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Nothing About Us Without Us

Observations on Ireland's first draft report to the UN under the Convention on the Rights of Persons with Disabilities.



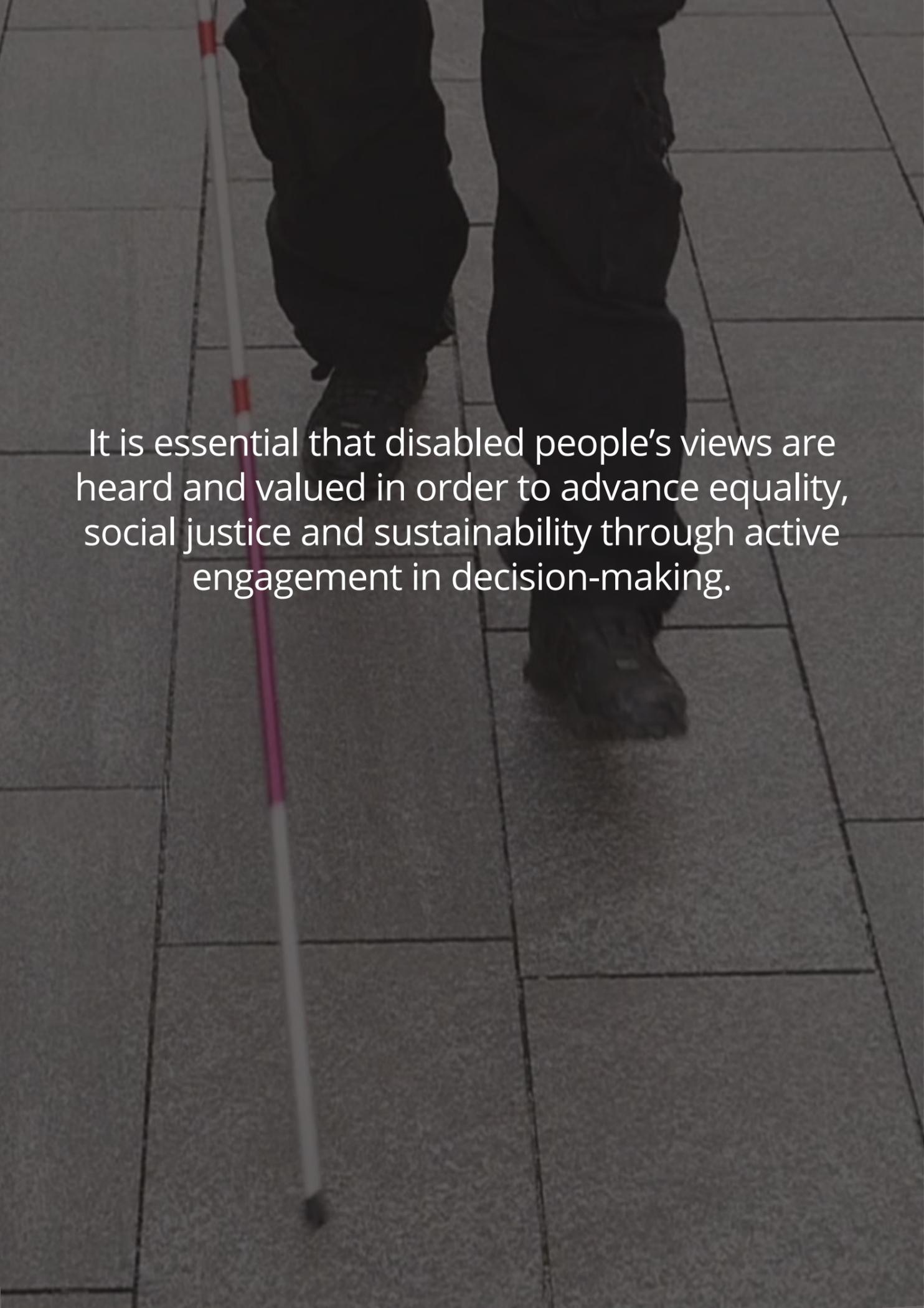
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It is essential that disabled people's views are heard and valued in order to advance equality, social justice and sustainability through active engagement in decision-making.

Foreword from our Chairperson

Ireland's ratification of the UNCRPD in March 2018 established a clear commitment to "promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms" of disabled people. The initial State report to the UNCRPD is a vital first step to establishing an implementation and monitoring mechanism at a national and international level. Full implementation of policies which advance the UNCRPD will be vital to build a genuinely inclusive Ireland by removing institutional and attitudinal barriers which prevent disabled people from participating in society as equals.

The process for the co-creation of inclusive policies must be built on the fundamental principle of "nothing about us without us". For far too long disabled people have been excluded from participation in decision making structures at all levels. Places at decision making spaces have been claimed by professionals from Disability Service Providers. This is contrary to articles 4.3 and General Comment 7 of the UNCRPD and new frameworks established by the State need to ensure an ongoing commitment to the primary role of Disabled Persons Organisations (DPOs).

It is essential that disabled people's views are heard and valued in order to advance equality, social justice and sustainability through active engagement in decision-making. For UNCRPD to be implemented in a meaningful way, Ireland needs to commit to investing resources to support this engagement through genuine representative DPOs.

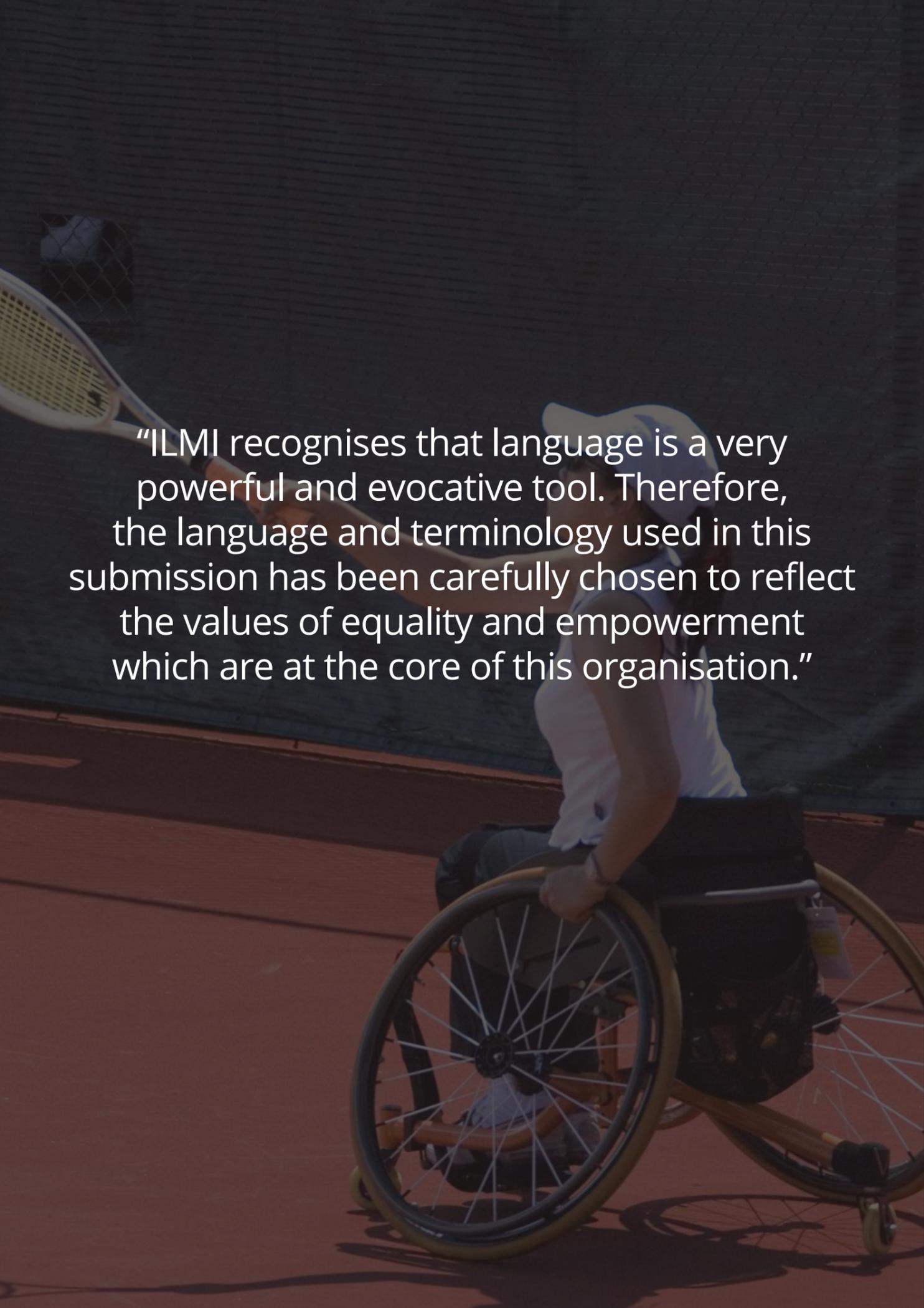
The role of ILMI as a national DPO is to create inclusive and participative spaces, bringing disabled people together as a collective on a cross-impairment basis. Our consultations to inform this report shows that technology such as Zoom presents possibilities to connect disabled people to build a shared analysis as a Movement.

That collective voice of disabled people can then inform and monitor Ireland's progress in fully meeting its commitments under the UNCRPD and build a more inclusive society.

During our consultation process for this submission, the active participation of hundreds of disabled people, on a cross-impairment basis, from young disabled people to older disabled people from across Ireland demonstrates our deep commitments to ensuring that all of our work is led and informed by disabled people.

I would like to thank every single disabled person who participated in our many online focus groups, and those who made submissions to inform ILMI's observations on Ireland's initial report to the UNCRPD. This approach represents not only the lived experience of disabled people, but a model for ongoing engagement in how to have our voices heard in future policy creation, implementation and monitoring.

Des Kenny, ILMI Chairperson

A person wearing a white visor and a white shirt is seated in a wheelchair on a tennis court. They are holding a tennis racket in their right hand. The background is a dark, textured wall, possibly a tennis court wall. The lighting is dramatic, with strong shadows.

“ILMI recognises that language is a very powerful and evocative tool. Therefore, the language and terminology used in this submission has been carefully chosen to reflect the values of equality and empowerment which are at the core of this organisation.”

Glossary of Terms

DPO: A Disabled Person’s Organisation is a rights-focused organisation that is led, directed and governed by disabled people.

IL: Independent Living is about having the freedom to have the same choices that everyone else has in housing, transportation, education and employment. Independent living is about choosing what aspects of social, economic and political life people want to participate in. Independent living is about having control over your life, to have a family, to get a job, to participate socially and to realise your goals and dreams. Personal Assistance Services (PAS) are the foundation of the Independent Living Movement.

PAS: The Personal Assistance Service (PAS) is a tool that allows us (disabled people) to live independently. The PAS enables us to do all the tasks that we cannot do for ourselves. It provides us with the freedom and flexibility we need to live our lives as we choose.

PA: A Personal Assistant (PA) is hired to assist us (disabled people) with a range of day-to-day tasks that we cannot physically do for ourselves to live independently.

AT: Assistive technology can be used to support a disabled to live independently, engage in employment or in daily living.

CRPD: The Convention on the Rights of Persons with Disabilities is an international human rights treaty of the United Nations intended to protect the rights and dignity of persons with disabilities. Ireland ratified the convention in 2018.

Medical model of disability: The medical / charity model of disability individualises disability and promotes the idea that people are disabled by their impairments or differences. The medical model always focuses on people’s impairments from a medical perspective. In some ways it still looks at what is ‘wrong’ with the person and not what the person needs. It creates low expectations and leads to people losing independence, choice and control in their own lives. The medical / charity model never recognises the rights of disabled people and assumes that disabled people need to be “looked after” or “cared for”. Under the medical / charity model professionals make decisions for disabled people.

Social model of disability: The social model of disability looks at how society is structured and how it disables people. It is not based on a person’s impairment, it is focussed on the barriers that exist in terms of attitudes, policy development, access or lack of supports that prevent people from participating in society as equals, with choice and control over their own lives. In this model it is society that disables people from achieving their hopes and dreams, not a person’s impairment.

Disabled person or disabled people: ILMI recognises that language is a very powerful and evocative tool. Therefore, the language and terminology used in this submission has been carefully chosen to reflect the values of equality and empowerment which are at the core of this organisation. The term ‘disabled people’ has been used throughout the submission in accordance with the UPIAS classification of disability and impairment which has been developed by disabled people themselves (UPIAS 1976). Disabled person refers to people on a cross-impairment basis to include all disabled people, including those with learning difficulties, people experiencing emotional distress and physical and sensory impairments.

Emotional distress is almost exclusively viewed in Ireland through the medical model of disability. The biopsychosocial model is predominantly an epidemiology (disease) model that looks at the interconnection between biology, psychology, and socio-environmental factors. Ultimately, as a medical model, it predominately looks at impairments relating to emotional distress as being something that is “wrong” with the individual that needs to be treated.

It states that people who have experienced distress are “broken” or “flawed” and that it is something “inherent” that needs to be “fixed”. Extreme forms of this medical approach can lead to refusal to engage with people’s lived experience and life history and can have medical professionals remove autonomy from people, including forced detention and denial of basic human rights.

Most discussions in Ireland around emotional distress use the term “mental health” in Ireland. A term that is assumed to be sensitive and neutral, “mental health” is actually a loaded statement. People who experience emotional distress are not sick and do not suffer from an illness. Taking a social model of disability approach we need to recognise that using terms like “mental health” medicalises and individualises people’s emotional responses to traumatic life events and societal pressures. Emotional trauma and distress is not an individual medical issue but a social issue and it cannot be “treated” as a medical condition.

Accessibility: Refers to access to the physical and built environment and access to information, communication and services.

Assisted Human Reproduction: services such as IVF.

National council for special education: NCSE.

Education for Persons with Special Educational Needs (EPSEN Act).

The EPSEN Act 2004 requires that a child with special educational needs (SEN) be educated in an inclusive environment with children who do not have such needs, as far as possible.

Special Educational Needs Organisers: (SENOs).

Reasonable Accommodations refers to modifications or adjustments which would allow a disabled employee or job seeker to either continue or to take up a position to enjoy equal employment opportunities.

DSG: Former Minister of State with special responsibility for Disability Issues, Finian McGrath formed the Disability Stakeholder Group. The group was formed to review and implement the National Disability Inclusion Strategy 2017 – 2021. The group contributed to the State’s programme of implementation of the United Nations Convention on the Rights of Persons with Disabilities following its ratification in 2018.

NDIS: The National Disability Inclusion Strategy 2017 – 2021 is a coordinated and planned approach, across Government Departments, to promote greater inclusion by disabled people in Irish society.

CES: The Comprehensive Employment Strategy for disabled people provides a framework which departments and agencies set out agreed actions to improve the employment prospects of employment for disabled people over a 10 year period.

Time to Move on from congregated settings: a national plan for the process of de-institutionalisation of intellectually and physically disabled people from congregated settings to the community.

The National Housing Strategy for people with a disability 2011 – 2016: The Government’s strategy to specifically address the housing needs of disabled people over the period of 2011 to 2016. The strategy was extended to 2020 and is being reviewed this year, 2021.

A Vision for Change: is a national policy, in place since 2006 that sets out the direction for Mental Health Services in Ireland.

The Disability Act 2005: The Disability Act 2005 places legal obligations on public bodies to make buildings, heritage sites and services accessible to disabled people. It supports the provision of disability specific health and education services through an Assessment of Need. It also places legal obligations on public bodies to support disabled people’s access to employment, to accessible communication, and to complaints mechanisms.

Public sector duty: The Public Sector Duty is based on Section 42 of the Irish Human Rights and Equality Act 2014. It outlines the legal obligations for public bodies to prevent discrimination and promote equality.

Value for money: an evaluation of the efficiency and effectiveness of all HSE-funded disability services in Ireland. The disability services were selected for review in consideration of the significant annual expenditure on the programme, the size of the population directly affected by the services and the scope and nature of services provided.



“State policies and investment need to prioritise what disabled people want in order to participate in society as equals.”

Executive Summary

Over the course of the ILMI CRPD Consultations, many themes recurred across discussions on various articles:

- The state report is aspirational and in instances lacks clear data on the impact of policies or the voices of disabled people.
- The report adopts a medical approach to disabled people's lives. In general disabled people made a call to stop using medicalised language which refers to us as “vulnerable” or having “special needs”.
- Overall, the report outlined how much “control” services and structures have over disabled people's lives. This needs to change. We as disabled people need choice, control and dignity in our lives.
- ILMI believes the pillars of independent living are housing, transport, employment and PAS. For many disabled people, the pillars are interlinked. The Initial State report lacks a clear message on how these pillars are interlinked. For example, policy in relation to housing requires similar policy to provide appropriate supports to live independently, such as personal assistance services. The State report needs to clearly state the link between housing and the supports a person needs to live in the home, to live in the community, to get to work and employment supports.
- More research is needed to include the voice of disabled people into statutory policy in a number of issues. For example, mechanisms need to be explored to ensure the voice of disabled women and girls (in relation to family life around parenting, for example) informs the National Strategy for Women and Girls.
- The current model around emotional distress treats people who have experienced distress as “broken” or “flawed” and that it is something “inherent” that needs to be “fixed”. We need to provide an alternative analysis based on lived experience that recognises the pain people experience as real but recognising what causes emotional distress is located in what has happened to people and how people have responded to trauma and threats to their identity.
- There is an overall erosion of the independent living philosophy. State policies and investment need to prioritise what disabled people want in order to participate in society as equals.
- There is a need for disability equality training in all schools. Transition points and supports need to be more seamless for disabled people in all aspects of their lives, from education to training to employment.
- The state report lacks a person centred approach. Health services need to be inclusive of the person where they are at the centre of the decision making process. There is a need for disability equality training among health professionals which would help to eradicate the medical model view of disability. This would separate the medical and social and daily needs of disabled people.
- The Initial State report fails to demonstrate clear measures to ensure education will become more inclusive, from early childhood education, to primary, post-primary, tertiary and adult and further education. A commitment to real inclusive education would include a review of the EPSEN act and removal of patronising medical language widely used in the education system such as “special needs”.

A man and a woman are sitting at a desk, looking at a document together. The woman is in a wheelchair. The man is pointing at the document with a pen. The woman is holding the document. The background is a plain wall.

“As a country Ireland has lots of policies in relation to disabled people’s lives however, as a country there is poor implementation of these policies.”

- The Initial State report fails to demonstrate “joined-up thinking” to increase participation of disabled people in the labour force. The state report does not outline clear implementation of reasonable accommodation to support disabled people in employment. The report does not outline how effective the employment supports for disabled people are (such as the wage subsidy scheme, work adaptation grant) and when they will be reviewed.
- People in distress and in pain need supports that give them safety and it needs to be person-centred which meets specific needs, and not a one size fits all medical / institutional approach.
- As a country Ireland has lots of policies in relation to disabled people’s lives however, as a country there is poor implementation of these policies.
- The State report lacks data to show whether policies are being implemented and are having an appreciable impact on the lives of disabled people, such as “A Time to Move On” and the National Housing Strategy for People with a Disability 2011 – 2016.
- There needs to be consultation and engagement through Disabled Persons Organisations (DPO’s) and not disability service providers. There is an historical absence of structural engagement with disabled people through resourced Disabled Persons Organisations. This includes DPOs representing the voice of lived experience of emotional distress.
- The policies listed in the Initial State report often lack measurable actions and achievable targets, for example in the National Disability Inclusion Strategy there are many actions not achieved.



“The social model looks at how society is structured and how it disables people. It is not based on a person’s impairment, it is focussed on the barriers that exist in terms of attitudes, policy development, access or lack of supports that prevent people from participating in society as equals, with choice and control over their own lives.”

Introduction

Independent Living Movement Ireland (ILMI) is a campaigning, national Disabled Person’s Organisation (DPO) that promotes the philosophy of independent living and seeks to build an inclusive society.

Central to the way we work is to ensure that policy decisions that impact on the lives of disabled people must be directly influenced by those whose lives are directly affected. Our philosophy can be summed up as: ‘Nothing about us without us!’ and ‘Rights Not Charity’. Our vision is an Ireland where disabled persons have freedom, choice and control over all aspects of their lives and can fully participate in an inclusive society as equals.

ILMI welcomed Minister Rabbitte’s announcement on the publication of Ireland’s first report to the UN under the Convention on the Rights of Persons with Disabilities. We as a national disabled person’s organisation (DPO) are extremely well placed to make an authentic written submission to the state report.

Social model of disability

The UNCRPD at its core is framed through an understanding of disability known as the social model of disability. From ILMI’s perspective, it is vital that there is a clear and full understanding of what the social model of disability is and how it should inform future discussions on policy development and improvement and policy implementation.

The social model looks at how society is structured and how it disables people. It is not based on a person’s impairment, it is focussed on the barriers that exist in terms of attitudes, policy development, access or lack of supports that prevent people from participating in society as equals, with choice and control over their own lives. In this model it is society that disables people from achieving their hopes and dreams, not a person’s impairment. The social model informs all aspects of the work of Independent Living Movement Ireland.

Language and representation of disabled people

Independent Living Movement Ireland recognises that language is a very powerful and evocative tool. Therefore, the language and terminology used in this submission has been carefully chosen to reflect the values of equality and empowerment which is at the core of this organisation. The term ‘disabled people’ has been used throughout the submission in accordance with the UPIAS classification of disability and impairment which has been developed by disabled people themselves (UPIAS 1976). Where disabled people are referred to in the submission this should be understood to include all disabled people, including those with learning difficulties, people experiencing emotional distress and physical and sensory impairments.

Consultation Process

As a Disabled Persons Organisation (DPO), ILMI is extremely well-placed to engage in direct consultation with disabled people to relay the lived experience of disabled people and make a robust submission on Ireland's state report. We believe it is the lived experience of disabled people that is vital to informing policy that impact on our lives and this way it highlights what is working and areas where improvement is needed.

ILMI conducted 10 facilitated consultations throughout February and March 2021 with an open call to disabled people through our online newsletter (eBulletin) and social media channels.

The facilitated discussions were hosted online using Zoom to bring disabled people together from across the country. Notes were taken in each consultation space. No names were used to ensure confidentiality throughout the process.

There was a facility to feed information into the ILMI Policy Officer where people could not attend consultations. Consultation spaces covered the following articles:

- Disabled women and young girls (article 6)
- Children and young disabled people (article 7)
- Access, mobility and access to information (articles 9, 20 and 21)

- Independent living (article 19)
- Disabled people and family life (article 23)
- Disabled people and education (article 24)
- Disabled people and health (article 25)
- Work and employment (article 27)
- Participation of disabled people in political and public life (article 29)
- Additionally a targeted series of focus groups took place with people with lived experience of emotional distress which informed a number of the above articles, and specific articles including Liberty and security of the person (Article 14) and protecting the integrity of the person (Article 17).

LMI valued the open and honest dialogue, information sharing, partnership and cooperation in this consultation process with disabled people on a cross-impairment basis which informs our submission based on the lived experience of disabled people in Ireland.

ILMI would like to take this opportunity to thank all the participants who were involved in our consultation spaces and to all those who shared their experiences with us.

Article 4.3 & 29 B

The UNCRPD makes specific references to state party commitments to ensure disabled people are effectively involved in all policy forums which article 4.3 and 29. B of the convention state. Article 4 - General obligations 3 outlines that state parties shall closely consult with and actively involve disabled people, including disabled children.

Article 29. B outlines actively promoting an environment in which disabled people can "effectively and fully participate" in public affairs, without discrimination and on an equal basis with others. Article 29 B also states participation of disabled people in non-governmental organisations and associations concerned with public and political life. Most importantly article 29 B states disabled people should be involved in "forming and joining organizations of persons with disabilities to represent persons with disabilities at international, national, regional and local levels". For far too long disabled people have been excluded from participation in decision making structures at all levels. Disabled people want to have their views heard and valued to advance equality, social justice and sustainability through active engagement in decision-making, rebalancing of power in this process, and investing resources to support this engagement.

"Nothing about us without us": the role of Disabled Persons' Organisations (DPOs)

DPOs, unlike disability services providers, are led by and for disabled people. It is vitally important that this is understood and we need to ensure that we have our contributions heard, represented and recognised in policy development.

The Initial State report refers to consultations with "disability stakeholder groups and wider civil society" and "disability organisations and individuals with a lived experience of disability" in consultations relating to the Comprehensive Employment Strategy, the National Disability Inclusion Strategy and the Disability Stakeholders Group. None of the above related to structured engagement directly with DPOs as representative organisations recognised under Article 4.3 and General Comment 7.

The State report references the newly formed Disability Participation and Consultation Network (DCPN) and claims that it is "comprised primarily of Disabled Persons Organisations". At present the majority of funded groups participating in the DCPN are not DPOs and the membership of the DCPN is much wider than established DPOs.

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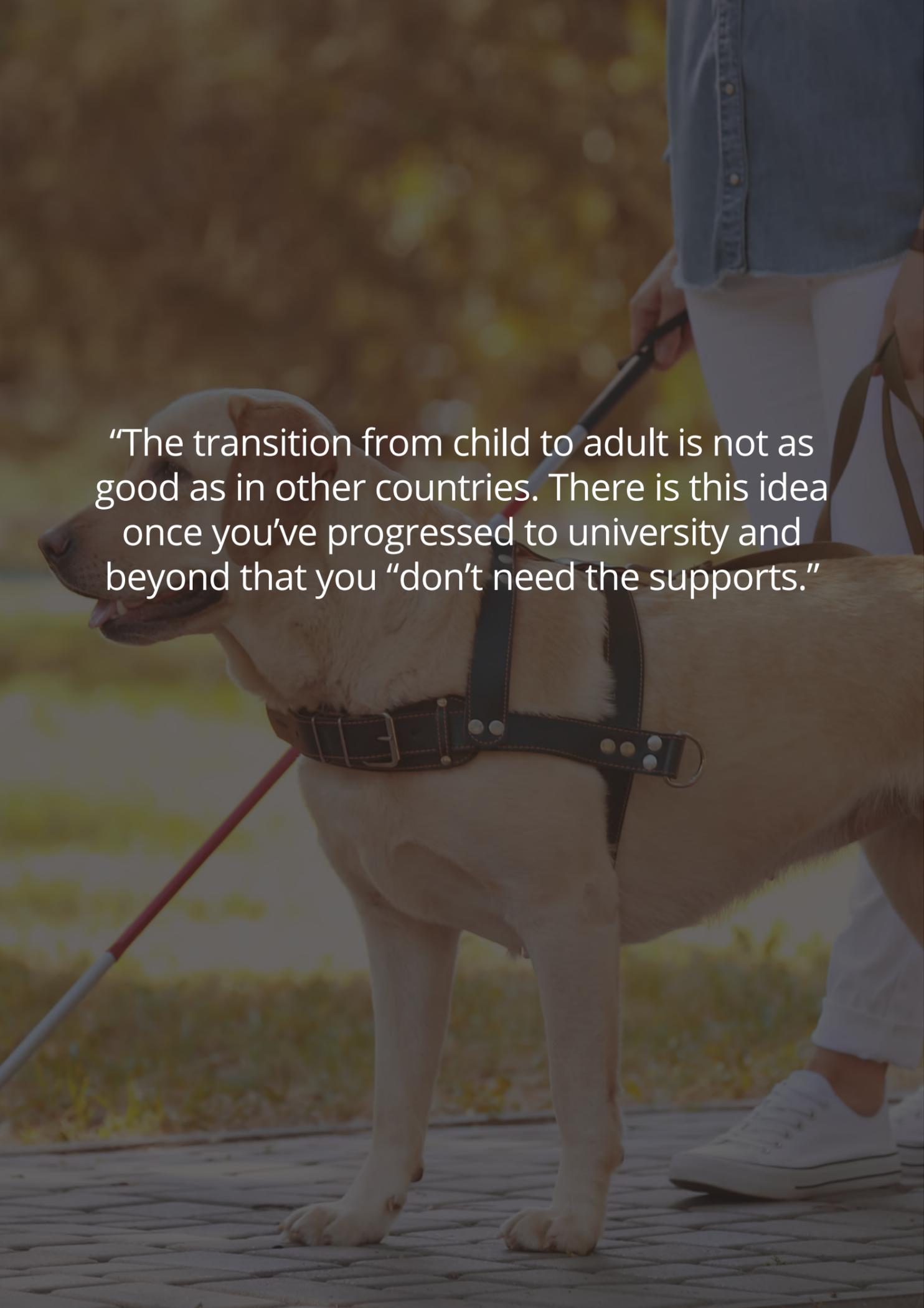
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Article 6 - Disabled Women & Young Girls

The State recognises that disabled women and young girls experience discrimination. The State will work to make sure that disabled women and young girls have the same human rights and freedoms as others. The State has made nine observations under article 6 relating to disabled women and young girls. For many disabled women being a woman and having a disability is like having a 'double disability' such is the level of discrimination experienced. The following information was gathered in the ILMI consultation relating to article 6 of the convention:

- State services are still adopting a medical model approach to disability. The person's primary impairment is seen as the 'issue' at all times and can prevent disabled women from accessing services and supports not related to their impairment.
- People assume disabled women know nothing and that "we cannot speak up for ourselves". In many cases people end up 'in services we don't want before we even know about it' such as, older persons services. "It becomes a subtle institutionalisation. It happens and you just don't realise until it is too late".
- A high percentage of disabled women are unemployed which leads to poverty and prevents access to private medical care. Many participants noted a delay in access to services through the public system with people waiting "ten months for an MRI". This also translates to the cost of medicines, with people "forced to choose what is affordable" rather than what is best for their body.
- An urgent review of maternity and gynecological services is required. For disabled women both can be "unnecessarily cruel". Requesting adequate pain management as a disabled woman can be difficult as medical staff dismiss requests and do not consult directly with the individual.
- There is a serious shortage of support services for disabled women accessing urgent supports. Rape Crisis Centers and Women's Aid are not equipped to deal with the additional needs disabled women present with. Lack of accessible spaces and inadequate equipment were noted as two areas preventing access to such services.
- Often there is a presumption that disabled women "do not want or cannot have fulfilling sexual relationships".
- Disabled girls are often unaware of their bodies and can enter puberty not knowing or understanding the changes happening to them. There is a severe lack of relationships and sexuality education in non-mainstream educational settings.
- Disabled women are often excluded from sexuality and relationship education and awareness programmes as there is a presumption that "it does not apply" to them. Disabled women have a right to a happy sexual relationship as much as anyone else and this begins with appropriate education from a young age.
- Many disabled women require continuing support as in-patients in a hospital setting. COVID-19 has presented new challenges in this area with Personal Assistants (PAs) not being able to continue to work alongside disabled women in hospital settings or inappropriate supports given without consultation. One participant noted, "Being assigned a male assistant" as an in-patient in hospital.
- There is a lack of consultation and readily accessible information for women's health. Disabled women are still not adequately consulted about medical decisions.
- A disabled woman's impairment is still seen first in medical settings. Many disabled women accessing health services are going for an issue not related to their impairment. However, lack of disability awareness can make communication beyond the primary impairment difficult and time consuming, leading "to a late diagnosis of a condition that should have been put into remission much earlier".
- Lack of awareness can in turn lead to a loss of confidentiality in medical appointments for disabled women.
- Many health settings do not have the necessary equipment to provide services to disabled women.



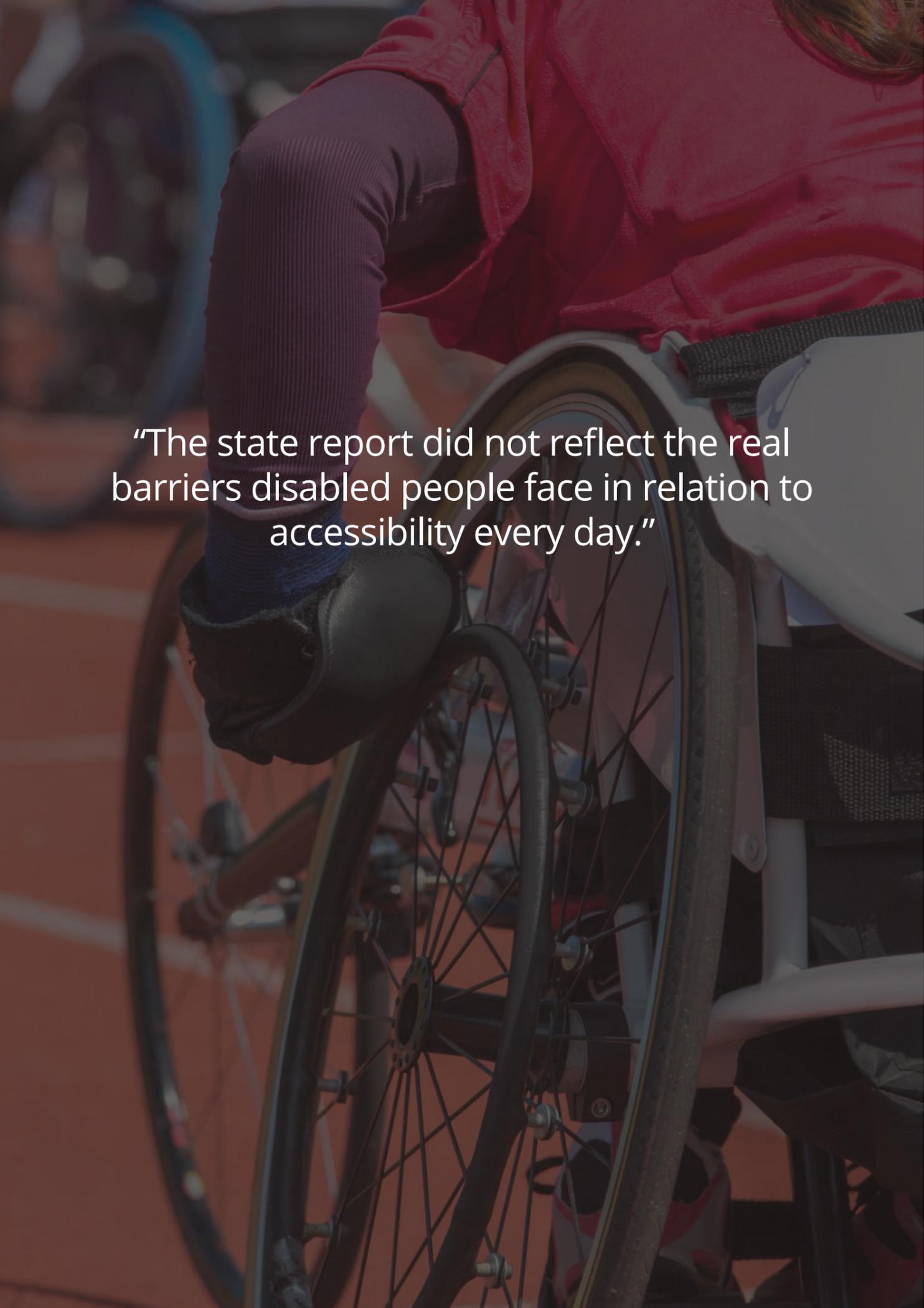
“The transition from child to adult is not as good as in other countries. There is this idea once you’ve progressed to university and beyond that you “don’t need the supports.”

Article 7 - Children and young disabled people

The State will make sure that children and young disabled people enjoy the same rights and freedoms as other children. The State has made sixteen observations under article 7 relating to children and young disabled people.

The following information was gathered in the ILMI consultation relating to article 7 of the convention.

- Young disabled people did not feel they have the same rights as their non - disabled peers. “Stereotypes, shame and stigma is still out there in society in relation to being a young disabled person”.
- Lots of young people like to “get up and go” however, lots of disabled people feel that lack of accessible transport, broken ramps and the lack of having appropriate supports impacts on their spontaneity as a young person. “We shouldn’t have to give notice, we can’t be spontaneous. We have to plan ahead all the time”.
- Young disabled people don’t feel they have the same access to cultural events and ticket booking for venues. Young disabled people often have limited choice on how they get their tickets. They often have to telephone rather than buying online “like everyone else”. Some ticket providers have moved to online purchasing of tickets however, these ticket providers now ask for “proof” of disability which means disabled people are asked to provide their medical card, travel pass or parking permit.
- A Personal Assistance Service (PAS) is only applicable for people over 18 years of age. This impacts the level of choice for a young disabled person under 18. For example in education a disabled person has a “Special needs Assistant “to support them in school however, there is no provision of support for social or extra - curricular activities for a disabled person.
- Those who are 18 and are “transitioning” or are “new” to a PAS often do not get to choose their service provider and this results in service providers taking a “medical” approach to the young person. This approach can lack confidentiality for the young person. The service providers provide staff but more often with no consultation with the young person and providing assistance during hours that “suit” the service provider and not the person.
- If appropriate for the young person there needs to be a move towards a personal assistance service model (and training) for the younger disabled members of society who will most likely engage in personal assistance once they turn 18 years of age.
- Young people noted that some service providers are allocated certain hours and are not fully using the allocated time to support the person. It was noted that if disabled young people were empowered to lead a PAS this could be avoided.
- Transport is not always accessible and transport companies should have resources / technology / infrastructure or an accessible system to allow a disabled person know whether a ramp or lift is broken down for example through an App on the young person’s phone.
- The state report is very focused on health and education and in this particular article it could be better.
- The transition from child to adult is not as good as in other countries. There is this idea once you’ve progressed to university and beyond that you “don’t need the supports”. Supports of any nature should follow the person and young disabled people felt they should not have to re - apply from one transition point to another in life.
- Spaces such as the ILMI youth group are spaces for young disabled people to come together and share knowledge and experience. Young disabled people should be involved in decision making structures from a young age such as green schools, student council, and students union and end up delivering the message to society in a true authentic manner.
- Parents can indirectly disempower their children by answering for them or “knowing what is best”. It was suggested that an independent advisory support person in transition points would be beneficial for young disabled people and their families. There is a paternal view to disabled children in Ireland and some parents “infantilise” their children. Parents are stuck in the “tragedy model” of disability, often seeking to “cure” or “treat” their disabled child.
- Language was also mentioned as extremely powerful in the consultation spaces. There was a “call” to stop using disempowering medical language such a “special needs”.



“The state report did not reflect the real barriers disabled people face in relation to accessibility every day.”

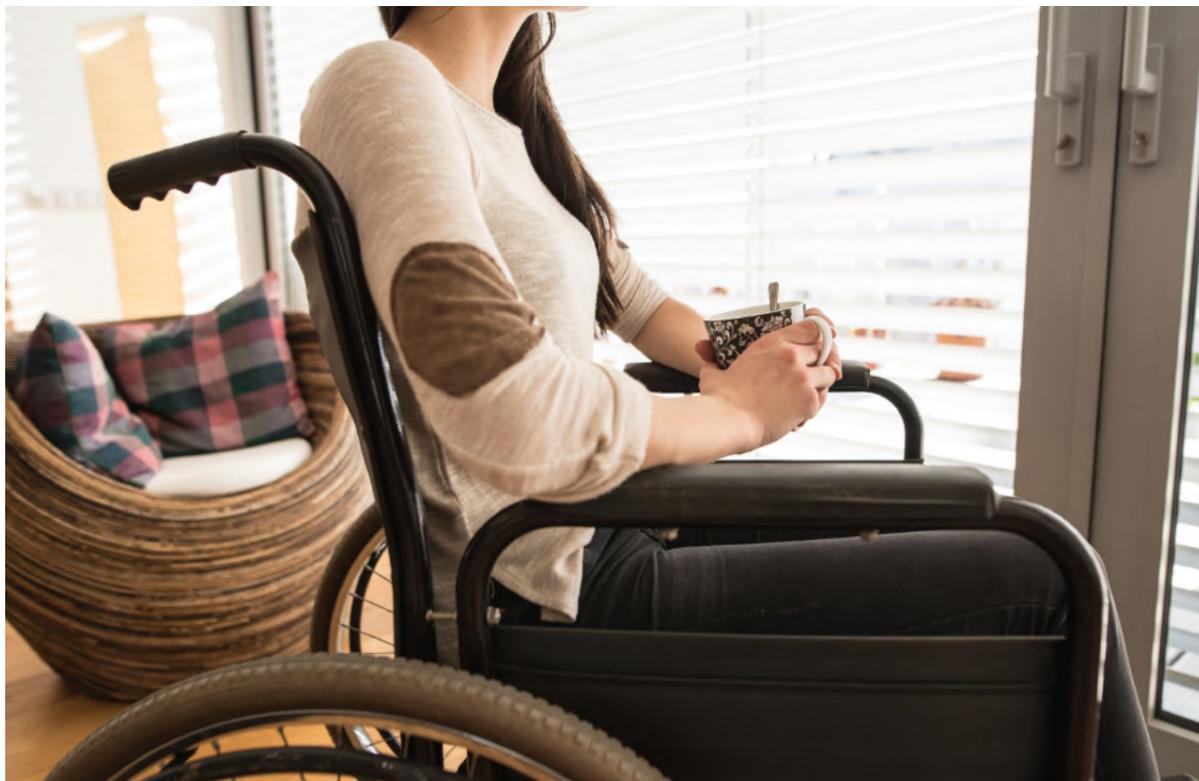
Articles 9, 20 & 21

Accessibility / Personal mobility / Access to information

Articles 9, 20 and 21 encapsulate accessibility, personal mobility and accessibility of information. Disabled people should have the same access as others to places, transport, information, communication, and services. The state collectively made sixty nine observations on these three articles. The following information was gathered in the ILMI consultation relating to articles 9, 20 and 21 of the convention:

- The Initial State report fails to note whether there has been an equality and human rights review of Part M of the Buildings Regulations 2010 in light of the IHREC 2014 Act.
- The State report fails to outline what mechanisms are in place for local authorities to assess compliance of Part M. Any mechanisms need to establish the role of qualified disabled people to perform assessment of new buildings under Part M and the penalties incurred for failure to comply.
- The state report did not reflect the real barriers disabled people face in relation to accessibility every day.
- Accessibility is often thought about as “wheelchair accessibility” and the physical environment impacting on those who are wheelchair users for example. However it is broader than that. Lack of accessible communication and information impacts members of the disabled community such as deaf people and visually impaired people. Accessibility impacts on being spontaneous as a disabled person. There is huge rural / urban divide in terms of access: transport, services and broadband. There is a complete lack of joined up thinking in how systems are developed in terms of accessibility and the state report did not capture this.
- Part M of the building regulations is minimum standard. That needs to be reviewed as “it is out of touch”. All local authorities should have an Access Officer and equality proof planning applications and local authority and services. Legislation needs to be reviewed as the Disability Act is over 15 years old. Ireland needs a new legal framework to promote inclusion.
- Some disabled people view access as having the right supports to get them outside of their homes. Accessibility is about a disabled person being able to live as independently as possible “from transport to hotel breaks to broadband and employment”. Accessibility impacts on the surrounding environment or location a disabled person lives in. A disabled person can have a house but not have access to their community. Lots of disabled people rely on their PAS for access in every single aspect of their lives. Yet often due to insurance, PAs can’t drive disabled people to places they want to go. In the absence of own car (and loss of mobility allowance and motorised grant scheme) education, employment and socialising are extremely limited, especially in rural areas. In addition in relation to hotel breaks there is an assumption that disabled people will be holidaying on their own. Therefore, there is little or no accessible family rooms, as if disabled people are “a singular entity”.
- The State report makes no reference Disabled Drivers and Disabled Passengers or Mobility Allowance and Motorised Transport Grant Scheme and whether these vital supports will be reinstated.
- There is a complete lack of oversight or enforcement in terms of access, including web accessibility. Inaccessible information is still being sent to people. For example letters to visually impaired people about their blind welfare allowances. Crucial information continues to be only provided on printed material such as pin numbers for Revenue, or banks. Automation and reduction of staff in services such as banks (especially in rural areas) has an impact on disabled people’s access to their finances.
- Services such as bank machines and banks in general continue to be inaccessible and there are very few accessible bathrooms that are fully wheelchair accessible and ones that also have space for assistance dogs, motorised wheelchairs or Personal Assistants if needed. This includes a lack of monitoring accessibility in relation to tactile paving and street furniture across towns and villages in Ireland. There needs to be more accountability in building regulations.

- Disabled people and access is mostly an afterthought. Designers don't have the expertise of lived experience. Disabled people need to be included from the start of any design process. Disabled people want services to be accessible and to be able to use them adequately - such as changing facilities for the children of disabled parents.
- Rural broadband and "technological poverty" impacts on disabled people's ability to work from home.
- Support for SMEs and the private sector in making their services and buildings more accessible needs to be invested in.
- Public transport is a huge issue and it needs to be possible from home to employment and take a "whole journey" approach. The "booking ahead" of transport in Ireland for disabled passengers needs to stop. Single spaces on buses for disabled people means it is difficult to access certain routes and quite often disabled people have to wait for another bus to come. Public transport in Ireland needs to implement universal access.
- We need to think about legislation such as Private Members Bills and different legislative instruments to change society. We need new rights in legislation about access that have "teeth". "It is not about disability awareness, it is about disability equality". There are also regressive changes in policy that impact on our access such as the mobility allowance and motorised grant scheme and the primary medical certificate. The criteria that enable people to access aids has to be broadened.
- There is a lack of opportunity for young disabled people in relation to accessing recreation and leisure. Disabled parents accompanying their children to recreational facilities face these challenges also.
- Accessibility can segregate disabled people too such as, the separate entrances, the separate queues, and the single lower counter in the banks and other buildings providing services. There needs to be more universal design.



Article 14 – Liberty and security of the person

Disabled people should have the same right to liberty and security of person and should not be deprived of their liberty unlawfully. The state report makes fifteen observations on this article. The following information was gathered in the ILMI consultation relating to article 14 of the convention.

- The review of the Mental Health Act 2001 and the timeline imposed by the Department of Health (one month) gives no regard to the involvement of people with lived experience and prioritises medical health professionals and their organisations in having resources to respond. Such a short timeline to prevent people with lived experience to have the opportunity to organise and respond is contrary to Articles 29(b) and General Comment 7 on the prioritisation of Disabled Person's Organisations in consultations relating to disabled people's lives.
- The Initial CRPD report references Mental Health Tribunal reviews after 21 days as policy but fails to provide data that this policy is being carried out in practice. There is a further policy and procedural silence that people with lived experience are encouraged to participate in all aspects of the role of the Mental Health Commission, including mandating that lived experience is a desirable attribute for lay members of mental health review boards.
- There is an absence in the State Report on how it will address the administration of "treatments" against people's expressed wishes which contravene Articles 14 and 15 of the CPRD in terms of the use of restraints, denial of liberty and use of ECT. Currently once a psychiatrist determines someone lacks capacity to consent such 'treatments' against someone's will, these 'treatments' are deemed lawful under the Mental Health Act 2001.
- The Initial State report does not give figures of how many people are in acute settings which are effectively congregated settings, for how long and how their denial of liberty is being reviewed. Many people are in acute units, which are then classified as being in a "hospital" receiving "treatment" and not as people in a congregated setting with no plan for de-congregation. The effects of long-term hospitalisation in approved psychiatric settings (under the guise of 'necessary' long-term treatment) is institutionalisation and dependency. Institutionalisation should no longer occur, its effects no longer experienced by individuals.
- The initial State report also fails to reference people in Community Residences and plans to ensure they can live independent lives of their choosing.

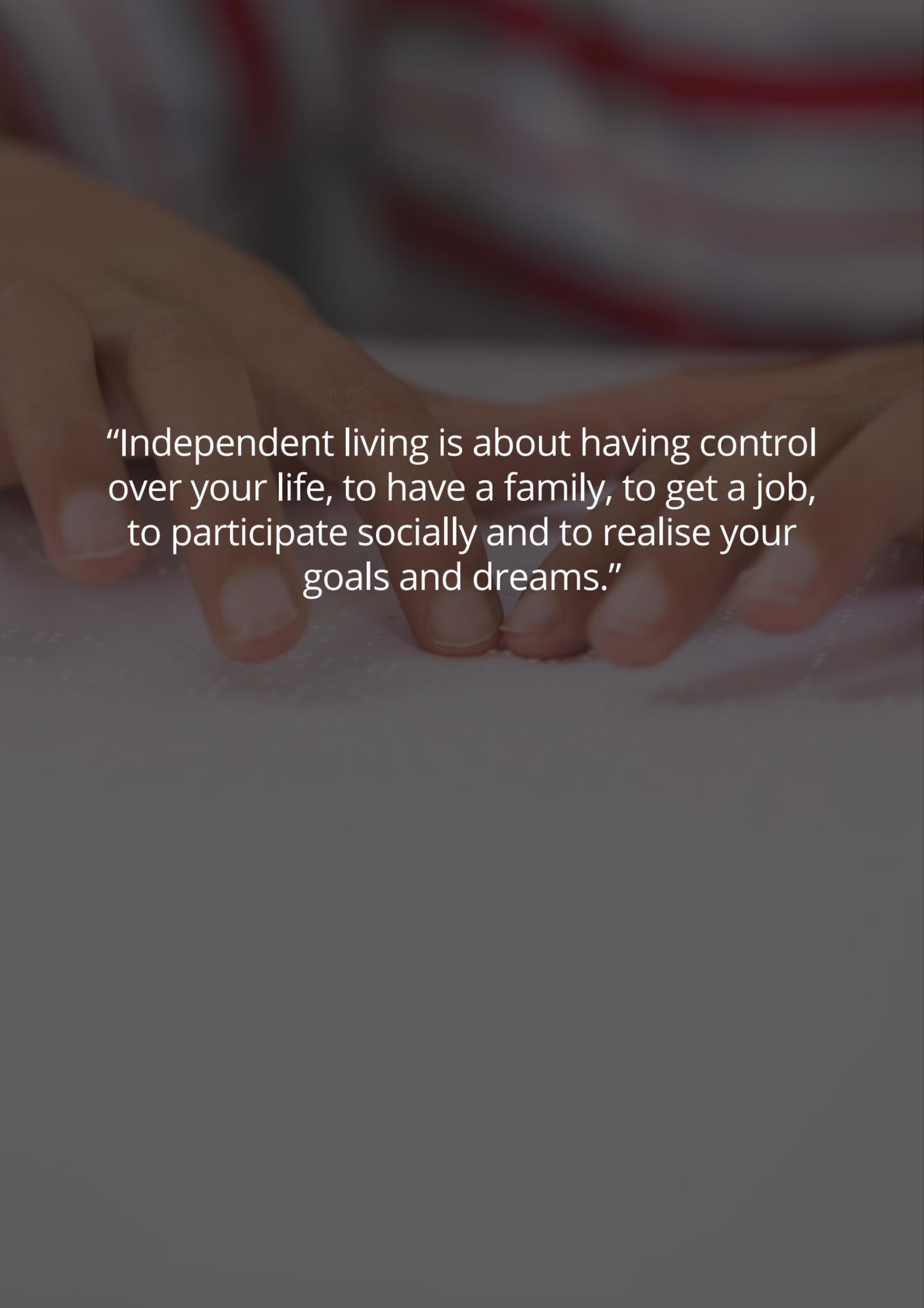


“There are huge concerns that so-called psychiatric “diagnosis” prioritises medical interventions which more often than not has a disabling effect as opposed to enabling people.”

Article 17 – Protecting the integrity of the person

Every disabled person has a right to respect for his or her physical and mental integrity on an equal basis with others. The state made thirteen observations on this article. The following information was gathered in the ILMI consultation relating to article 17 of the convention.

- The State Report states that if a person has been on medication for three months that this must be reviewed. The State report lacks data on how this is put into practice and precludes the role of peer advocates to support a disabled person in this process and prioritises medical professionals.
- There are huge concerns that so-called psychiatric “diagnosis” prioritises medical interventions which more often than not has a disabling effect as opposed to enabling people.
- Disabled people with lived experience have raised concerns of the over medicalising as a public health concern, including mass medicalisation of children. There is no commitment in the CRPD to engage people with lived experience to review the over emphasis on medication and how this impacts on people’s lives.
- The initial State report neglects to highlight the lack of legally binding advanced healthcare directives for disabled people to define what supports they would like to access or not access where they experience emotional distress.
- The concept of consent and choice remains unexplored in the initial State Report. People often “consent” to “treatment” on the basis that there are no perceived choices. Real choice to a suite of holistic supports and therapies needs to be prioritised away from a medical system that denies control and choice.
- Informed consent also needs to include evidence-based discussions on the long-term negative impact of medication and whether medication has any real basis for addressing emotional distress caused by trauma, social isolation, poverty, racism and so on.
- At the moment most “interventions” are adding to pain and distress. There are many practices which happen under seclusion or are recorded in ways to avoid being registered, including how physical restraints are in place, recorded and monitored for their impact on people.
- Often persons who experience or have experienced emotional distress (and receive mental health “diagnosis”) are not seen as credible plaintiffs, witnesses and victims particularly when pitted against healthcare professionals. “As disabled people we do not receive a fair hearing in the Courts if we were able to secure representation to begin with. Often it is assumed we do not know what is in our best interests and more or less the evidence of non-disabled people” is taken as more credible than the disabled person”.



“Independent living is about having control over your life, to have a family, to get a job, to participate socially and to realise your goals and dreams.”

Article 19 - Independent Living

Disabled people have the right to live in, be part of, and use services and amenities in their communities. They should choose where and with whom they live with appropriate and adequate supports. The state has made twenty observations in relation to article 19.

The following information was gathered in the ILMI consultation relating to article 19:

- The Initial State report states “A significant number of actions committed to under the NDIS address the provisions of Article 19.” However, there is an absence of reference to the centrality of Personal Assistance Service (PAS) in the NDIS and the initial State report reflects this with a single reference to PAS yet it is central to achieving independence for so many disabled people on a cross-impairment basis.
- For example the NDIS Section 6 (“Person-centred disability services”) and specifically “Achieve maximum independence” (Actions 69-71) do not make any reference to the Personal Assistance Service, despite it being central to many disabled people’s lives and independence, and that many disabled people are unable to avail of a PAS or only have access to a limited service or a home help service based in their home as opposed to a PAS which would allow them to have full control of their lives.
- Independent Living is about having the freedom to have the same choices that everyone else has in housing, transportation, education and employment.
- Independent living is about choosing what aspects of social, economic and political life people want to participate in.
- Independent living is about having control over your life, to have a family, to get a job, to participate socially and to realise your goals and dreams.
- Personal Assistance Services (PAS) are the foundation of the Independent Living Movement.
- The narrow term of ‘PA’ needs to be moved away from and “independent living” needs to be expanded to include all the supports a disabled person may need to live independently, regardless of the support model they use.
- To enable a disabled person to live independently they need access to safe accessible housing. It is extremely difficult for disabled people to find suitable accommodation.
- The lack of universal design and lack of real accessible transport options act as a primary barrier to Independent Living, particularly for those living in rural areas. The need to notify public transport authorities 24 hours in advance of public transport is extremely restrictive.
- Employment is one of the cornerstones of Independent Living. Many disabled people live in a poverty trap cycle. In order to escape it they need access to meaningful employment.
- There is lack of awareness and understanding of the social model of disability from members of the public and this can restrict the desire of disabled people to access public services or amenities.
- Adaptations to vehicles are also difficult to access and secure. This has many ramifications particularly in terms of access to meaningful employment and medical appointments.

“Independent living is about having control over your life, to have a family, to get a job, to participate socially and to realise your goals and dreams.”

- Many service providers still have a huge amount of control over disability services. The individual has very little say in the service provider model and the lack of choice and control restricts the individual's ability to live independently – this is not independent living. Service providers also present as if they are speaking for the disabled person and are still viewed as such by policy makers and legislators. This very culture prohibits a movement towards true independent living.
- The lobby of family members in a caring role also needs to be separated from the individual. The system needs to be challenged to separate the supports required from a carer's allowance. As a disabled person progress through life a child should not automatically qualify for a disability allowance. In doing so the system is supporting the notion that the individual will remain on social welfare.
- There is a need to enable people to move towards independent living and not support the notion of care.
- Collective activism is the way forward but the apathy shown by the disabled community is fuelling the lack of progression. Disabled People are exhausted with fighting the system. It is a fight to access the system and then once in it the challenge continues.
- “Disability” is a huge political issue. The current negative economic situation is terrifying for disabled people who are reliant on services to live and that are “dependent upon financial resources”.
- A national approach needs to be implemented in relation to the provision of supports and services to enable disabled people to live independent lives. The lack of a standardised approach and a “postcode lottery” causes huge barriers to real independence. A disabled person cannot simply move house. They cannot access the same services in one county as they do in another.
- There needs to be a national approach to services and supports that are easily transferable.
- The state report references “New Directions” but the data is weak in this area too. The report does not give an update on progress on New Directions as a policy and whether it is having a positive impact on disabled people's lives, such as progress into higher and / or further and adult mainstream education.

Article 23 - Respect for the Home and Family

The State recognises that disabled people have the same rights as others to parenting, relationships and family planning. The state has made fourteen observations in relation to article 23 with reference to relationships, family planning, supports within the home and protections for children. The following information was gathered in the ILMI consultation relating to article 23:

- Parenting is often more defined in terms of physical tasks as opposed to emotional supports such as love, security and nurturing which are the main roles of a parent.
- The definition of family is not just about having children. It also includes married life. There are barriers to acquiring a family home based on means testing and income.
- There needs to be a right to support disabled parents need, including Personal Assistance Services.
- There is a genuine fear of being “judged” as a disabled parent, a fear of a perception of not being able to “look after” children and on that basis for many disabled parents there is a delicate balance of seeking support and not wanting to be judged.
- The medical model judges how people “parent”. Some disabled parents need support with certain physical tasks and that can be perceived as not being able to look after children.
- Disabled parents often have to explain to medical experts and members of the public why they need a PA. It needs to be made clear that supports such as PAS are about enhancing parenting ability.
- Disabled parents faced judgements and attitudes of health care professionals and other statutory agencies most of the time. Often people talk to the PA assuming they are the parent and this is very damaging and disempowering.
- Disabled people are also family members and in the absence of supports such as PAS, we are often “dependent” on family supports and feel shame about this situation because we are someone who seeks assistance in relation to their family.
- There is an assumption that often disabled people in a relationship are not expected to have children. There needs to be an awareness raising that disabled people can and do have sexual relationships.
- There are no statistics or data for the number of children who have disabled parents in care, especially parents with emotional distress impairments. Ireland is poor on data collection in this area.
- Foster parents get huge financial supports, but often families who are struggling do not get that and children are taken into foster care.
- Research shows that children are better served by staying out of care. Ireland needs to look at European models where foster parents support the family unit.
- Assisted Human Reproduction services such as IVF are very expensive. Disabled people on medical cards who require IVF will have only one chance for treatment. “Going private” is often outside the means of many disabled people through barriers disabled people face such as lack of employment.
- An urgent review of maternity and gynecological services is required.
- Accessibility in terms of built environment, information, communication access to these services can be a huge barrier. Health “experts” need to realise that disabled people are sexually active and engage in family planning just as non – disabled people do.
- In relation to adoption many countries where children can be adopted exclude disabled parents.

“There is a genuine fear of being “judged” as a disabled parent, a fear of a perception of not being able to “look after” children and on that basis for many disabled parents there is a delicate balance of seeking support and not wanting to be judged.”

- The right to accessible homes impacts on disabled people’s rights to have a family, as does accessible rural transport and personal mobility. This impacts on disabled parents bringing kids to school, shopping and so on.
- Notably the group agreed that there is a “cost of disability” which is an issue in terms of a household.
- In terms of Rebuilding Ireland, some disabled people don’t earn enough to qualify for a mortgage but cannot access social housing. Often disabled people “hide” their impairments or don’t declare in order to access jobs, mortgages or insurance.
- The right to family life in the home needs to be resourced and for disabled people including the right to make decisions and be in control of their own lives.
- Disabled people and non-disabled people age and go through transitions in life - from child to adult, and from adult to older person. Disabled people need to be in control of their own lives, on where they want to live and who they want to live with. This includes disabled people institutionalised in their own homes.



Article 24 - Education

The State recognises that disabled people have the same rights as others to education. The State has made forty one observations under article 24 relating to education. The following information was gathered in the ILMI consultation relating to article 24 of the convention:

- There are many barriers within the education system for disabled people including accessibility, attitudinal, accessing resources and accessing appropriate supports. The state report did not provide a focus on how the education system can be more inclusive.
- The curriculum quite often is not accessible and teachers are under-resourced. Assessment needs to be looked at as every student does not “learn the same”. A huge barrier is the attitude of some educators at all levels, primary, secondary and especially in third level. In education settings disabled people often felt as “other”. For example “if you don’t have your homework done “it’s okay”. Tests in schools for career guidance are very much based on the medical model of disability and disabled students “might not be able for the job”. There is little support in relation to literacy and numeracy (spelling and grammar and very little accommodation for maths class) in the class other than being “segregated” or taken out of the class. Disabled people felt their education can be affected when this happens.
- Many educational institutions have a poor understanding of the support needs of disabled students and are directed by Special Educational Needs Organisers (SENs) who seem to “dictate” what is best for the disabled student in schools which is an outdated medical model of disability.
- People with Intellectual Disability can be excluded from learning if it is not accessible while access for physically disabled students is an issue in local schools. In Urban regions, parents are encouraged to send kids to “special schools” as opposed to mainstream national schools because in special schools they have access to medical support and in some cases not based on their child’s educational needs. This often leads to poor literacy and numeracy among some young disabled people.
- In higher education, accessing supports for part-time courses is extremely poor. “Catherine’s Law” is a fantastic development. However, we need to ensure that disabled students who progress in any element of education are not penalised or that it does not affect the disabled persons supports (disability allowance) or secondary benefits (travel pass or medical card). This law does not include part time PhD’s or other postgraduate courses disabled students want to complete and the state report does not address this.
- The transition from primary to secondary and secondary to third or further education can be daunting for anyone. However, disabled students experience additional barriers in relation to securing adequate and appropriate supports.
- Young disabled people feel that there is a body of work to be done in relation to relationships and sexuality and education and the “conversation” needs to involve young disabled people. Young disabled people are entitled to appropriate relationships and sexuality education as part of their development to express “who they are, this is all part of growing up”. Often young disabled people are “de-sexualised” and quite often not seen as “sexual beings” when transiting into adulthood by non-disabled people.
- Subjects such as physical education (PE) are not fully inclusive. There needs to be more diversity and inclusion in the curriculum from the onset.
- Inclusive and accessible youth work needs to involve disabled people in its development and delivery.
- School transport system needs monitoring and improvement in terms of accessibility.
- There needs to be a move away from the tokenistic approach to employing disabled people after or between education transition points.

“Young disabled people feel that there is a body of work to be done in relation to relationships and sexuality and education and the “conversation” needs to involve young disabled people.”

Article 25 – Health

Disabled people have the same right as others to access mainstream and specialist health services in their communities. They should experience the same standard and quality of care as others. The State has made twenty nine observations under article 25 relating to health. The following information was gathered in the ILMI consultation relating to article 25:

- The involvement of the medical and social model should be included into college, university and future education and training courses. There is still perceptions among teachers and careers guidance professionals the notion “that course wouldn’t be for you”.
- The NCSE educational plan has never been used effectively and disabled people are not involved. There should be more of disabled people involved in their learning.
- Technology can be inclusive. It is important that people are trained properly to use technology including parents of young disabled children. The use and effectiveness of technology should be evaluated as a disabled person progresses through the education system to make sure it meets the needs of the person. Technology software requirements should be linked to the student as opposed to the school.
- Staff need training to provide effective supports. However, young disabled people need to be encouraged to take control and responsibility for their decisions in an age-appropriate way.
- Learning supports are not fully effective in third-level education. It should be re-evaluated with direct engagement and consultation of disabled people.
- Examination supports in universities are good, such as additional time for an exam or an additional centre. Supports such as note takers get general training but not specific to support people’s varying impairments.
- Supports such as SNA’s can also disempower disabled students.
- Students need more control and need to be central to the process to be ready for third-level / further level education.
- Disabled students with lived experience can educate new teachers what works best for them. Culturally the teacher “knew best” but there is a shift to more “student centred” learning which will benefit both parties.
- There is a big divide between public and private services for disabled people and often wait times are a big problem. The system is very fragmented and no joint up thinking.
- There is a “bottleneck” between assessment and getting into services for treatment, from access GP care onwards.
- Despite additional cost to disability some disabled people have paid beyond their means for a private consultations because they felt they “couldn’t wait” for the “six months waiting list”.
- Waiting lists can be a problem even for counselling services. It can be up to five months and issues can compound within that time.
- The system has been decimated with private practices using public equipment. This has affected everyone especially disabled people as issues can be complex and become more urgent.
- The public health sector services are often inadequate to cater for acute care for wheelchair users. They do not have adequate equipment that can be used easily. In some circumstances disabled people have to bring in their own equipment such as, a hoist.
- In some cases disabled people cannot access the building or the equipment to get a procedure done which results in delaying appointments, this has happened to several disabled people in this consultation. One disabled woman could not access breast check equipment and was told to “come back”. The procedure was carried out in another hospital.
- Often hand rails are placed inappropriately in hospitals and specialised equipment is not present, such as specialised mattress.
- Bathrooms in hospitals are not constructed adequately to take all equipment. Sometimes the bathrooms are not accessible for wheelchair users and does not contain all facilities needed. This leads to loss of dignity in having to use alternative toileting options.
- It should be mandatory to have a wheelchair accessible toilet on each floor built to maximum standards.
- Accessing private supports in relation to emotional distress is unsustainable for many disabled people, especially those who do not work. There needs to be acknowledgement how a physical, sensory or intellectual impairment diagnosis and social exclusion caused by lack of inclusion can cause emotional distress
- The training of healthcare professionals needs to include social model / lived experience training.
- The COVID-19 pandemic has made disabled people “become invisible again”. Disabled people’s needs are not being represented. “As a visually impaired person my hearing loss was not taken seriously and no one knew how distressing that would be and impact on day to day life. Health professionals need to see the broader picture”.
- PAs not being able to do their jobs in hospitals means the disabled person are sometimes left in a hospital bed with no assistance to drink, eat or go to the toilet when they choose.
- There is no standardised approach to disability services “it is the lottery based on where you live based on your CHO area”.
- There is a concern that assisted decision-making is not referenced. Informed consent decision-making not referenced and this is huge if a disabled person becomes ill.

“Many disabled people live in a poverty trap cycle. In order to escape it they need access to meaningful employment.”

- In interactions with health care staff on any medical issue, a “mental health diagnosis” becomes primary mode of analysis as always on referral. There is a supposition that any other underlying health issue is a figment of imagination, or a reflection of stress or psychosomatic. This “diagnostic overshadowing” can have serious health implications. It masks and blurs underlying co-morbidity illnesses having serious implications on the physical well-being of an individual.
- The Initial State Report lacks any sort of independent analysis of the very real side effects of medication on people’s lives. Many people on long term medication have developed metabolic syndromes, the causes of which are attributed to their individual behaviour (such as smoking and lack of exercise) rather than to systemic factors such as over reliance of medication, lack of regular review of polypharmacy and lack of appropriate healthy lifestyle opportunities.



Article 27 - Work and Employment

Disabled people have an equal right to work and should be given the supports they need to access or retain employment and to have the same career opportunities as others. The State has made thirty five observations under article 27. The following information was gathered in the ILMI consultation relating to article 27:

- Disabled people felt they do not have the same rights as non-disabled peers in relation to work and employment. Although Ireland has a comprehensive employment strategy in place the state report makes reference to excluding disabled people from certain careers such as the Defence Forces, An Garda Síochána, the Prison Service, the Fire Brigade, the Irish Coastguard, and the Ambulance Service. This feeds into the notion and expectation that disabled people occupy “jobs” not careers. This should be reconsidered and alternative recruitment to areas within these professions should be reviewed. Disabled people who feel “they are most qualified for the job” might not get it because of barriers including lack of accessibility, equipment and lack of PA support in the workplace.
- Reasonable accommodation needs to be implemented to allow disabled people to gain meaningful employment and should be used more effectively. For example jobs should be more flexible or be shared part-time leading to a better quality of work and better teamwork. In some cases disabled people need to work twice as hard as non-disabled peers and can “burn out”. Assistive technology is hugely important and access to it at different levels of employment for disabled people however, employment grants are not effective, such as the work adaptation grant.
- Inaccessible public transport is a barrier and accessible transport is non-existent in certain parts of the country to gain employment.
- Self-employed disabled people are not eligible for supports that are aimed at employers and disabled people who begin to earn above certain thresholds can lose secondary benefits which many disabled people rely on, such as a free travel pass, blind pension and so on and impacts on employment of disabled people. Cost of living and professional development is a barrier again because of fear of losing benefits, such as the medical card. There was a suggestion that disabled people should be able to earn and pay it back through taxes rather than “taking away benefits”.
- Autistic people felt that they face additional barriers in getting employment as there is a lack of awareness or understanding. It was noted that there is a lot of barriers for visually impaired people. “Time efficiency” is the biggest barrier and often quoted for not getting a job. There is difficulty at application stage, discrimination by forcing “us” to disclose personal information and to say “we need x, y, z”.
- The COVID-19 pandemic has made barriers worse, disabled people seen as “vulnerable” and “at risk”. Remote working should be used to increase the number of disabled people in the workforce but not “Pidgeon hole” disabled people to only work at home. However, broadband quality is poor in rural areas which impacts remote working.
- There is still serious attitudinal barriers and employers have perceptions about “work productivity” among their disabled employees. These attitudinal barriers are unintentionally reinforced by Government schemes such as the wage subsidy scheme tells employers that disabled people will only be 80% productive as a non-disabled person.
- Employment schemes which aim to “include” disabled job seekers are not effective in Ireland and need to look at international best practice such as the “work access scheme” in the UK. All supports are initiative based and pilot projects. If an initiative works then it should be adopted as policy.



“Societal attitudes and stereotypes and ableism is a big issue too for disabled people participation in community and public life.”

Article 29 - Participation in Political and Public Life

Disabled people have the same rights as others to take part in political and public life. The state has made six observations under article 29. The following information was gathered in the ILMI consultation relating to article 29:

- Disabled people reported that there is not enough disabled people involved in public and political life. Some of the reasons for this is the lack of promotion, accessibility (built environment and information / communication) and the lack of resources for disabled people to canvass, to access transport, to get adequate PA hours to engage in public and political life.
- Representation of disabled needs to be broadened and it needs to be seen at every level local, regional and national.
- Representation must be from the top down and the bottom up and disabled people felt “we don’t have a platform in the media”.
- Education is a good instrument and way to ensure that there a push for politics in education in primary and secondary which will feeds into disabled people being represented in our communities such as avail of vacancies in local structures such as PPNs.
- There is disparity in the variation of how political parties prioritise “disability issues”. Ireland needs to ratify the optional protocol.
- Disabled people felt that “being a disabled person can be seen often as your expertise” and intersectionality of the person is not often reflected.
- Lived experience is really important in public and political life but in a party it can cause a situation. In terms of political participation it was noted that some political parties may have more financial resources to assist those who may need support such as disabled people.
- Societal attitudes and stereotypes and ableism is a big issue too for disabled people participation in community and public life.
- Disabled people need capacity building to support development into political life and consultation needs to be meaningful and not as “tokenistic”.
- Disabled people’s voting powers needs to be recognised more.
- It was noted that the culture needs to change on consultation in Ireland. There should be alternative and accessible methods used in all consultations. It should strive to include everyone including the use of language / information sharing and communication.
- DPOs need to push into the political arena too, encouraging the participation of disabled people and there needs to be a push to form a disabled person representation in government preferably a political party.
- There are massive barriers to voting at polling stations and there still remains issues with the postal voting system in Ireland. There is a loss of lived experience in policy and roll back from Vision for Change and commitment to participation and co-creation of policy / oversight implementation of policy of people with lived experience. Vision for change also had commitments to enabling people with lived experience to participate in and deliver services. There has been an according change in vocabulary which has moved towards a more medical approach.
- In resourcing DPOs, it should be on a cross-impairment basis and resource and support the voices of lived experience of emotional distress and survivors of psychiatric systems to work collectively. Structured supports are needed to bring people together to inform authentic lived experience representative based on a collective voice which is free to critique functions of the State.



Conclusion

ILMI as a national DPO created a series of participative online consultations which brought disabled people on a cross-impairment basis together to analyse the Initial State Report to the UNCRPD.

During the thematic discussions on specific articles of the UNCRPD, disabled people not only identified specific institutional and policy barriers that disabled them from participating in society, but broader cross-thematic issues which are identified in the executive summary of this report.

Crucially the process of bringing disabled people together on a cross-impairment basis demonstrated that collective voice of disabled people can and should inform and monitor Ireland's progress in fully meeting its commitments under the UNCRPD and build a more inclusive society.

An Ireland where disabled persons have freedom, choice and control over all aspects of their lives and can fully participate in an inclusive society as equals is possible, but it can only be created by disabled people through their representative DPOs being actively involved in designing that society. "Nothing About Us Without Us" needs to be the driving principle for the implementation of the UNCRPD in Ireland.

Nothing about us without us

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