like that is the type of story that is low in cost. Getting someone to tell his or her story is a low-resource form of reporting and typically gets engagement because it invokes a sense of emotion. While personal stories are important, I would be curious, perhaps after my current research project, and interested in a subject I invite others to consider, namely, the effects of private citizens sharing their personal stories in the media. Research shows that when people share their personal stories in the media, it contributes to action by Government. In terms of the audiences who engage with those stories, research proves that it shifts attitudes from an individual issue to a wider social, political or cultural issue. It can be effective but at what cost?

Bringing it back to my opening statement on people having the right to live with privacy, dignity and discretion, for disabled people, and possibly for autistic people - I might ask Mr. Harris to chip in on that - that is a privilege I have not enjoyed, even before the PhD issue that I had.

Lastly, while joint committees obviously cannot influence how journalists and section editors do their jobs, the media is so important because we get mediated messages through the media. That is how we know what was happening in the budget this week. It is where we got our information on anything to do with Covid over the past couple of years. While the sample of coverage in my research was not deemed to be particular informative in terms of information-rich reporting on cocooning, I would welcome people taking a read of that article. It is publicly available.

It is worth considering Government communication strategies because journalists and media people such as me can only work on what is available. If certain Departments or Ministers are not prioritised behind the scenes in the Government communications strategy on any given issue, they will not have the platform to be able to come out to speak on these platforms. That is why political communication is important. It includes the media sphere, the political sphere and also us as a public.

Sorry, I meant to keep it briefer than that but it is something I am particularly interested in. We need to consider the harm caused by private people, who have other things to do in their days and weeks, and lives, coming out. I do not believe it is sustainable, although I understand why it happens. I understand why people feel they need to come out because I myself have had to do it. I understand why it happens, but maybe another committee meeting might consider how we raise issues, particularly, maybe, for people who are not involved in, aware of or a member of DPOs.

Co-ChairmanDeputy Michael Moynihan: Following Mr. Harris, we will go to Mr. Cawley.

Mr. Adam Harris: In terms of the level of engagement we see from Departments, as I alluded to earlier, we see some really good engagement in some places, and it is proactive and is very much an ongoing engagement. In other instances, we see less engagement. What that partially comes to is that ongoing dance between the desire to centralise and have a strong centralised disability policy on the one hand and every Department realising this is still for everybody as well on the other . We need space to strategically think about disability but it is a job for every Department as well under the UNCRPD. That is very much a culture piece that still needs to be worked on.

The other concern I have is that often consultations are not accessible. That is why these new NDA guidelines are important. I have been at round-table discussions on autism in loud rooms with no quiet space with minimal information in advance and that does not get the best out of everyone. Not only that, it does not show respect for the people who are coming to offer their expertise.

What we have to think about is that disabled people are very often called on to be consulted frequently. Not everybody within the disability community is interested in getting or has the capacity to get involved in these issues. It is often a small cohort of volunteer advocates who are being invited to a huge amount of meetings. We need to think more about how we can resource and support people to do that. The reality is that many people within our community are still living on a disability allowance that, even after the increase in the budget, is offensive. It is not possible to live a decent life on it. When people are being asked to travel long distances, there is an expense aspect to that that needs to be considered as well.

In respect of our own organisation and where we struggle a little, we have one policy officer and we get approximately half of that person's salary contributed. That is the sole resourcing we have for our policy work. Every year we have our own work plan. For example, this year we are preparing a report on access to education in autism, looking specifically at suspension, expulsion and reduced timetables. One of the challenges is that we also have to respond to whatever pops up on the news, such as the issues with schools and CAMHS that arose during the summer. We also get sudden surprises from an Oireachtas committee or a Department wanting to consult with us. All of those opportunities are very welcome, but with one person they are very hard to manage. That is a challenge.

On the point that Ms Gallagher asked me to chip in on, I very much agree with everything that she said. I will definitely read the paper. For us, the depiction of autistic people in the media is an ongoing challenge. Sometimes it can be really positive, and we even see positive shifts in popular culture. I can even point to the fact that the Thomas the Tank Engine "Thomas & Friends" series will soon feature an autistic train called Bruno the Brake Car, actually voiced by a nine-year-old autistic boy in the UK. These sorts of initiatives are important. However, when we look at the media every week we are told that there is a new cause for autism or read some sensational headline. Very negative language can be used about autism at times, which does stigmatise and damage. There is a need to have more media education. I think that is most important.

Mr. James Cawley: I thank Deputy Cairns for asking such a great question. It is an opportunity to actually talk about the UNCRPD implementation plan. We have all heard about the UNCRPD, but in respect of its implementation, any implementation plan needs to be in line with the SMART policy framework, whereby our policies need to be strategic, measurable, achievable, relevant and time-bound. It is a policy framework that a lot of the DPOs, through the DPO network, work together on. That SMART framework allows us to look at how the policies should be strategic and measurable. The NDIS, for example, is a very broad policy with lots of actions and themes. It is really important that we go back to looking at how our policies can be SMART in their implementation. The framework can align really well with the articles of the UNCRPD, and thematically be sorted to fit in with all our intersectionalities as well. It is important that Deputy Cairns raised the issue, because our policies need to align with the articles of the UNCRPD. We must be SMART in our approach.

Mr. Desmond Kenny: I want to amplify what Mr. Cawley said in response to Deputy Cairns, which has also been touched on by Mr. Harris. We participate in consultative processes, and as Mr. Harris said, some of us travel distances, at some expense, to do so. Meetings are also held during working hours, and if you are fortunate enough to have a job as a disabled person, your employer does not take too lightly to you taking time off. I know we have to look for an answer to the Deputy's question. The resourcing of DPOs has to be seen as an integral part of the way forward. We spend nearly €2 billion on service provision that has been analysed to the nth degree in terms of value for money in different reports over the decades. It does not change. The language around separation changes. I may get into some trouble for saying this, but we have what I would call an industry around disability that continues, by accident, to create a dependency on it, rather than liberating us through they type of things we have been talking about today. It can happen by accident that somehow or other the liberation that has been won gets accidentally sidetracked into other areas by campaigning parents who rightly cry out loud because of neglect. It is appalling that the media should be used, because of the ineptitude of people responding or people who are deliberately deaf to what is going on, to shift the dial to a point where there could be perception that segregated education is best for all disabled people, and not specifically one set of disabled people. It took decades to get the Department of Education to agree that children with disabilities should be educated in their local schools, rather than in St. Mary's, Baldoyle, the Central Remedial Clinic or St. Joseph's School for the Blind. There is a danger that somehow, in the rightful arguing for a special place for children who might have autism, that could be swept up by planners who are not thinking or consulting, into a generality that segregated education is where people should go. Support for segregated education shifts could also mean that in the case of my grandson, for example, who has Down's syndrome, the speech therapy services he has access to in going to an inclusive school will be taken away, and his family will have to find the funds to pay for the therapy. The rightful response to the neglect and huge policy deficits has swept everything away along with it. There is an accidental shift behind it.

Senator Tom Clonan: I thank our guests for attending and for all of the contributions thus far. My question comes from personal lived experience. I went on a personal journey as a parent and a carer. Due to the fact that my son had an unusual medical condition, we, as a family, did not belong to any grouping, as it were, for example, Down's syndrome or cerebral palsy. I only have knowledge of our own journey and the challenges that confronted my son. It is only since I was elected that I have become more aware of the broader concerns within our community. I have met a number of DPOs thus far. It is becoming clearer to me that those who lead and drive the DPOs, including the spokespersons and the people who are most visible, need to be from the disability community. How do we support the DPOs as a committee? How do we ensure that we get to the point - and this is something that I feel very passionate about - where these issues are not led by service providers? A representative of one of the DPOs told me that having the service providers represent the interests of disabled persons is like having employers' groups, such as IBEC, representing workers at the Labour Court. Workers do not want to be represented by employers' groups; they want to be represented by trade unions and have their own voices. That is my interpretation, by way of a clumsy analogy, insofar as I can read myself into the situation. How can we support DPOs to be front and centre? I know from some of my meetings that funding seems to be a core issue. There needs to be a great deal of financial support provided. I imagine that will be part of the response. I congratulate Des Kenny on a great article in *The Irish Times* this week. I am just sorry that it was in the health section. It should have been in the main part of the newspaper. I also congratulate Catherine Gallagher and thank her for her contribution this morning.

Dr. Aideen Hartney: The National Disability Authority, NDA, is not a disabled people's organisation, DPO, or a statutory advisory body but our advice to Government has been reflective of the UN Convention on the Rights of Persons with Disabilities, UNCRPD and the provisions in Article 4(3) and we advise that DPOs should be consulted and participate throughout any matter of policy and practice relevant to the lives of people with disabilities. We are conscious that there many people who do not wish to belong to a DPO or who do not have a DPO for the particular disability with which they are concerned. Our advice and practice is to try to cast the net as widely as possible, in addition to consulting with DPOs, because it is important to capture as many perspectives as possible in order that they can inform the advice we give to Government or the guidance we develop. We agree that the funding model needs to be examined. I understand that the Department of Children, Equality, Disability, Integration and Youth is looking at that now as part of a development of a longer-term UNCRPD implementation strategy.

Mr. Desmond Kenny: What we see in the urgency of parents and the development of campaigns that come from parents is that organisations then sweep that into themselves and think that they can become the voice for those campaigns. In some way, Aideen Hartney touched on it. There are go-to organisations for the blind and the deaf and the wheelchair user. This committee, going forward, could insist that all of those organisations - a bit like the two Houses of the Oireachtas - create their own senate of people with disabilities within those organisations to whom they can commit time and State resources, which they receive in copious amounts, to creating that voice for a disability and then we can look to sweep that disability classification up into a generality of the DPOs. Separate organisations would ultimately amalgamate into DPOs. The Independent Living Movement Ireland is a cross-disability DPO. That is the way it has to go forward. There is a commonality of need and remedy that we could be wastefully dissipating if we do not, first of all, look for the segregation of organisations into creating a voice for their disabled service users and then amalgamating that into DPOs. That is frightfully important.

Ms Catherine Gallagher: I will keep it brief. Covid is always on my brain, unfortunately, because of what I research. Covid is still very much with us but there will come a time where we will enter a post-Covid society and country. In times of crisis and after times of crisis, history tells us that it is an opportunity to lay down a new foundation of how we want to live, treat people and work. Even the fact that I am here tuning in remotely might not have been possible before.

We hear terms such as work-life balance. Disabled people have been calling for remote working for a very long time. It was only when everyone, overnight, was in a collective global crisis that accessibility was granted to everybody. I know there were challenges in an online world and it does not work for everybody but accessibility can benefit everyone and it is all our interest.

Independent Living Movement Ireland, ILMI, is an example of a cross-impairment DPO. I have known people in ILMI and other DPOs I am involved in for the past two or three years and I have no clue of what those friends' conditions are, because we talk of the collective experience of being disabled. I am physically disabled but I am not a wheelchair user. However, I often have concerns that would be similar to those a wheelchair user would experience. Similar points were made about acoustics and sound. As my impairment affects my balance, I find it harder to concentrate going through crowds when it is very loud or if it is too bright or too dark. With regard to supporting DPOs, it is important to have us involved at every stage of every process and mot just in the middle and not just at the end. We should be front and centre and, as Senator Clonan was saying, told from the beginning and involved from the brainstorming sessions.

There is a point that I make when it comes to engagement. A dialogic form of communication should be used whereby DPOs and ordinary private citizens in who might not be attached to an organisation are brought in to communicate and a safe, accessible and close environment is created where people feel that they can contribute. Disabled people are part of a community we can see has had a history of belonging, unfortunately, to the spiral of silence. This idea comes up in the social sciences of this idea there are multiple examples in that people identify with belonging to a community that has been oppressed and discriminated against and has not been listened to. There is a history there with disabled and autistic people. It is a history that hurts.

If I was to sit and think about it for long enough and how, unfortunately, parts of history are still with us, it would be incredibly upsetting. Disabled people and DPOs should be front and centre at every stage. It is not just about just. Disabled people should be hired. The members' should hire disabled people in their parties and areas of work. We should be hired.

I do not want to single out or vilify anyone or go on a witch-hunt but I see a considerable amount of information online published by political parties and politicians without captions or screenshots of budget information without alt text. Maybe if they had a disabled person on their team who had a qualification in communications, that person would be more than able to point that out and capable of pointing that out, without having to think about it for too long.

We are very much here. Of course there are difficulties with us entering the work force and that is a conversation for another day but we are very much here. Whether it is DPOs as organisations or disabled people as potential workers or collaborators, there is a talent pool. I always say is that if one has an organisation - not necessarily one that looks at disabled issues - or decides to create a communications or engineering organisation or business, having disabled people with qualifications in roles in communications, business, finance, education, sustainability and management in that organisation would put many people out of a job. It involves being able to think outside the box. Unfortunately, based on my experience as an early career academic, I feel people do not see me as competition - not that I am a particularly combative personality. It is important to bear in mind that disabled people are part of the talent pool and if you are not tapping into disabled people, you are not tapping into the full complement of the talent pool.

Mr. James Cawley: Senator Clonan raised a really good point about what people can do to support the work of disabled persons organisations, DPOs. We all know that DPOs are led by and are for disabled people. There are specifics there around 4.3.29B and general comment 7 of the UNCRPD. It is really important to state that our communities can amplify the work of DPOs. If we look at the personal assistant service, we can see it is still not a legal right in Ireland for disabled people. Sometimes there is a misconception that this is just an issue for disabled people. It is not. It is a human rights and equality issue. We need to make sure we can mobilise our communities to ensure that they are bringing issues like personal assistant services and inaccessible housing and transport to our Deputies and councillors all the way from the grassroots up to national level and back down again. This is how we will see movement in rights and services that allow disabled people to have choice and control over their lives. Regarding when we see allies coming along to amplify those issues, for example, if Deputies and Senators could go back to the Minister and say the personal assistant service is one that allows disabled people to have choice and control over their lives from a human rights perspective. It is really important that we state that people can amplify the work of DPOs while we are doing that led by lived experience as well. We would be happy to engage with allies who would love to work to progress this and other issues as a human rights and equality issue. It is a great question.

Mr. Adam Harris: I probably touched on some of the challenges around funding a moment ago. I will focus on capacity building, which is particularly important. The reality for autistic people is that they must advocate on two dimensions all the time. They are all constantly engaged in battles just for own lives, services and supports. At the same time, there is the broader, more collective effort concerning shifting policy and consultation. There are many autistic young people. One of the realities is that from a young age, autistic people are not being given the tools to articulate what their needs are and to understand their needs not as a nuisance or difficulty but a need they have a right to have met. A lot of work must be done starting with very young people around giving them a positive self-identity. This in turn will lead them to feel more confident and assertive around their rights and set them up better around the engagement with DPOs. As people grow up, more needs to be done to train and support autistic people around engaging in self-advocacy. When people and DPOs are engaged in consultations, part of how we make sure it is not tokenistic is by making sure there is support there that can support and facilitate people's participation through the process.

Deputy Marian Harkin: I thank all the people who presented this morning. I was speaking in the Dáil so I had to chase out so if I ask a question that has already been asked, please let me know. We are told the obligations and duties of public bodies are clear. They are fairly simple and straightforward. There are common things that people get wrong. How easy would it be to deal with some of the more common and straightforward ones? In that context, how can the witnesses be both proactive and reactive? Perhaps somebody needs a certain amount of assistance or guidance. Not everybody knows about Web design. I would put myself at the top of that list. What is the witnesses' role in being proactive as well as reactive? What sanctions are there, if any, particularly for repeat offenders?

My next question is for the witnesses from Independent Living Movement Ireland. I support what Senator Clonan said about DPOs 100%. He said it - I do not need to repeat it - but that is a crucial point. They must be independent. "Nothing about us without us" is a phrase that trips off all our tongues but that is the reality of having DPOs. That is their job. That is what they do. My specific question concerns cycling and the promotion of cycling, which was mentioned. Many people like to cycle. It is good for their health, etc., but it does present a challenge for visually impaired, blind and older people who are no longer as nimble on their feet as they once were. Have there been any talks taken place between Independent Living Movement Ireland and organisations that promote cycling? Is there any way we can begin to find solutions before the problem just blows up? We have already seen it between car drivers and cyclists. We all share a common space and must find ways to make it work. Is anything happening in this space?

I will address my next question to Mr. Cawley. In other countries, people are taking a human rights approach to this. Could he briefly outline some of that. My next question is addressed to Mr. Harris. I was impressed by his candour when he spoke about the fact that accommodation and adjustment for people with autism cannot be codified in the same way as physical adjustments, etc., and that needs can vary and sometimes even conflict. That is just the reality. Can Mr. Harris elaborate on that? Am I asking too much when I ask whether there are common denominators? Are there things that can be put in place that might not work for everybody all the time but begin that journey?

Dr. Aideen Hartney: I will make a general comment about how we are proactive as well as reactive in our work and hand over to Dr. Craddock, who will talk about some of our engagement on cycling and some things relating to the Web accessibility directive. Dr. Fitzpatrick will then speak about the European Accessibility Act, sanctions and penalties.

The NDA monitors compliance but at the same time, we engage extensively with public bodies to guide and offer suggestions as to how their performance can be improved. That is where our practical guidance and technical know how come in. We are not just naming and shaming. We are engaging to bring people along on a journey of constant quality improvement. Dr. Craddock will talk about the specifics of the web accessibility directive and the common errors there.

Dr. Gerald Craddock: I thank Deputy Harkin for her questions. We took over the role of national monitoring centre for the web accessibility directive in January 2021. Last year, we monitored over 300 websites on a weekly basis. In-depth monitoring of 56 websites, including mobile applications, showed that common errors include colour contrast. It is a significant issue. We found that on more than 70% of the websites we monitor, or in the region of 150,000 to 200,000 pages weekly, colour contrast is a significant issue. PDFs are the bane of many people’s lives, particularly those with disabilities, for whom they are a significant problem. Online forms and form-filling are also a significant barrier for many people, not only in terms of the language used but also their accessibility and usability.

As part of the proactive approach, we work closely with the Irish Computer Society. Last year, we ran ten online training programmes. We can send members a link to those if they would like to try them out. They are approximately one hour long and kind of lunch-and-learn sessions. We had more than 1,000 public officials engaged on the training last year. We are being proactive on that.

On cycling, we have made progress as a nation. We started off by having spaces that were shared between pedestrians and cyclists. Since then, we have learned, particularly from looking at Denmark in recent years, that cyclists need to be segregated from pedestrians and a physical barrier between them created. The physical space we have in cities is very restricted for what we are trying to implement in terms of having preference for pedestrians, cyclists and motorists. We have been working closely with the National Transport Authority, NTA. Gary Kearney has been mentioned several times at the committee. He is very much the eyes and ears in terms of what is happening in Dublin, anyone who has engaged with him will now. Probably the best practice we have seen is out of San Francisco. We have engaged with the NTA on looking at some of the designs. In particular, the issue of getting to the kerb, which came up earlier, is significant not only for people with disabilities, but also for older people and children. I traverse a very crowded area every morning to get to public transport and I see the major difficulties in that regard. There is work to be done. We are looking at best practice internationally on that and engaging on it regularly not only with the NTA but also with other key stakeholders. Cyclists are very much part of those discussions because it is pointless talking about the pedestrian space unless you are talking to cyclists.

I will hand over to Dr. Fitzpatrick to discuss sanctions, particularly under the European Accessibility Act which is upon us.

Dr. Dónal Fitzpatrick: I thank Dr. Craddock. The European Accessibility Act is currently undergoing transposition activities. It is a European directive that aims to provide a much more homogenised approach, or to resolve diversification and divergent accessibility standards across nation states and bring everything into one market with the objective of creating more widely available accessible products and services for people with disabilities and also affording businesses and organisations the facility to sell their products and services into a larger market. As noted, there are sanctions as part of the Act. They are not seen as the only solution but very much as an aid to inform and penalise under-performing organisations. The Act is clear that the sanctions need to be proportionate, and designed in such a way that they are not seen as an alternative by companies that decide they do not want to make a product or service accessible and will just pay the fine or take the hit. It is important to realise that, in any kind of accessible design, mindset is the key to making something accessible. If one can get across to the organisations that are providing services, designing services or products or manufacturing products that if they make the product or service accessible, that will greatly increase their market share, in addition to them having the moral obligation to do so, it plays to the strengths of organisations. The sanctions are in place and play a part but it is equally important to get that mindset right. There is a lot of cross-government and cross-departmental work, led by the Department of Children, Equality, Disability, Integration and Youth, on this topic to identify appropriate sanctions and penalties and also to give appropriate guidance to organisations on how to make their products and services accessible and how to conform with the requirements of the Act, which will start to come into force in June 2025.

Mr. Desmond Kenny: We are a light-touch society when it comes to regulations and sanctions. Dr. Craddock mentioned the Americans with Disabilities Act, ADA, in America. It has sanctions such that if one does not do as obliged under the Act, one can end up in court. The committee should seek to have introduced the protocol to the UNCRPD that was not included in Ireland’s ratification of it. If that protocol were in place, we would be talking about actions that people can take as individuals for infringement of their rights rather than having to go and have them mitigated through charities or your good selves on the committee or the NDA. We have to work on the basis that what has come forward through the UNCRPD are individual rights that have to be delivered to each individual, and each individual has a right of recourse including having sanctions imposed on those who do not adhere to their obligations. It should not be a light touch or do it when you get around to it approach. It should be done because that is what you have to do and if you do not, there will be sanctions.

It is very difficult to engage with the cyclist lobby because the cyclist, at present, is an enthusiast. They are like ourselves. Cyclists are advocates of something that has been denied to them. They are a lost population of people who felt victimised by motorists or whoever else in the past. The freedom they are now trying to win for the bicycle as a means of transport is all-important to them. Nobody wants to listen to the difficulties. The NDA can talk to the NTA about a cycling code and point out that shared space is difficult, but planners in the various local authorities will then decide that they cannot stop cyclists at bus stops because that would be too dangerous, so they will let the cyclists go through the bus stop, as it were. Those getting off the bus then have to rely on the goodwill and learning of individual cyclists. Let us not forget that this is a new discipline for people, particularly young people, in terms of knowing when to give way to a pedestrian. The Minister is in no way interested in sanctions for cyclists. He will not penalise them in any way, no matter what representations are made to him on those who are invading pedestrianised spaces. Whatever about moving cars off the streets, moving pedestrians off the streets is a totally different matter. Many people turn a blind eye to it and do not consider it to be something that should be sanctioned. It can be sanctioned. If one does it in other countries, one’s bicycle will be confiscated and one will have to go to a police station to reclaim it. That is how they identify those cycling in areas reserved for pedestrians. We may have to do something like that in this country.

May I make a final comment regarding the employment of disabled people? The NDA gave a good example of practice in the context of the number of people with disabilities who are employed. There are 40,000 people employed in the sector looking after disabled people. As all of those organisations see each of their coterie of clients as specific to themselves, their employment ratio of disabled people is phenomenally low. In the context of their employment of disabled people, a 6% quota should be imposed on organisations that are receiving statutory funding. Such organisations should look beyond their disability coterie, where somebody working in the area of residential intellectual disability would employ somebody with autism or whatever to carry out the jobs that can be done by other disabled people. Somebody with an intellectual disability can do less arduous jobs in an organisation such as the Irish Wheelchair Association. We have got to open that up as an employment opportunity for disabled people. We cannot look to others all the time to do things for us. We have the answer to many of the questions ourselves.

Mr. Adam Harris: The point around codification, and even contradiction or conflict, is very interesting. It is important to say that while the needs of every autistic person will be different, the domains we need to consider from a design point of view will very often be common or shared. There are some instances where the needs will contradict but not necessarily conflict, which is an important point to make. We are trying to create an environment that is as supportive a canvas as possible for an autistic person whatever his or her needs might be.

It is also about empowering the individual to make choices. If people know what an environment is like, they then have the ability to apply additional tools in order to make that environment more manageable for them. For example, if a very calm environment is created, an autistic person who needs additional stimulation can then, if that individual knows in advance, choose to bring headphones that have music playing to help them to navigate that environment. People will have heard of personal protective equipment, PPE, during the pandemic. Very often, people have sensory PPE that they need to use on a day-to-day basis. If they know about the environment and are empowered to use that sensory PPE in advance, that can go a long way.

We should think about some of the domains within the aspects framework I mentioned, for example, escape space. The reality is that if an escape space is created within the environment, one autistic person might use it because lighting has become overwhelming for that individual. Another autistic person might use it because of certain smells in the environment and another because they have spent too much time talking to an individual. If we think about safety, certain safety considerations can be important for an autistic person. By putting them generally in place, a person who does not have that safety concern will not be disadvantaged in any way. To respond to Dr. Craddock's point, it is more about putting in place a mindset around how we think about design as opposed to it having to be a one-size-fits-all model.

Co-ChairmanDeputy Michael Moynihan: Does the Co-Chairman want to make a few remarks?

Co-ChairmanSenator Micheál Carrigy: I thank the witnesses. I was struck by what Mr. Harris said in his introduction about being equal, valued and accepted, and the use of the words "accessible" and "inclusive". That applies across all disabilities and it is what we have to strive for. Both committees have to make sure the Government puts the funding in place and makes changes to ensure we have a society like that. There was a significant increase in the disability budget to €2.4 million yesterday, which I welcome, but it is still not enough. For parents on waiting lists for assessments of needs, in particular, an extra €39 million has been set aside to try to clear the backlog of thousands of children throughout the country who are still waiting for such an assessment.

There have been changes. Supermarkets now have a two-hour slot where the light is dimmed and the audio is down. A lot of changes have been made but one issue I have found, and I have written to every local authority about it, is the fact we do not have any hidden disability car parking places. We have disability car parking places, for which there must be a badge on the car, but there is none for hidden disability. Something that I would like to push on is that every local authority, when putting in new parking places, would place them adjacent to a disability space for parents, beside a supermarket or whatever. That is something that needs to be put in place. We have made moves on this with regard to Leinster House. I spoke to the Clerk of the Dáil in the past week. Sometimes, things can move very slowly within the Government so we want to speed that up and implement it over the next number of weeks. When witnesses come to our committee and to Leinster House, some of whom are autistic persons, it is important that it should be in place. We are ten years behind Stormont. That is not acceptable.

I welcome the DCU project. I look forward to seeing that rolled out throughout the country and across all third level institutions. Many advances have been made and funding has been put in place by the Department of Further and Higher Education, Research, Innovation and Science as regards putting in sensory rooms and making our third level colleges more accessible for young autistic persons. Work on 20 autism-friendly towns was mentioned. We should put funding in place to make sure that every town in the country is an autism- and disability-friendly town. That is a minimum.

I have a couple of points and questions. I apologise if I am going on too long. Mr. Kenny mentioned EVs. I am a father of young children and the sound of EVs and, in particular, not being able to hear them, is an issue. I ask for a comment on that. On the census, I firmly believe we need to change the form so we can future-proof our need for services. We have an issue at present regarding our children's disability network teams, where we do not have a significant number of professionals, such as occupational therapists and speech and language therapists, coming through our system. That is the fault of the HSE. It is not future-proofing the supply of professionals we need across those teams to provide services for children.

It was mentioned that the NDA is the only organisation of its kind in the world. In the NDA's interaction with the Government and implementation of what it proposes, where are the blockages for it not being implemented?

I have a question on housing for Mr. Cawley, my fellow proud Longfordian, who I have known for a long number of years and who is a very strong advocate. We spoke about local authorities building houses. Are we building houses that are accessible? Do they have level-access showers downstairs and so on? It is not happening enough. We have to put significant funding in place to adapt houses at a later date. If level-access showers were put into every single house, we would not have to adapt houses at a later stage. I ask for comments on those points.

Co-ChairmanDeputy Michael Moynihan: We will start with Mr. Harris, followed by Mr. Kenny and Mr. Cawley, and then maybe Dr. Hartney.

Mr. Adam Harris: I do not think the Senator asked me a question as such, but we echo his points on all the areas he mentioned. We look forward to continuing to work with the committee on some of those pieces in the time ahead.

Mr. Desmond Kenny: The EV question would be resolved through working with the likes of Marian Harkin and others like MEPs. The regulation regarding sound - the acoustic vehicle alerting system, AVAS - was explored through a combined study in America and the EU involving the big motoring manufacturers in order to come up with a sound that did not sound like something from outer space, but had the right type of pitch and sound. It was hoped that it would not be something that people with autism would find difficult but would be such that it would alert them to the movement of the car when the car was travelling below 20 km per hour. This was on the basis that if it was faster, they would hear the tyres of the car. In addition, that system was to be designed in such a way that it could not be turned off. It was to be an inherent part of the car that the sound could not be switched off at any stage. Otherwise, the danger would be that it would stay switched off. There are commitments from the Department of Transport, and from the Tánaiste, Deputy Varadkar, when he was Minister in that Department, that this will be adhered to in Ireland but, again, it falls between the stools so it is not done at present. That is where it came from and it has been explored and agreed to by the manufacturers. As far as I know, it is fitted to all EVs now coming into the country.

Co-ChairmanDeputy Michael Moynihan: It would be wrong of me not to let a “fellow proud Longfordian” address the committee. I have never heard the word, “Longfordian”, before. Does Mr. Cawley want to make a comment to his fellow Longfordian?

Mr. James Cawley: Of course. I would love to. I thank Senator Carrigy for the question. The key thing we must remember is the same people are being hit with a crisis in housing, the energy crisis and the cost-of-living crisis. The question was asked as to whether housing is always accessible. The answer is that it is not. The question was also asked as to whether housing is always affordable for disabled people. Again the answer is that it is not. We welcomed the national housing strategy for disabled people launched at the start of the year. It covers the period from 2022 to 2027. It looks at having strategic plans in all local authority areas. We welcome that disabled people and disabled person organisations are getting on the local authority housing disability steering groups that are tasked with the local strategic plans. We need to see the implementation of these plans. We need to make sure more houses are accessible and built to an accessible universal design standard to enable disabled people to live in them. We often say that one issue is to have the four walls of a house but another issue is the system. We have raised this in many of our reports, which we can circulate to the members. It seem to be the systems, policies and structures that exclude disabled people from living true independent lives. An example is that people applying for houses quite often cannot get independent living supports to match it.

Another issue is the misconception held by many people that disabled people occupy only social housing. There are disabled people who are trying to access private rental accommodation and trying to buy privately. We are locked out of the market. Affordability is not tied to what we are. It is tied to the market value. We could spend the whole meeting speaking about the housing issues that disabled people face. These are some of the high-level issues. It would be great to get more interagency collaboration on them so that disabled people can live independently.

Dr. Aideen Hartney: I thank the Co-Chairman, Senator Carrigy, for the questions. I will hand over to Dr. Fitzpatrick, who has something to say about the census and Dr. Craddock, who has something to say about the sounds of electric vehicles and scooters. The Centre for Excellence in Universal Design is the only statutory centre of its type in the world. Even the National Disability Authority is unique. There is no comparable organisation in other European countries. Often disability advice and guidance is encompassed in a governmental department. We are very pleased to be able to be a resource to the Government in this respect.

The Co-Chairman, Senator Carrigy, asked where some of the sticking points are. There has a lot of progress recently in the take-up of advice and guidance and a willingness to implement and realise the rights of people with disabilities. Where we see most of the challenges arise is where there is a need for cross-departmental collaboration. These hurdles are still very difficult to overcome. Often these issues are tied to budget lines being siloed and no mechanisms in place to share budgets and share ways of working to overcome some of the disability challenges that can cross the entire span of life.

On the request to have autism friendly or disability friendly towns, we have worked on a tool with the NTA and other stakeholders. This is the walkability audit tool we have developed. We piloted it in Kilrush and the local authority was able to use the findings of the audit to secure funding to make a large number of improvements in the town. It is now very much more disability friendly. This is something that could assist the Co-Chairman, Senator Carrigy, in this quest.

Dr. Dónal Fitzpatrick: The NDA very much welcomes the fact that an opportunity will be afforded to people to complete the next census online. I will correct the record on this if necessary but to the very best of my knowledge it was not possible to complete the most recent census in any form other than paper. As members can imagine, this excluded a significant number of visually-impaired people from being able to complete it independently. I have several anecdotal pieces of evidence from myself, friends and acquaintances. We very much welcome that the census will move online. It highlights a very interesting point which Mr. Harris mentioned earlier. It is very important that various modalities can be used by people to acquire information or to complete forms. I will give a quick example. We have specific requirements regarding the forthcoming European accessibility act to make answering the 112 emergency services number accessible to include real-time text or real-time video. This is a great example of what can be done by working at European level and the importance of a multimodal approach. People may still like to complete the census form on paper. There may be people with low technical literacy or who simply do not want to do it online and find it more comfortable to write. Having only this modality available excludes a significant number of individuals. This is why the NDA very much welcomes the fact that various modalities will be available.

Dr. Gerald Craddock: I want to come back on several comments. I echo Mr. Kenny's comment on electric vehicles, particularly on having a sound system built in. Deputy Harkin made a point on cyclists. We have a big issue with e-scooters taking over the same space. We have made representations and submissions on e-scooters particularly on their speed. It was amazing to hear on a "Prime Time" programme that e-scooters could clock up speeds of 120 km/h. I am not sure where they could be used. Another issue is where they are stored. Anybody who has been to any other European country has seen that they are just left on the sidewalk or in the middle of the road. There should be the same set-up in cities as for the standard bicycles. There should be a designated place where they are parked. We have made submissions to the NTA regarding this.

With regard to housing, as already been mentioned we are pushing for Part M to be revised. It needs to be updated. Mr. Cawley mentioned that much of our housing stock must be retrofitted. This is a huge cost. To go back to the human rights issue, housing is a key requirement under Article 28 of the UNCRPD on independent living.

The world ageing report in 2015 outlined that government support, resources and capacity building are required to support and advance universal design. Mr. Harris and Mr. Kenny have raised these issues. The three ingredients, according to the world ageing report, are resources, capacity building and government support. The report had us in the same sentence as Norway and Singapore with regard to advancing universal design. We have a bit to go but it was nice to see it in the report.

Deputy Marian Harkin: Earlier Mr. Cawley spoke about the fact that many videos have captions and auto text. The idea was put forward to have a disabled person on the team. This is a good idea. I suggest, in light of the web accessibility legislation, that this is a real business opportunity. Such a business could be established. An individual Deputy or a small company might not be in a position to employ somebody on the team but if they could access expertise many people would be very interested in doing so. I apologise because I must leave the meeting to go to the Dáil Chamber.

Co-ChairmanDeputy Michael Moynihan: Does Senator Garvey wish to contribute?

Senator Róisín Garvey: I am not sure how this works but I had my hand up for a long time.

Co-ChairmanDeputy Michael Moynihan: I apologise for that.

Senator Róisín Garvey: There is a very important point on which we must be very careful here. I worked with active travel and people with disabilities for more than 15 years in my previous job dealing with children with disabilities in active schools. We must be very careful when we talk about cars and cyclists. The bigger issue as I see it is that we do not even design for able-bodied people. We have been designing for cars only. I wish any mother who is fully able bodied and trying to cross the road with her child good luck. I normally cycle, but as I have a foot injury I have been trying to walk around Dublin for the past few weeks and I cannot even cross the road without the light going to orange. It is super stressful.

That is not to mention cyclists perhaps frightening some people. There is a much bigger issue here. We have best practice, which is known as universal access, and that is the one we need to talk about. There is only one place in the entire country where one can park a disability bike. It is in Trinity College. We also have people with disabilities who cannot walk, but they can cycle and they use hand cycles. We must be very careful in this discussion in how we talk about universal access and design. There should be so much space for walking and cycling and for people with disabilities and the visually impaired. The bigger question is how we have given so much space to metal boxes. Have we become totally reliant on them so that we are literally not thinking outside the metal box? We have all the different groups fighting against each other for space. We must be very careful.

I know people with autism who get stressed out just trying to cross the road because of the lack of time - approximately ten seconds - that we give to the green man. I am not disabled but I have a crutch and a big boot on my foot at the moment and I cannot cross the road in Dublin without getting stressed out. I am not an elderly person, a person trying to cross the road with a two-year-old kid or a person with a full disability. We have a major issue here. We could have a whole committee just about design. I do not think cyclists are the beginning or end of our problems because we also have people with disabilities who cannot walk who use hand cycles. Space and how we prioritise it is a significant issue. The question is whether it is for people, no matter what their ability or disability, or if it is for cars. I had to say that because we must be very careful with the debate.

Co-ChairmanDeputy Michael Moynihan: I apologise to Senator Garvey. I saw her hand up but I thought it was from her earlier contribution. Universal access is a major issue. We must seek to incorporate everybody into society to make sure we accommodate them.

The Joint Committee on Autism is doing significant work and must report by the end of March 2023. I wish the committee well. Autism is a significant issue that must be properly addressed. Some great work is being done in that regard. On behalf of both committees, I thank Mr. Adam Harris, CEO of AsIAm; from the Independent Living Movement Ireland, Mr. Desmond Kenny, Ms Catherine Gallagher and Mr. James Cawley; and from the National Disability Authority, Dr. Aideen Hartney, Dr. Gerald Craddock and Dr. Dónal Fitzpatrick.

Every Thursday we have evidence and questions from members of the joint committee. Today’s sitting is of the two committees. People are genuinely looking for guidance as to how we can tackle inclusivity in society and deal with the existing challenges. All public representatives come across families, and they have their own families, and they see the challenges and barriers that exist. A number of witnesses spoke this morning about the barriers and the challenges that exist and how we get beyond them. We come across this daily. Sometimes we tear our hair out trying to see how we can rectify an issue for a very genuine case. It is only because of the work the witnesses do, the evidence they have given and their willingness to come before us and give us their honest appraisal of where things are at that we can then go on and try to do something proper for the challenges of the people we are duty-bound to represent in the autism committee and in the disability matters committee. It is most important the witnesses keep up their work.

Dr. Craddock referred to a submission he made to the National Transport Authority. I would appreciate it if he could provide a copy to the committee as I would like to follow up on it. I urge the witnesses to keep up the good work and to keep in contact with us. If there are things we are not doing properly, that we should be doing better or that we should be better at challenging, they should please not be afraid to come back to us and tell us. We will come back to the witnesses for further evidence and information. The press officer for the autism committee is also in the Gallery.

I thank our team and the autism committee’s team. A significant amount of work goes on behind the scenes. It is the research and evidence the team puts together that make the committees work properly. I urge them to keep up the good work. We will try as best we can to make society better for people with disabilities, their families and their lived experience.

The joint committee adjourned at 12.16 p.m. until 9.45 a.m. on Thursday, 6 October 2022.