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**An Comhchoiste um na Nithe a Bhaineann le Míchumas**  
Seirbhísí Míchumais a Ailíniú le Coinbhinsiún na Náisiún  
Aontaithe ar Chearta Daoine faoi Mhíchumas

Feabhra 2023

**Joint Committee on Disability Matters**  
Aligning Disability Services with the United Nations  
Convention on the Rights of Persons with Disabilities

February 2023



## Membership

- Holly Cairns T.D., Social Democrats
- Seán Canney T.D., Independent
- Emer Higgins T.D., Fine Gael
- Neasa Hourigan T.D., Green Party
- Michael Moynihan T.D., Fianna Fáil, (Cathaoirleach)
- Jennifer Murnane O'Connor T.D., Fianna Fáil
- John Paul Phelan T.D., Fine Gael
- Pauline Tully T.D., Sinn Féin, (Leas-Chathaoirleach)
- Dessie Ellis T.D., Sinn Féin
- Senator Tom Clonan, Independent
- Senator Eileen Flynn, Independent
- Senator Erin McGreehan, Fianna Fáil
- Senator Fiona O'Loughlin, Fianna Fáil
- Senator Mary Seery Kearney, Fine Gael

## Joint Committee on Disability Matters



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*Social Democrats*



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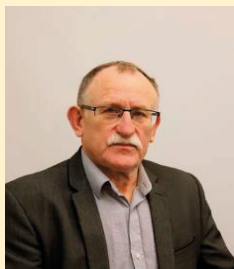
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Senator Erin  
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Senator Tom Clonan,  
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Senator Fiona  
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Senator Mary Seery  
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## Cathaoirleach's Foreword

Urgent action is needed from Government on Disability Services to ensure the rights of children and adults with disabilities are upheld in line with the UN Convention on the Rights of Persons with Disabilities (UNCRPD). Government crisis talks must be undertaken to ensure action from all relevant actors.

The Committee heard about the crisis in children's disability services from parents of children with disabilities, including parents who were forced to form advocacy groups because they were not receiving early intervention. Parents experienced significant distress watching their children regress as a result of a lack of early intervention. Parents were forced to impact their privacy and dignity by engaging with the media to tell their personal stories to raise awareness and access services. There is also a significant range of court-cases taken against the HSE where parents are advocating for the rights of their children to access services. A crisis of culture, recruitment and retention exist in Disability Services. There is significant capacity for transformation in line with the dignity, will and preference and rights-based provision of care as outlined by the UNCRPD.

The Committee also heard about the crisis in adult services. Adults residing in disability residential centres have a lower quality of life where their rights and will and preference are not respected. Access to advocacy and rights-based person-centred planning must be developed to support people, as well as programmes to deliver independent living. Better access to community and rehabilitative supports is needed, as well as mainstreaming disability under Sláintecare.

An urgent All of Government approach is critical to enable these individuals to live the life they want.




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**Michael Moynihan**

**Cathaoirleach to the Joint Committee on Disability Matters**

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## Engagement with stakeholders

1. In line with its Terms of Reference to monitor the UNCRPD, the Joint Committee on Disability Matters (the Committee) developed a module of public meetings which examined the limitations of the current disability service provision as well as meetings to examine future disability service provision and innovation. The Committee values the living experience of individuals with disabilities, and heard from individuals, those caring for children with disabilities, Disabled Persons Organisations (DPO's) and Disability Service Providers. The Committee prioritised hearing from individuals who had made submissions to the Committee's public consultation undertaken in 2020 as part of this engagement.
2. The Committee examined Disability Services over a total of 13 meetings. The module of meetings entitled 'Aligning Disability Services with the UNCRPD' comprised of two parts. The first part of the module comprised of four meetings and considered the current disability service and heard from service users, DPO's, parents and carers across the groups of physical and sensory disability, autism and intellectual disability, acquired disability and chronic disease. The second part of the module comprised of three meetings and considered the future system and innovation and heard from those organisations representing service providers or involved in service provision.
3. The Committee separately held three meetings on Progressing Disability Services Model and heard from the Minister of State with responsibility for Disability, the Department of Health, HSE officials, and the Department of Children, Equality, Disability, Integration and Youth. The Committee also held a joint meeting with the Joint Committee on Children, Equality, Disability, Integration and Youth and heard from the Minister of State with responsibility for Disability, the Department of Health, the CEO of the HSE and officials. Three further meetings that are included are the examination of Equality and Non-Discrimination, 3 February 2021, Accessibility and Assistive Technology, 6 October 2022 and Consideration of Family Centred Practice and Parent Training Interventions, 26 January 2023. Please see list of all public meetings in Appendix 1.

## Executive Summary

4. People with disabilities in Ireland access to mainstream health services is severely impacted, due to inaccessible services, a lack of expertise, therapies, and individualised services as well as a significant cost of disability and a lack of disability awareness training across all areas of the service. Disability Services, which deal with more complex disabilities, has a broken organisational structure that impacts transformation of a service, and is based on a medical approach to disability, sustains segregation through a lack of mainstreaming early intervention, and ultimately impacts the rights of people with disabilities under the UNCRPD. This is sustaining a culture of mistrust in Disability Services.
5. Policies and legislation which would enable progress to a social and rights-based model of disability and care continue to be delayed. There are also serious issues with regard safeguarding in Disability Services, as well as instances of disregard to individuals free and informed consent in the provision of care along with lack of implementation of policies and/or legislation to address the problems. The lack of a standard and monitoring of person-centred planning further impacted delivery of rights for people in disabilities in day-to-day service provision in residential centres as well as day services. The Committee were concerned to hear evidence of the inappropriate use of antipsychotic medication as well as intervention therapies in health services.
6. In general, the public are not aware of the issues that people and children with disabilities face in the health service. The lack of a national disability awareness strategy to raise awareness of these issues, and because of the inequity in service provision, parents and individuals with disabilities are impacting their privacy and dignity through engaging with the media to raise awareness and access services. This is also occurring through parental action in a range of court-cases taken against the HSE to access to services.
7. Under the medical model of disability people with disabilities are viewed as objects of charity that are incapable of living independently and contributing to society. Based

on this approach people with disabilities, especially intellectual disabilities, can spend their lives living in congregated settings and institutions, segregated from, and with no access to, local communities. Individuals in these settings have a lower quality of life, increased risk of poor-quality standard of care and support and safeguarding issues. Adults with disabilities can also experience low quality of life in their homes with elderly parents who are not receiving support to provide appropriate care. Day Services that are not operating in line with the principles of the UNCRPD can also sustain segregation and set individuals further on the segregated pathway. There is need for a wider person-centred support plan for community inclusion to target the development of community-living infrastructure, care and support, including respite and support for agencies to re-configure their services, along with renewed and strengthened commitment to people with disabilities under the integration of SláinteCare. Otherwise, the State will be locked in health services that are medicalised and segregated and impact people with disabilities rights.

#### 8.Children's Disability Services, and children's mental health services are also in crisis.

The Progressing Disability Service model is not achieving early intervention as a standard for children with complex disabilities. Parents are distressed as they see the negative impact of the lack of intervention, compounded by the routine disruption caused by non-standard delivery of service across Children Disability Network Teams. In this regard, the Committee believe that the PDS model must be urgently developed to fully align with the UNCRPD and Article 25(b). There is significant disconnect between health and education sectors in the provision of health services and supports for children with disabilities and special educational needs attending special schools or classes or mainstream school. There is need for more joined up thinking and working by applicable Departments through a national strategy to deliver inclusive education and inclusion in society.

#### 9.There is also significant opportunity for transformation in Disability Services in consultation with people with disabilities and their DPO's, through personal assistance, independent advocacy, and Assistive Technology. There is a need to develop a centralised and rights based National Disability Long-term Care and Support scheme across all sectors, and funding for a new ecosystem and market of

service providers along with different models of support for those transitioning from congregated settings. This would enable funding to be allocated to the individual who would have a choice of the service they wanted and needed.

## Introduction

10. Health is essential to individual well-being and happiness, allowing individuals to reach their full potential. Health and Life, Article 25 of the UNCRPD requires the enjoyment of the highest attainable standard of health, without discrimination on the basis of disability, through the equal access to mainstream and specific services within general health services, inclusive health insurance, and the application of free and informed consent.
11. In Ireland, the Department of Health is responsible for health and social care policy and strategy. The Health Services Executive (HSE) are responsible for service delivery and service commissioning. Disability Services are part of Community and Social Care within the HSE. Disability Services include income maintenance, early intervention, multi-disciplinary therapies, habilitation, rehabilitation, and behaviour support, staffed supported housing, specialist end of life care, respite/short breaks to support carers, day services and support for community engagement, personal assistance, home help and assistive technology.
12. 635,000 people in Ireland have been identified as having a disability. Disability Services are delivered to 9% of this cohort, c.56,000 people, with either an intellectual or a physical and sensory disability (c. 29,000 and c.27,000 respectively).<sup>1</sup> Some services are provided directly by the HSE. Community, residential and rehabilitative training services are also provided by voluntary organisations with grant aid from the HSE.
13. The *Programme for Government: Our Shared Future* commits to a policy of mainstreaming public services for people with disabilities in Ireland, and

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<sup>1</sup> Department of Health, *Disability Action Plan Framework Review of Disability Social Care Demand and Capacity Requirements to 2032*, pp. 1

implementation of the UNCRPD should further progress this policy. Mainstreaming disrupts the medical model and offers a pathway to services aligned with the social or human rights model of disability. Mainstreaming supports society to transform as people with disabilities are included across all sectors, in local communities, and can enjoy the same rights as everyone else.

14. Reform is underway in Disability Services to transition to a person-centred service model through the *Transforming Lives Programme* where supports are individualised and based on a standardised independent assessment of individual needs. This programme is a broad policy which includes, but not limited to, *New Directions*, *Time to Move on from Congregated Settings*, *Neuro-rehabilitation Strategy and Implementation Framework*, Personalised Budgets, Progressing Children's Disability Services and Autism Policy. The Committee heard from the HSE that many of these policies were developed in the context of, and aligned with, the UNCRPD.
15. Access to health care is still a challenge for persons with disabilities. Significant unmet and capacity needs of Disability Services have been identified through various reviews. The recent Disability Capacity Review up to 2032 (the Review) identified the significant unmet need in the Irish population. Committee public meetings highlighted the lived experience of this unmet need. It has been highlighted by Independent Living Movement Ireland (ILMI) that the Review is inadequate in revealing the reality of unmet need, because it reflects the medical model of disability and not the need of a rights-based model of disability.<sup>2</sup>
16. The Committee believe that the key to developing Disability Services in alignment with the UNCRPD is implementing the rights-based model of care along with strengthening accountability of person-centred delivery. This is proposed by the Working Group under the *Time to Move on from Congregated Settings (TTMO)* report. This level of service delivery includes transitioning to integrated services which ensure a whole of person and lifecycle approach.

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<sup>2</sup> Independent Living Movement Ireland (2021), *Overview of the Department of Health Disability Capacity Review to 2032: A Review of Disability Social Care Demand and Capacity Requirements up to 2032*

## Chapter 1: Rights based disability services provision

### Introduction

17. Article 25, under the UNCRPD calls for State Parties to recognise that people with disabilities have the right to the enjoyment of the highest attainable standard of health without discrimination on the basis of disability and take all appropriate measures to ensure access for persons with disabilities to health services that are gender-sensitive, including health-related rehabilitation. Key areas of focus under this article include sexual and reproductive health, early intervention, quality care on the basis of free and informed consent, human rights, dignity, autonomy and needs of persons and ethical standards for public and private health care and provision of health services as close as possible to people's own communities.
18. This right also focusses on the freedom from non-consensual or degrading treatment as well as the entitlement to health care that is accessible, good quality and culturally acceptable. This includes the full spectrum of essential health services, from health promotion to prevention, treatment, rehabilitation, and palliative care.<sup>3</sup>
19. The Health Information and Quality Authority (HIQA) have developed several national standards which make high-level reference to a human rights-based approach to care and support, with emphasis placed on protecting and promoting people's rights and respecting their autonomy, privacy, dignity, values, preferences, and diversity. HIQA highlight that a human rights-based approach is an important pillar of all health and social care, which should run in parallel with other statutory and regulatory frameworks. HIQA have produced guidance for all staff working in health and social care services, applicable to people using services, their families, carers, friends and advocates. This guidance will also support staff and organisations to comply with their Public Sector Equality and Human Rights Duty in respect of Section 42 of the Irish Human Rights and Equality Commission Act 2014.<sup>4</sup>

<sup>3</sup> Office of the United Nations High Commissioner for Human Rights (2008), *The Right to Health* Fact Sheet No. 31, pp. 1-4.

<sup>4</sup> HIQA, *Guidance on a Human Rights-based Approach in Health and Social Care Services* (2019)

20. The National Disability Authority (NDA) in their paper, *Article 25 Right to Health*, highlighted that the standardised mortality rate for ‘persons with disabilities was 4.1 times higher than that of persons without disabilities’, ‘females with a disability was 4.5 times higher than that of females without a disability’, and ‘males with a disability was 3.9 times higher than that of males without a disability’.<sup>5</sup> The Committee note the NDA comment that an increase in relative standardised mortality rates for persons with disabilities compared to persons without disabilities may reflect a lack of access to health or social care or poorer quality health and social care for persons with disabilities.
21. Equal access to health treatments is key to Article 25, however the Review highlights that in practice, there is often restricted access for children and others with disabilities to mainstream therapy services delivered through primary care, like speech and language therapy, occupational therapy, psychology, and physiotherapy. The Review further states that it is essential to ensure that people with disabilities are not disadvantaged in this regard.<sup>6</sup> The Committee believe that SláinteCare presents an opportunity to further integrate and develop primary care services for people with disabilities.
22. A key aspect of delivering rights-based disability services is ensuring that all applicable legislation is UNCRPD compliant and does not impact the rights of people with disabilities through medicalised provision. The UNCRPD Implementation Plan should reflect the significant interdepartmental collaboration needed to progress these provisions. However, there is no indication of a date for the publication of the UNCRPD Implementation Plan.
23. The HSE has primary responsibility for the provision of specialist disability services to all eligible persons with disabilities in Ireland. In cases where the HSE are unable to provide these services directly, primary responsibility is transferred to locally based voluntary, non-statutory organisations. These provider organisations may be

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<sup>5</sup> National Disability Authority, *Overview of UNCRPD Article 25 in Ireland Health*, (2021), pp. 5-6

<sup>6</sup> Department of Health, (2021), *Disability Capacity Review to 2032 A Review of Disability Social Care Demand and Capacity Requirements up to 2032*, pp. 116



classified as follows, statutory services delivered directly via the HSE, non-statutory organisations funded under Section 38 of the Health Act 2004 and non-statutory organisations funded under Section 39 of the Health Act 2004.<sup>7</sup> Some areas may have a larger distribution of these organisations than others and this may sustain inequity in service provision.

24. As highlighted in *Moving Ahead: From Congregated to Community Living*, Disability Services in Ireland have evolved from the charity model of disability, which is based on similar principles to the medical model. In 1922, when the Irish State assumed responsibility for providing supports for those in need, for example, those with intellectual disabilities, epilepsy, or mental health difficulties, as well as unmarried mothers and their children, the State delegated many aspects of health, social care and education, to religious orders. Numerous charities were set up to provide care and support for people with disabilities. Under this model, services have developed from the ground up where those in the community identified a need and introduced a service in response to that need.
25. There are concerns regarding a lack of co-ordination, organisation and oversight, as well as policy implementation with regard voluntary services in Ireland.<sup>8</sup> This has led to the development of a three-strand health and social care system in Ireland with voluntary (independently owned and governed, not-for-profit), public (fully state-owned and governed, not-for-profit), and private (for-profit) hospitals and other organisations catering for the needs of the population.<sup>9</sup> The Committee heard that this has resulted in patchwork of services, where the organisational structure of these services often reflect a third world structure. The benefits of this ground up service development approach is that it is truly needs led, as it is a response to needs in that community and provides access to people with disabilities within that community. However, this ad hoc service development, lack of organisation,

<sup>7</sup> Trinity College Dublin, Health Research Board, *Moving Ahead: From Congregated to Community Living, Mapping the National Disability Policy Landscape*, pp. 1

<sup>8</sup> *Moving Ahead: From Congregated to Community Living, Mapping the National Disability Policy Landscape*, pp. 1

<sup>9</sup> The Department of Health, *Report of the Independent Review Group established to examine the role of voluntary organisations in publicly funded health and personal social services*, pp. 20

strategic funding and policy response has led to, and maintains inequity in service provision and will impact the progress of UNCRPD implementation.

### **Mainstreaming person-centred disability under Sláintecare**

26. The *Programme for Government: Our Shared Future* commits to a policy of mainstreaming public services for people with disabilities in Ireland. Mainstream health services, include primary care, hospitalisation and rehabilitation are being centralised under a universal single-tier health and social care system, Sláintecare, where everyone should have equitable access to services based on need, and not ability to pay. This centralisation is an opportunity to ensure access for children and adults with disabilities to mainstream therapy services delivered through primary care on an equal basis to everyone else. Mainstreaming disability issues is an integral part of relevant strategies and a key tool for implementation of the UNCRPD.
27. The National Advocacy Service (NAS) highlighted the level of change needed to respond adequately to the unmet need and demand in the system as highlighted in the Review. NAS noted that there is a need for joined up funding and devolved decision-making to communities around cross sectoral disability issues. NAS also highlighted the importance of political drive in realising this level of change as well as reverting to the principles of Sláintecare.

### **Delay in the provision of rights for people with disabilities**

28. Ireland must ratify the Optional Protocol. The Committee call for this ratification and are concerned with the continued delay. The Committee heard from the International Disability Alliance, 10 November 2022, that Ireland is one of only three EU member states not to have ratified the protocol. The Committee are also concerned about the significant delay with the publication of the UNCRPD Implementation Plan.
29. "It is important, from an international level, that we give people who think their rights have been violated under the convention, a recourse outside of the country" Mr Schefer said. Not ratifying the Protocol, Mr Schefer said, had "legal and political"

impacts for those countries taking that decision: “and as with all areas of law, if you leave out the judiciary, something is lacking, and implementation will suffer”<sup>10</sup>.

30. The UNCRPD requires that people with disabilities and their DPOs be consulted on policies that affect them. The Committee are aware that there is a need for clarification, funding and capacity building to enhance DPO development in Ireland. However, in the interim, with the lack of a Government DPO platform, the Committee believe that the DPOs must be funded to provide a cross disability consultation service on health services policy and legislation. This must be considered in tandem with a registration process for DPOs as previously recommended by the Committee.
31. The Committee recognise the need for Government Programmes to consult with individual service users as experts on the service and as per requirements of Article 4 (3) of the Convention.
32. On foot of the establishment of the current Dáil, responsibility for specialist community-based disability services was to transfer from the Department of Health to the Department of Children, Equality, Disability, Integration and Youth. The transfer of functions includes government level responsibility for disability policy development, oversight of specialist Disability Services and budget. The Committee heard from the Minister of State with responsibility for Disability that it was envisioned the transfer would be complete by March 2022. The transfer is still not complete.
33. The Committee are also concerned with the lack of progress across key legislation which will help transform and align Disability Services with the UNCRPD. Legislation includes the non-commencement and delayed reform of enacted legislation, the Mental Health Act 2001, the Disability (Miscellaneous Provisions) Bill 2016, the General Scheme of a Health (Amendment) Bill 2022, the Inspection of Places of Detention Bill 2022, implementation of the Irish Sign Language Act 2017, and a review of the Education for Persons with Special Education Needs Act 2004 and the

<sup>10</sup> Irish Examiner, 30 May 2021, *UN criticises Ireland for failings on disabilities legislation*. Accessed 14/02/2023 at [UN criticises Ireland for failings on disabilities legislation \(irishexaminer.com\)](https://www.irishexaminer.com/UN-criticises-Ireland-for-failings-on-disabilities-legislation)

Disability Act 2005 which predates the UNCRPD.<sup>11</sup> The Committee aware that the Disability Act 2005 needs to be reformed in line with the UNCRPD. This is discussed in more detail in Chapter 3.

34. The NDA highlight continued delays and challenges regarding progress of actions to deliver the National Disability Inclusion Strategy (NDIS) and person-centred disability services;

- a) Action 93 and 94: slow pace of decongregation. No progress included in the December 2021 Traffic Light Report to show how many people moved out of congregated settings in 2021. The update noted that 144 people were expected to move to new homes in the community in 2021, however, it has not been confirmed if this was achieved
- b) Action 73: Department of Health planned evaluation of pilot Local Area Co-ordination projects to support inclusive living in communities did not go ahead
- c) Action 74: Local Authorities did not develop actions at community level to build and sustain disability-competent and welcoming communities

35. There are also significant delays in aligning the delivery of disability schemes and supports to a rights-based disability service including the delay in publication of the *Disability Capacity Review Action Plan*, the *Roadmap for PDS*, Personal Assistance, Personal Budgets, and the decongregation process. The Committee believe that there is need for an 'All of Government' approach with real commitment to implement the UNCRPD and the rights of people with disabilities.

36. The *Disability Capacity Review Action Plan* covering 2022-204 will be instrumental in shaping disability services to meet the unmet need highlighted in the Review and aligning services further with the UNCRPD. The Committee call for the urgent publication of this plan.

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<sup>11</sup> Irish Human Rights and Equality Commission, *Consultation on Terms of Reference and Work Programme for the Joint Oireachtas Committee on Disability Matters Submission by the Irish Human Rights and Equality Commission* (2020), pp. 12-13

37. The Committee are aware that the transfer of functions, along with the appropriate governance, will help ensure that health-funded disability services are progressed to meet obligations under the UNCRPD. The Minister of State with responsibility for Disability told the Committee that the most significant change will be with regard the reporting mechanism for the HSE from one to two-line Ministers under the Department of Children, Equality, Disability, Integration and Youth. The HSE will continue to fund services for Section 38 and Section 39 organisations, and private providers, under the existing service level agreements.
38. The *Report of the Independent Review Group* established to examine the role of voluntary organisations in publicly funded health and personal social services (the Catherine Day Report) highlights that the relationship between the voluntary sector and the HSE has broken down and that it is necessary to find better ways of working together.<sup>12</sup> Dr. Catherine Day also stated that a new start is needed through building a new relationship of mutual trust and respect between parties, as well as State recognition of the role and value of the voluntary sector, and by recognising its separate legal status.<sup>13</sup>
39. The Committee note that the Dialogue Forum with Voluntary Organisations was established in 2019 on foot of the recommendations of the Catherine Day Report to provide a regular platform for dialogue between the State and voluntary providers. However, the Committee believe that the mandate and focus of the Dialogue Forum must be updated to include UNCRPD implementation and implementation of the recommendations of the Catherine Day report. The Dialogue Forum must also consider including DPOs in their Membership. DPOs must be funded accordingly to fulfil this function.
40. There are multiple projects and policies across Departments which are supportive of the rights for people with disabilities. However, a lack of co-ordination and significant

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<sup>12</sup> *Report of the Independent Review Group established to examine the role of voluntary organisations in publicly funded health and personal social services*

<sup>13</sup> Joint Oireachtas Committee on Health, 19 June 2019, *Opening Statement by Dr. Catherine Day, Chair, Independent Review Group, established to examine the role of voluntary organisations in publicly funded health and personal social services*

delay in publishing the UNCRPD Implementation Plan, impacts the delivery of a rights-based approach. Change can only be delivered through the development and implementation of policies rooted in meaningful inclusion and consultation. This will be discussed in more detail across the paragraphs below.

## **Strengthening the National Clinical Programme**

41. The National Clinical Programmes (NCPs) were established in 2010 to achieve three objectives, improve quality, access, and cost effectiveness in the health service.

Over thirty NCPs are established to improve and standardise patient care throughout the HSE Services by bringing together clinical disciplines and enabling them to share innovative solutions to deliver greater benefits to users of the services.<sup>14</sup>

42. The Committee heard how the National Clinical Programme for People with Disabilities, established in 2020, is a transformative programme as it is orientated towards the implementation of the UNCRPD. The programme does not use medical terminology when describing people with disabilities but instead identifies people with disabilities rather than diagnosing them. The HSE established this programme with a clinical design function to design how services should be delivered. The Committee also heard that the programme was designed to have good consultation and representation of other voices and is grounded on identifying the needs of people with disabilities.

43. The HSE highlighted that the programme comprises three service users, four service providers and several different professions, a confidential recipient and the chair is a person with a disability and is independent of the HSE. The model of care being promoted under this programme also involves putting children and families first and seeking to serve them in the community rather than in a specific centralised location.

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<sup>14</sup> Shaw, G. *National clinical programmes in the Republic of Ireland: a qualitative study of acute hospitals (2020)*, Journal of Research in Nursing, 25(5): 421–440.

## Awareness raising and dignity

44. Research highlights that the medical model is applied across many areas of social science and human services, including the therapeutic and educational fields<sup>15</sup> and the Committee heard evidence of its application in health and disability services. The UN Convention's understanding of human rights includes the respect for the inherent dignity, individual autonomy, including the freedom to make one's own choices, and independence of persons.<sup>16</sup>
45. The Committee heard from Catherine Gallagher, 29 September 2022, that a trajectory had begun with the Covid-19 Response where people with disabilities felt they needed to share their private lives to bring about awareness and action. Ms. Gallagher highlighted that this is not a sustainable model of advocacy. People with disabilities have the right to live with privacy, dignity, and discretion. Private lives are further impacted where individuals and parents depend on social media for information and services. The Committee heard that individuals use social media to access peer support and information, hand down accessibility supports when a child has grown out of the support, as well as using crowdfunding platforms to fund accessible supports.
46. State Parties to the UNCRPD are responsible for awareness raising under Article 8 of the Convention. The Committee believe that radical and systematic action is needed from Government so that individuals, parents, and families do not have to fulfil the role of raising awareness and impact their dignity by sharing their stories of a service that does not support their rights. The Government must step in and work with DPOs, individuals with disabilities, disability organisations and service providers to develop a campaign to help raise awareness with the public of the issues that people with disabilities experience. The 'Every Australian Counts' campaign undertaken in Australia is discussed in Chapter 4 in this regard. A campaign on this level is necessary as a cultural shift is needed to support meaningful implementation

<sup>15</sup> Shyman, E. *The Reinforcement of Ableism: Normality, the Medical Model of Disability, and Humanism in Applied Behavior Analysis and ASD*, (2016), *Intellectual and Developmental Disabilities*, 54(5):366-376

<sup>16</sup> National Disability Authority, *Ethical Guidance for Research with People with Disabilities*, Disability Research Series 13, pp. 7



of the UNCRPD as highlighted in the Committees previous report, Ensuring Independent Living and the UNCRPD.

47. The Committee also believe that in tandem, the HSE must develop the relationship with their service users, DPO's, parents and advocates for those with disabilities and develop a rights-based service management and complaints mechanisms for service users to secure timely resolution of service issues.

48. The Office of the United Nations High Commissioner for Human Rights (OHCHR), recommend the development of a national disability awareness raising strategy and/or plan for the implementation of Article 8 which aims at combating stereotypes against persons with disabilities. The media play a central role in upholding the rights of people with disabilities when they are reporting on relevant issues. The OHCHR also recommend that this plan must also include specific measures for how media regulatory authorities can encourage the adoption by mass media and media outlets of human rights for people with disabilities.<sup>17</sup>

49. Article 25 requires health professionals to provide care of the same quality to people with disabilities as to others, including on the basis of free and informed consent. Article 25 continues that this can be enhanced and further supported by raising awareness of the human rights, dignity, autonomy and needs of persons with disabilities through training and the promulgation of ethical standards for public and private health care.<sup>18</sup> The Committee believe that equitable provision of the same quality of care to people with disabilities as to others is only possible by including the adoption and mainstreaming of accessible equipment and practices and inclusive communication as inaccessible communication and equipment, and inflexible appointment-booking have been identified as a significant healthcare barriers to disabled people. These barriers are often overlooked and may not come under the remit of awareness training.

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<sup>17</sup> United Nations, Human Rights Office of the High Commissioner, *SDG-CRPD Resource Pack, Article 8: Illustrative indicators on awareness-raising*

<sup>18</sup> United Nations Convention on the Rights of Persons with Disabilities, Article 25 – Health. Accessed 14/02/2023: [Article 25 – Health | United Nations Enable](#)

50. The Committee continue to hear about the impact of the lack of awareness of human rights across public services and particularly Disability Services and the need for standard disability awareness training. This training must also include invisible disability and chronic illnesses as the Committee heard about the difficulties these individuals face accessing and using services.

51. The Committee also heard about the distress people feel having received a diagnosis of a lifelong or long-term illness for themselves or their children and the impact of the lack of information and advice on services and supports available. Parents of children with disabilities, highlighted the grief they feel as they watch the impact of a lack of access to services and early intervention on their child. Parents also highlighted how this grief can impact how parents and carers engage with the services for a significant period of time.

52. The Committee heard from the National Federation of Voluntary Service Providers (FEDVOL) about the Informing Families Project which is evidence based best practice guidance developed in collaboration with families, service providers and healthcare professionals throughout hospital, community, and disability services to examine the way in which diagnosis is provided to families. The 'Informing Families' website was developed to provide a source of good quality, appropriate, accurate and up to date information to parents at the time of diagnosis. FEDVOL highlights that the national research for the project revealed that over 60% of families did not receive written information when they were informed of their child's disability. Action 70 in the NDIS commits to rolling out the 'Informing Families' guidance nationally.

### **Free and informed consent**

53. As mentioned previously, Article 25 requires health professionals to provide care of the same quality to people with disabilities as to others, including on the basis of free and informed consent.

54. The Assisted Decision-Making (Capacity) (Amendment) Act 2015 is long-awaited legislation interlinked with the reform of the Mental Health Act 2001. Article 12 of the UNCRPD states that State Parties shall recognise that persons with disabilities enjoy

legal capacity on an equal basis with others in all aspects of life. Article 14.1(b) of the UNCRPD states that people should not be deprived of their liberty unlawfully or arbitrarily and that the existence of a disability shall in no case justify a deprivation of liberty.<sup>19</sup>

55. However, the Committee are aware that there are serious concerns that people involuntarily detained under the Mental Health Act 2001 are excluded from the provisions of Assisted Decision-Making (Capacity) (Amendment) Act 2022 and how people who are detained in hospital for mental health treatment will be specifically excluded from legally binding advance healthcare directives which may increase their risk of receiving treatment against their wishes including electro-convulsive therapy and neurosurgery.
56. Throughout its public meetings the Committee were concerned to hear about instances of disregard to individuals free and informed consent in the provision of care. The Committee were concerned to hear that 50% of people with intellectual disability in Ireland who are on antipsychotic medication may not have psychotic symptoms. The Committee also heard that a person with attention deficit hyperactivity disorder (ADHD) could be accessing support and taking medication that is detrimental to their health because they do not know they have ADHD. The Committee believe that this is in direct contravention of Article 15, Freedom from torture and cruel, inhuman, or degrading treatment or punishment.
57. The Committee recommend the Department of Health and the HSE, work with Community Health Organisations (CHOs) and Disability Service Providers to urgently undertake a review of the individuals who may be affected by over-medication and eliminate this practice.
58. Current research highlights significant controversy in the field of Applied Behavioural Analysis (ABA) between the application of humanistic and behaviouristic tenets and

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<sup>19</sup> Mental Health Reform, Opening Statement for Disability Matters Committee 13 October 2022, pp. 3. Accessed 14 February 2023: [\\*main.pdf \(oireachtas.ie\)](#)

evidence about the effectiveness of these interventions remains unclear.<sup>20</sup> The Committee heard that autistic people consider ABA and behavioural interventionist therapies to be medicalised and significantly impact their rights.

59. The Committee are aware that positive behavioural support (PBS) which is reported as being consistent with human rights as documented in the UNCRPD and places a person's behaviour within an ecological context<sup>21</sup> is considered by people with disabilities, activists, and advocates, to be founded on the same underlying approach as ABA. In this regard, there is evidence to suggest that PBS risks the same harms as ABA and there is significant opposition to the use of any of these related behaviourism-based therapies by the autistic community and their representative DPOs.<sup>22</sup>

60. The Committee are aware that in consideration of this issue, the Committee did not hear evidence from ABA/PBS practitioners. However, the lived experience of people with disabilities is a priority of the Committee to build awareness of the issues that people with disabilities face in their daily lives. In response to this lived experience the Committee are aware how behavioural interventionist therapies such as PBS, ABA are medicalised and differ crucially from the principles underlying Speech and Language Therapy (SLT), and Occupational Therapy (OT). Behavioural interventionist therapies are ultimately founded on modifying disabled people's behaviour to meet goals decided by others; often to conform more closely with neurotypical communication, behaviour and/or norms and therefore the Committee believe cannot uphold the UNCRPD principles of autonomy, dignity, right to identity and freedom from non-consensual or degrading treatment.

<sup>20</sup> Rodgers, M., Simmonds, M., Marshall, D., Hodgson, R., Stewart, L. A., Rai, D., Wright, K., Ben-Itzhak, E., Eikeseth, S., Eldevik, S., Kovshoff, H., Magiati, I., Osborne, L. A., Reed, P., Vivanti, G., Zachor, D., & Couteur, A. L. (2021). *Intensive behavioural interventions based on applied behaviour analysis for young children with autism: An international collaborative individual participant data meta-analysis*. *Autism*, 25(4), 1137–1153. <https://doi.org/10.1177/1362361320985680>

<sup>21</sup> Chan, J. & French, P. & Webber, L. (2011). *Positive behavioural support and the UNCRPD*. *International Journal of Positive Behavioural Support*. 1

<sup>22</sup> Therapist Neurodiversity Collective, *Why not Positive Behavior Support (PBS), Positive Behavioral Interventions and Supports (PBIS), or Positive Reinforcement?* Accessed 14 February 2023: [Positive Behavior Support \(PBS\) | Therapist Neurodiversity Collective \(therapistndc.org\)](https://therapistndc.org/)

61. The Committee support AsIAM's call for much greater regulation so that services can deliver rights-based supports. The Committee agree that there is a need for State Bodies to work with autistic people and their representative organisations to develop ways to support autistic people that are positive and effective and in line with the UNCRPD.

62. The Autistic Paddies highlighted recommendations for ensuring rights-based services for autistic people including the need for a review of diagnostic and post-diagnostic service provision for autistic adults, routine autism screening of adults with mental health or learning disabilities and development of additional care pathways. The Autistic Paddies also highlighted medicalisation regarding language and awareness, particularly with regard to the Autism Spectrum Disorder Bill 2017 in that it refers to autistic people as being disordered which is very dehumanising. This Bill also aims to develop and implement an Autism Spectrum Disorder Strategy. The Committee recommend that the Joint Committee on Children, Equality, Disability, Integration and Youth ensure meaningful consultation with autistic individuals and DPOs in their scrutiny of this bill in line with the social and human rights model of disability. This highlights the importance of consulting with people with disabilities at the beginning of all policy and legislation processes.

63. The Committee believe that, as recommended by the OHCHR, that State Parties must ensure the repeal all legal provisions that legitimise non-consensual psychiatric treatment on the grounds of perceived or actual impairment and establish a monitoring mechanism to ensure that persons with disabilities are not subjected to forced treatment and have access to the same range, quality and standard of health care on an equal basis with others.<sup>23</sup> Further, there is a need to ensure safeguards, including advocacy, legal and all other necessary assistance, to protect the right to free and informed consent of all persons with disabilities, regardless of their impairment and to ensure that the rights of all persons with disabilities, including individuals with mental health conditions, are equally protected under all applicable existing and future legislation. The Committee believe this is important to ensure

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<sup>23</sup> United Nations, Human Rights Office of the High Commissioner, *SDG-CRPD Resource Pack, Article 12: Illustrative indicators on equal recognition before the law*

legacy issues of inequitable treatment of people with psychosocial disabilities are brought into compliance with the CRPD.

64.NAS undertake a huge amount of work with regard free and informed consent and upholding a person's fundamental right to make decisions for themselves. NAS highlighted that they continue to encounter poor practice regarding consent matters in healthcare settings, social care services and financial institutions.

65.NAS informed the Committee that during the Covid-19 Response and roll out of the Covid vaccination programme, there was a prevalence of next-of-kin decision-making which sought consent from third parties regarding people with disabilities. NAS stated that there is no legal basis for next-of-kin decision-making in Ireland, except under legal instruments such as ward of court or enduring power of attorney. NAS also highlighted that 'Do Not Attempt Resuscitation Orders', where individuals' own wishes are not being sought should they be facing end-of-life or emergency decisions. Individuals' decisions around treatment choices as to whether they should be accessing healthcare services are often ignored in preference to seeking families' wishes as to how they want their loved one to be cared for.

66.The Decision Support Service (DSS) also highlighted this as they noted that there is a widespread but incorrect belief that an adult's closest family member or next-of-kin is entitled to make decisions on their behalf if the adult lacks decision-making capacity. The DSS stated that this is not the case outside of a formal legal arrangement, and it will be important that this misunderstanding is addressed when it comes to the Assisted Decision-Making (Capacity) (Amendment) Act 2022. The Act provides a valuable opportunity for a person's family member to step into one of the formal roles for assisted decision making and allows a secure right-based model with better protections to be adopted for all concerned.

67.NAS also highlighted that the issue of free and informed consent is impacted by the HSE's consent policy which is not often understood or is inconsistently implemented across many divisions of healthcare services and therefore impacts a person's rights.

68. The Committee agree with NAS that the work undertaken by the HSE Human Rights and Equality Office must be continued and funded to address the issue of free and informed consent in all sectors, as well as standard roll out and training on the HSEs Consent Policy in line with the Assisted Decision-Making (Capacity) (Amendment) Act 2022.

### **Seclusion, restraint and safeguarding**

69. In 2021, the Mental Health Commission (MHC) published their report *The Use of Restrictive Practices in Approved Centres; Seclusion, Mechanical Restraint and Physical Restraint, Activity Report 2020*, which highlights the use of restrictive practices across 66 inpatient mental health centres in Ireland. This report shows that there were 5,830 episodes of restrictive practices reported to the MHC in 2020, with 1,880 people being secluded and/or restrained during that time. Physical restraint was the most frequently used restrictive intervention.<sup>24</sup>

70. The Director of Regulation for the MHC highlighted that there is an overall reduction in the use of restrictive practices in 2020. The MHC state there is no evidence of a therapeutic benefit associated with the use of seclusion, mechanical restraint or physical restraint, and they should never be regarded as a therapeutic practice.<sup>25</sup> In this regard, the MHC strongly advocates for the use of de-escalation measures over restrictive practices and for staff to be appropriately trained in de-escalation and in clinical risk management.

71. Safeguarding Ireland notes that safeguarding means living safely, free from abuse or neglect, where people's choices are heard and respected and where action is needed to make sure that nobody experiences abuse or neglect, particularly those who are vulnerable.<sup>26</sup> Safeguarding Ireland also notes that the protection and

<sup>24</sup> Mental Health Commission, 30 December 2021, Statement on launch of report, *1,880 people were restrained or secluded across mental health services last year*. Accessed 14 February 2023:

[1,880 people were restrained or secluded across mental health services last year | Mental Health Commission \(mhcirl.ie\)](https://www.mhcirl.ie/1,880-people-were-restrained-or-secluded-across-mental-health-services-last-year)

<sup>25</sup> Mental Health Commission, 30 December 2021, Statement on launch of report, *1,880 people were restrained or secluded across mental health services last year*. *Mental Health Commission, No evidence of a therapeutic benefit associated with restrictive practices*. Accessed 14 February 2023: [Restrictive Practices 2020 statement FINAL.pdf \(mhcirl.ie\)](https://www.mhcirl.ie/Restrictive-Practices-2020-statement-FINAL.pdf)

<sup>26</sup> Safeguarding Ireland, *What is Safeguarding?* Accessed 14 February 2023: [Safeguarding - Safeguarding Ireland](https://www.safeguardingireland.ie/)



promotion of human rights for all will ensure people are enabled to participate in their communities, maximise their independence and help prevent them from being abused, exploited and/or neglected.<sup>27</sup>

72. The new 2019 National Standards for Adult Safeguarding, developed by HIQA and the Mental Health Commission, provide a framework for best practice in safeguarding adults in health and social care services in Ireland. These standards recognise that any adult may be at risk of harm as a result of circumstances and or a condition and may need help to protect themselves at any point in their lives.

73. However, HIQA have reported serious concerns regarding safeguarding in certain centres for people with disabilities along with ongoing concerns about the HSE's ability to sustain effective governance and oversight of designated centres for people with disabilities in certain CHOs in the area of safeguarding. In these cases, HIQA has recommended service providers to address poor oversight and governance arrangements at local, regional, and national level and improve its assurance mechanisms at regional and national levels to ensure that safeguarding arrangements to protect residents from the risk of harm are effective. The Committee are concerned that in HSE designated centres serious safeguarding incidents are occurring and not being appropriately escalated to the Chief Inspector as required under the HIQA regulations nor are appropriate arrangements being put in place in response to the safeguarding incidents.<sup>28</sup>

74. The Committee were concerned to hear from the HSE about disciplinary processes arising from HIQA reports which have identified incidents of harm in residential care settings. The Committee believe that an urgent solution must be developed, ensuring due process, so that staff under investigation are not allowed to continue *in situ* with individuals who are vulnerable.

75. HIQA told the Committee, 31 March 2022, that there was a need for changes to the legislative framework to better support people who may be vulnerable. This would

<sup>27</sup> Safeguarding Ireland, *Submission on Draft Initial State Report Under the United Nations Convention on the Rights of People with Disabilities*, pp. 2.

<sup>28</sup> HIQA, *Overview report of governance and safeguarding in HSE designated centres for people with disabilities in Donegal in January 2022*, pp. 15

include reform of the Health Act 2007 and 2013 regulations made under the Act. HIQA also noted that they continue to campaign for the introduction of strong and effective adult safeguarding legislation to ensure the most vulnerable people in our communities are protected and that placing adult safeguarding on a statutory footing acknowledges the State's commitment to adults at risk and the duty of civil society to adopt a zero-tolerance approach to adult abuse. However, ensuring people with disabilities are free from exploitation, violence and abuse can only be achieved when all parties understand and exercise their responsibilities. The primary responsibility for protecting people with disabilities in designated centres rests with providers, who must ensure their staff can recognise and report any suspicions of abuse and that residents are empowered to do the same. When suspicions are reported, it is essential that providers have measures in place to prioritise the protections of residents and to investigate these allegations.

76. At this meeting Sage Advocacy stated that abuse and neglect of vulnerable adults is significantly under-reported in Ireland due to a lack of public awareness of what constitutes abuse, cultural issues and a lack of comprehensive policy and legal safeguards to prevent the abuse of adults at risk and to protect them from abuse.

77. HIQA further noted that there is a higher risk of organisational abuse in congregated settings than in community-based houses, including examples of residents abusing other residents but also of sustained organisational abuse where the provider has failed adequately to protect residents and meet their needs. Residents who live in congregated or campus-based settings often experience inequalities in the quality and safety of their services, control over their own lives and the ability to exercise their rights and choices independently.

78. In 2017 the Government approved the Department of Health's development of a national policy on adult safeguarding in the health sector, together with such legislation as may be required to underpin it.<sup>29</sup> The Department of Health noted at the Joint Committee on Health's public meeting on the 23 November 2022 that the

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<sup>29</sup> Department of Health (2020), *Evidence review to inform development of a national policy on adult safeguarding in the health and social care sector*, pp. 1

Department is at an advanced stage of development with regard to the safeguarding policy and they expected to go to public consultation shortly on it along with internal review within the Department before the end of the year.

79. The Health (Adult Safeguarding) Bill 2017 will inform a national health sector policy on safeguarding vulnerable or at-risk adults in the health sector by establishing the National Adult Safeguarding Authority and requiring certain persons to make reports to the National Adult Safeguarding Authority in respect of adults at risk of abuse or harm in certain circumstances.

80. The Committee do not accept the Government's inaction, where on the one hand there is significant delay with transitioning people from congregated settings to community settings with appropriate supports, while on the other, appropriate action is not taken to ensure the rights of these individuals are upheld and that they can live lives in these settings in the interim, that are free from exploitation, violence, and abuse. The urgency of ensuring human rights to the estimated 6,000 persons with disabilities living in HSE-designated centres of ten or less residents which are therefore not classified as congregated settings<sup>30</sup> and approximately 2,000 living in congregated settings of ten or more, must be considered under Government crisis talks as highlighted further under Chapter 2 and 3 below.

81. Safeguarding legislation must be introduced urgently and aligned with the UNCPRD. Further, legislation and policy must be strengthened to ensure that residents are empowered to recognise and report any suspicions of abuse, staff can do the same, and measures in place so that when suspicions are reported, providers must prioritise the protections of residents and to investigate these allegations. In the interim, the Department of Health and the HSE must introduce measures to strengthen oversight, governance, and assurance arrangements to ensure that safeguarding arrangements to protect residents from the risk of harm are effective.

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<sup>30</sup> Disability Federation of Ireland & Citizens Information Board, *The Right Home: the Housing Needs of People with Disabilities A Social Policy Report by the Citizens Information Board and the Disability Federation of Ireland*, pp. 27

82.The Autistic Paddies stated, 04 November 2021, that;

‘Isolation, seclusion, and restraint of disabled people are employed by schools and care services across Ireland as standard practice and can cause extreme trauma and have long-term mental health impacts. These practices are disproportionately used against intellectually disabled, neurodivergent and ethnic minority children.’

83.The Committee are aware, as highlighted by Inclusion Ireland in their report ‘*Shining a light on seclusion and restraint in schools in Ireland: The experience of children with disabilities and their families*’ that there are rules on seclusion and restraint where children are in services run by the State. However, there are no rules on how people working in schools should use seclusion and restraint on children. Inclusion Ireland further highlight in this report that the Department of Education has been repeatedly asked to issue guidelines to schools on the issue of restraint and seclusion. Inclusion Irelands report notes that the National Council for Special Education (NCSE) highlighted the seriousness of the situation around supporting children with “challenging behaviours in school” and that these students require specialist supports but are being supported by SNA staff without specialist training in behaviour management and called for “immediate action”, warning of “very serious consequences for students and staff”.

84.Of further concern to the Committee, as highlighted by Inclusion Ireland in their report ‘*Shining a light on seclusion and restraint in schools in Ireland*’, is that there is currently no obligation for parents or guardians to be informed about the use of restraint or seclusion on their child in school. There is need for an obligation to inform guardians to be included in these guidelines along with mandatory reporting to guardians to ensure that they have the information they need to safeguard the child's wellbeing and use the reporting mechanism in cases where it is necessary.

85.The Autistic Paddies also highlighted to the Committee that service providers need to consider the impact of the environment when an autistic child or individual is in distress and not try and change the individual through seclusion and restraint. The Committee note the application of seclusion and restraint in response to autistic

children, or children with disabilities behaviour often reflects a medicalised response. A social model response could consider the school environment, as highlighted by AsIAM in their *Autism Guidance for Teachers*, as the learning experience is more challenging for autistic students, for example the sensory environment, transferability of skills from subject to subject or lack of direct or clear instruction. Sometimes autistic students might need more learning reinforcement to cement the concepts they are learning.<sup>31</sup>

86. The Department of Education and schools must ensure compliance with the Children First Act 2015 and practice obligations as set out in *Children First: National Guidance for the Protection and Welfare of Children 2017*. The Department of Education must also develop specific policies and procedures on how to create a safe environment to prevent deliberate harm or abuse to the children using their services. Each school must have a Designated Liaison Person (DLP) in place for dealing with child protection concerns, with responsibility for ensuring that the standard reporting procedure is followed, so that suspected child protection concerns are referred promptly to the designated person in TUSLA, the Child and Family Agency or in the event of an emergency and the unavailability of TUSLA, to An Garda Síochána.<sup>32</sup>

87. The Department of Education has not yet published guidance on the use of seclusion and restraint in schools. The Committee recommend that the Department issue this guidance immediately, and that this guidance should include an obligation that all uses of restraint or seclusion in schools be reported to the student's guardians as soon as possible. Training to support teachers and Special Needs Assistants (SNAs) on how to appropriately deal with behavioural issues is required. A standard reporting mechanism must also be introduced where parents, children or young adults can report concerns regarding the inappropriate use of seclusion or restraint in schools to the DLP, who can refer to TUSLA where necessary. This must include mandatory reporting to guardians to ensure that they have the information

<sup>31</sup> ASIAM, *Autism Guidance for Teachers*, Accessed 14 February 2023: [Autism Guidance for Teachers - AsIAM.ie - Irish National Autism Charity](#)

<sup>32</sup> Department of Education, *Child Protection in schools - information for parents and guardians*. Accessed 14 February 2023: [gov.ie - Child Protection in schools - information for parents and guardians \(www.gov.ie\)](#)

they need to safeguard the child's wellbeing and use the reporting mechanism in cases where it is necessary.

### **Translating human rights into day-to-day service delivery**

88.NAS have an important role in advocacy work with those who are most marginalised, individuals residing in congregated settings, wards of court and those whose voices often do not get heard in decision-making forums. NAS supports people's access to justice, ensuring equal opportunity and fair process, ensuring that people understand and have support. NAS told the Committee that to ensure rights for people with disabilities, it is essential that people's voices are heard, and they have the opportunity to make decisions for themselves. However, at a very basic level, rights are not being respected in day-to-day decision-making.

89.The Committee understand that there are multiple levels where change is needed to deliver rights for people with disabilities particularly in relation to services. Firstly, change is required in social and health care services, where care is medicalised and where there is a lack of free and informed consent decision making. Secondly, there is a cultural shift and strengthening of rights based person-centred planning needed in all services, particularly in congregated settings or services that continue to reflect medical models of disability, so that the day-to-day decision-making of people with disabilities can be respected. Thirdly, as highlighted in the Committees report, *Ensuring Independent Living and the UNCRPD*, a cultural shift and disability awareness raising is needed as a standard across all public bodies in line with implementation of the UNCRPD and the Assisted Decision-Making (Capacity) (Amendment) Act 2015 where people with disabilities are presumed to have capacity and be capable of contributing to society.

90.Finally, noting the concerns raised by Disabled Women Ireland and others that any current allocation of services which can be means tested against households, rather than determined on the basis of individual need, may be a significant contributory factor to the disproportionate levels of coercive control and increased vulnerability to abuse experienced by people with disabilities. In this regard the Committee

recommend that disability supports, and rehabilitation services should be administered on an individual needs-led basis not tied to household circumstance.

91. HIQAs *Guidance on a Human Rights-based Approach in Health and Social Care Services* describes key human rights as set out in the European Convention on Human Rights Act (ECHR) 2003 and the UNCRPD which are relevant to health and social care. HIQA highlight that health and social care practitioners, and organisations can find it difficult to translate human rights principles into day-to-day practice and service delivery. The Committee agree with HIQA that by understanding the social and relational dimension of disability, including, the barriers faced by people with disabilities, human rights for people with disabilities can begin to be translated into day-to-day practice and service provision.<sup>33</sup>

92. The 2018 National Framework for Person Centred Planning in Services for People with Disabilities is intended to inform and guide how person-centred planning (PCP) is implemented consistently across services in Ireland. The Committee are concerned that a lack of adequate monitoring of implementation of person-centred planning in line with the UNCRPD means that the rights of people with disabilities are being impacted, with regard daily decision making but also meaningful choice about where and with whom to live.

93. The Committee believe that the *National Framework for Person-Centred Planning in Services for Persons with a Disability* must be updated to ensure that an individual's will, and preference can be assessed. Accountability must be developed by establishing formal monitoring processes for PCP implementation aligned with the UNCRPD. This monitoring procedure must include individuals whose will, and preference is being assessed, family, friends and advocates, and other relevant parties supporting the individual. It is crucial that this process is strengthened to determine and record how people with disabilities are being provided choice aligned with the UNCRPD and with an individual's will and preference.

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<sup>33</sup> HIQA, *Guidance on a Human Rights-based Approach in Health and Social Care Services* (2019)



94. The Committee believe that staff working in disability services must be supported with appropriate education and training programmes, as highlighted in the HSE National Service Plan 2022. This training must comply with person-centred planning, the Assisted Decision-Making (Capacity) (Amendment) Act 2022, the HSE National Consent Policy, Part 3 of the Disability Act 2005, the Irish Human Rights and Equality Act 2014 (Public Sector Duty) and other human rights and equality policy and legislation.<sup>34</sup> This training must also include how staff can fully comply with HIQA Regulation 9: Residents' Rights and ensure positive outcomes for residents by supporting the residents to make their own decisions about their lives and in a way that maximises their autonomy and independence. See Chapter 2 for further discussion on this.

## Priority recommendations

**1.1 Transfer of Functions:** The Government must ensure that the transfer of functions is completed urgently to support a high level of collaboration across Departments and Local Government to progress all outstanding policies and implementation plans to ensure compliance with the UNCRPD.

**1.2 Review of Legislation:** The Government must undertake a review and provide a timeline for alignment of all relevant legislation with the UNCRPD that includes an intersectional approach and repeal all legal provisions that legitimise non-consensual psychiatric treatment on the grounds of perceived or actual impairment and establish a monitoring mechanism to ensure that persons with disabilities are not subjected to forced treatment and have access to the same range, quality and standard of health care on an equal basis with others.

**1.3. Safeguarding legislation:** Safeguarding legislation must be introduced urgently and aligned with the UNCRPD and developed in robust consultation with DPOs and other priority stakeholders as identified under Article 4(3) of the Convention to ensure adequate stakeholder engagement from as early in the process as possible. In the interim the Department of Children, Disability, Equality, Integration and Youth, the Department of Health and the HSE must introduce interim measures to strengthen oversight, governance and assurance arrangements to

<sup>34</sup> [HSE National Service Plan 2022](#), pp. 111

ensure that safeguarding arrangements to protect residents from the risk of harm are effective.

**1.4 UNCRPD:** The Department of Children, Equality, Disability, Integration and Youth must publish the UNCRPD Implementation Plan and ratify the Optional Protocol to the UNCRPD and strengthen the process where all public bodies are mandated to provide regular updates to the NDA under the UNCRPD Implementation Plan to facilitate reporting against each action of the implementation plan.

**1.5 Disability Capacity Review Action Plan:** The Department of Health must publish the Disability Capacity Review Action Plan immediately and ensure implementation of the Review recommendations.

**1.6. Dialogue Forum:** The Department of Health must update the mandate and focus of the Dialogue Forum to include UNCRPD implementation and Person-Centred Planning, as well as implementation of the recommendations of the Catherine Day report. The Dialogue Forum must also include DPOs in their Membership. DPOs must be funded accordingly to fulfil this function.

**1.7. National Disability Awareness Raising Strategy:** The Government must develop a national disability awareness raising strategy for the implementation of Article 8 which aims at combating stereotypes against persons with disabilities and under this strategy;

- a) include a plan for the provision of advocacy supports to support meaningful awareness raising
- b) introduce a plan to include specific measures for how media regulatory authorities can encourage the adoption by mass media and media outlets of human rights for people with disabilities
- a) support the development of a centralised service for people with disabilities, across all groups of disabilities, including chronic and rare disability, where appropriate advice and information on supports and services is made available

**1.8 Guidance:** The Department of Education must issue guidance on seclusion and restraint immediately, in line with the UNCRPD and rights-based approach, and that

this guidance should include an obligation that all uses of restraint or seclusion in schools be reported to the student's guardians as soon as possible.

**1.9 DPO's:** The Department of Children, Equality, Disability, Integration and Youth must develop a plan and funding for the DPOs to provide a cross disability consultation service on policy and legislation that affects people with disabilities.

**1.10 Over Medication:** The Department of Health and the HSE, work with CHOs and Disability Service Providers to urgently undertake a review of the individuals that are affected by over-medication and eliminate this practice. This review must include children under CAMHS (Please see Chapter 3).

**1.11 Rights-based provision of care in autism:** The Department of Children, Equality, Disability, Integration and Youth and the Department of Health must examine a rights-based provision of care in autism in consultation with autistic people and including consideration of ABA/PBS and other behavioural interventionist therapies in Ireland and whether regulation is needed and to further develop a standard to ensure this intervention is rights based and in line with the UNCRPD.

**1.12 Mainstreaming of accessible equipment and practices:** The Department of Children, Equality, Disability, Integration and Youth include measures to ensure the adoption and mainstreaming of accessible equipment and practices, and inclusive communication under Article 25 in the UNCRPD Implementation Plan and specifically target healthcare barriers such as inaccessible communication and equipment and inflexible appointment-booking, and ensure these barriers, and any others, are reflected in the remit for standard disability awareness training. The Department must consult with people with disabilities as part of this.

## Chapter 2: Community-based health services and support

### Introduction

95. Good health and wellbeing are crucial for participation and active engagement in society. Similarly, social inclusion supports physical and mental health and resilience. The TTMO model envisions a wider person-centred approach for people with disabilities. People with disabilities are not only more susceptible to worsening health but also are more frequently in need of healthcare services. Therefore, they can be more vulnerable than others to the impact of low quality or inaccessible health care. Access to diagnosis and treatment in the community was highlighted as crucial to also support witnesses to return to work and participate fully in society.
96. The specialist community-based disability services function for c.56,000 people, as noted earlier, is to transfer to the Minister for Children, Equality, Disability, Integration and Youth and Minister of State with responsibility for Disability. Responsibility for disability equality policy and specialist community-based disability services will be centralised in a single Department for the first time. The HSE will retain responsibility for delivering the services. It is envisaged that centralisation will strengthen strategic policy development, including implementation of the UNCRPD. However, the transfer has still not been completed.<sup>35</sup>
97. Within specialist community-based disability services, two thirds of these services, such as residential and respite care and home support, are provided on behalf of the State by voluntary sector organisations, Section 38 and Section 39 organisations, referred to as Disability Service Providers.
98. Adult services include basic health services as well as assessment, rehabilitation, income maintenance, community care and residential care provided by the HSE and voluntary organisations. HSE Administrative Areas have appointed Disability Services Managers to co-ordinate the delivery of services to people with disabilities.

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<sup>35</sup> Dáil Éireann debate - 10 February 2022, *Health (Miscellaneous Provisions) Bill 2022: Second Stage*. Accessed 14 February 2023: [Health \(Miscellaneous Provisions\) Bill 2022: Second Stage – Dáil Éireann \(33rd Dáil\) – Thursday, 10 Feb 2022 – Houses of the Oireachtas](#)

Disability therapists working with adults are usually attached to a particular Disability Service Provider.

99.Children's services are being reorganised into area-based Children's Disability Network Teams (CDNTs) under the *Progressing Disability Services for Children and Young People* policy. Therapists are recruited from the same pool across the health service, and there are significant recruitment and retention issues driving the increase of waiting lists and the inability of Disability Services to provide equitable service in line with demand.

100.The Review highlights a significant level of unmet need for Disability Services up to 2032, which was re-enforced by people with disabilities, DPOs, Disability Service Providers and parents of children with disabilities who attended the Committee's public meetings. The Review estimates the scale of the current need for HSE-funded disability services, and how the need for services is likely to evolve over the years to 2032.<sup>36</sup> The Review estimates to address unmet need, alongside demographic change, requires current disability spending in 2032 to rise by €550 million to €1,000 million.<sup>37</sup> The *Disability Capacity Review Action Plan* mapping out how to progress this work to 2025 for specialist community-based disability services continues to be delayed.

101.The Review highlights a significant gap in service provision for adults with disabilities in highlighting that, with the exception of public health nursing and community support workers, therapy services in the community are predominantly focused on the under 5s and over 65s, with many in the 18-64 age group routinely unable to access therapy services.<sup>38</sup>

102.The *Report on the Demonstration Project 2019 Supporting the Implementation of the National Framework for Person-Centred Planning in Services for Persons with a Disability* highlights that an individual and their families can find the transition from

<sup>36</sup> Disability Capacity Review to 2032

<sup>37</sup> Disability Capacity Review to 2032 pp. 24

<sup>38</sup> Disability Capacity Review to 2032, pp. 105

children's services to adult services very difficult. This can be exacerbated by the lack of clinical supports in adult services. This report also highlights that often the working relationships between clinicians and staff in adult services are not established in the way they are in children's services. In some circumstances in adult services, there is little understanding of the roles of the clinician.<sup>39</sup>

103. Throughout public meetings, the Committee heard about the impact of these gaps in Disability Services, particularly at transition points where Government bodies need to work together to provide a service. Currently 64% of the budget is allocated to residential care which may sustain the medical approach to disability where people are placed in congregated or segregated residential settings. The Committee continue to recommend the need for redistribution of the budget in line with UNCRPD and for more funding to be invested in community-based services.

### **Wider person-centred support plan of community inclusion**

104. The TTMO model envisions a wider person-centred approach for people with disabilities to be supported to live independently, in line with their will and preference, in dispersed forms of housing in communities, having the same entitlement to mainstream community health and social services as any other citizen, access to primary care teams, as well as access to specialised services and hospital services based on an individual assessment.

105. It is concerning that there is no national plan outlining how specialist community-based disability services will be delivered across all sectors, including reporting requirements on the transfer of functions. It is vital to ensure meaningful collaboration to support all parties to transition to the rights-based model of care as proposed by the TTMO report and supported by the implementation of the UNCRPD. There is a significant lack of capital assistance funding, supports and infrastructure in communities, including rehabilitative supports, to support people with disabilities live independently within a rights-based model of care in the community. The Committee

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<sup>39</sup> HSE, New Directions, *Supporting the Implementation of the National Framework for Person-Centred Planning in Services for Persons with a Disability A Report on the Demonstration Project 2019*, pp. 28. Accessed 14 February 2023: [report-of-demonstration-project-2019.pdf \(hse.ie\)](https://www.hse.ie/eng/health/mental_health/mental_health_services/mental_health_services_report_2019.pdf)

recommend that the UNCRPD Implementation Plan specifically target and progress collaboration, action and funding on delivery of specialist community-based disability services and supports for people with disabilities.

106. The Committee believe that in tandem with a wider person-centred support plan for community inclusion, there must be a renewed and strengthened commitment to people with disabilities under the integration of SláinteCare to support mainstream access to services.

107. With regard to the inclusion of people with disabilities in local communities, the Committee's report *Ensuring Independent Living and the UNCRPD* highlights the need for UNCRPD implementation teams at both Local Authority and CHO Area level. The Committee's recent report on *Participation of people with Disabilities in Political, Cultural, Community and Public Life* further highlights the important role of Local Authorities and Local Area Coordination in terms of UNCRPD implementation. The UNCRPD Implementation Plan will provide the framework for the role of public bodies, including Local Authorities, in implementing UNCRPD. Currently, implementation of the NDIS is monitored by a Steering Group which does not include Local Government representation. The Committee recommend that the UNCRPD Implementation Plan target action and progress at Local Authority level and that the steering group consider including Local Authority representation.

108. The Committee are aware that delivering a rights-based approach to inclusion in the community with appropriate supports, as highlighted by the ERSI in their report *Specialist Support for Persons with Disabilities Living in the Community*, would mean that services are not rationed through the use of waiting lists, but rather through the needs-assessment process.

109. The *HSE National Service Plan 2022* states that the reform of Disability Services will include the implementation of a standardised assessment tool that enables each person's support to be based on their individual assessed needs. As highlighted in, *A Human Rights Approach to Disability Assessment*, the UN Committee has expressed concerns about assessments that focus on individual impairment rather than on



interactions with social environments and the barriers faced by persons with disabilities. The HSE must produce updates on implementation and progress on their service plans. Please see Chapter 3, Developing early intervention pathways, for further discussion on assessment and the Disability Act 2005.

110. Linehan et al (2014) highlight in their report *Moving Ahead - Mapping the National Disability Policy Landscape* that the transition to a more personalised model of supports for people with intellectual disabilities in Ireland has been characterised as a 'slow and tentative drift', with agencies at many different stages of this journey. Linehan et al (2014) further state that 'in the absence of formal monitoring processes for implementing this transition, it is reasonable to raise concerns about how effective the process will be in meeting national and international obligations and expectations.'<sup>40</sup>

111. The Committee heard how the Covid-19 pandemic has added urgency to implementation of policies across Disability Services. A significant proportion of patients admitted to ICU with Covid-19 who are anticipated to have significant complex impairments requiring specialist rehabilitation consultant and multidisciplinary team input may require transfer to specialist rehabilitation units. Many other patients with milder symptoms may also need access to rehabilitation in the community.

112. The HSE has developed an interim *Model of Care for Long COVID* since September 2021. This model aims to build on existing service provision, in addition to supporting new services and supports across a number of different health care settings including acute hospitals, general practice and community services. There are concerns about the ability of the Health Services to manage the impact of Long Covid based on the previous poor management of chronic illness.<sup>41</sup>

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<sup>40</sup> Linehan, C. O'Doherty, S. Tatlow-Golden, M. Craig, S. Kerr, M. Lynch, C. McConkey, R. and Staines, A. (2014). *Mapping the National Disability Policy Landscape*. School of Social Work, Trinity College Dublin, Ireland. pp. 31

<sup>41</sup> Timoney, A. Oireachtas Library & Research Service, *Long Covid: Definition, incidence and healthcare issues*

113. There has been a national effort between the Department of Health and Disability Service Providers to bring about a fundamental change in Disability Services in Ireland through the *Transforming Lives Programme* (2018). This programme was established to support person-centred disability services and aims to improve the quality of life for people with disabilities in Ireland. The HSE note that this programme of reform is grounded in a move from organisation-led services to community and individualised supports, which are focussed on the achievement of meaningful personal outcomes.<sup>42</sup> The *Disability Action Plan Framework* also notes that Transforming Lives aims to support individuals to live lives of their choosing, through supports that are tailored to their needs, built on the principles and values of the UNCRPD especially Article 19.

114. Individual supports may include assistance provided by others, whether in the form of personal care, communication, or advocacy support, learning support, therapeutic interventions, aids and equipment, adaptations to the physical environment, amongst others.<sup>43</sup>

115. A *National Framework for Person-Centred Planning in Services for Persons with a Disability* developed in 2018, is relevant for all services for persons with disabilities, including day, residential, home and community.<sup>44</sup> A demonstration project was established in 2019 to support a small number of organisations to implement the framework. The first step of implementation was to evaluate current person-centred planning practice against the framework. The *Report on the Demonstration Project 2019 Supporting the Implementation of the National Framework for Person-Centred Planning in Services for Persons with a Disability* recognised that organisations, and the services within them, are at different stages when it comes to person-centred planning. During the demonstration project, individuals and organisations raised several concerns and challenges in relation to implementation. These challenges

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<sup>42</sup> HSE, New Directions, *A National Framework for Person-Centred Planning in Services for Persons with a Disability*, pp. 6

<sup>43</sup> National Federation of Voluntary Bodies Providing Services to People with Intellectual Disability, *Next Steps Project Vision Statement Individualised Supports for an Ordinary Life*

<sup>44</sup> *A National Framework for Person-Centred Planning in Services for Persons with a Disability*

present significant barriers to the delivery of quality services and supports to persons with disabilities, and to the implementation of *New Directions* and include;

- Equity of service provision
- Institutional practices
- Staff learning and development
- Provision of supports (Staff ratios, Homecare packages)
- Leadership and working relationships (the local leader, relationships between day and residential services, involving families)
- Important to and important for the person (the separation of personalised care and support plans from person-centred plans, multi-disciplinary supports, independent advocacy supports, respite facilities, the management of medication)
- Accessible environments (transport, Accessible bathroom facilities, the physical environment, the provision of accessible information)
- Independent planning
- Circles of Support
- Data protection<sup>45</sup>

116. The NDA note in their report on *Person Centred Planning for People in Ireland who have Disabilities* that;

‘PCP is a way of discovering how a person wants to live their life and what is required to make that possible. PCP has its roots in the normalisation and independent living movements. It is grounded in a social model of disability and a strengths-based approach.’

117. Under this model, PCP supports should enable a person to make informed choices about how they want to live their life, now and in the future.<sup>46</sup> In this way the PCP model aligns with the vision of the UNCRPD, enabling a transition of services from the medical approach to the social or human rights-based model of disability.

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<sup>45</sup> *Supporting the Implementation of the National Framework for Person-Centred Planning in Services for Persons with a Disability A Report on the Demonstration Project 2019*, pp. 24-31

<sup>46</sup> *Supporting the Implementation of the National Framework for Person-Centred Planning in Services for Persons with a Disability*, pp. 5

118. The NDA further highlight that PCP has the potential to be an instrument of real change, by bringing about a greater degree of choice and better standard of living for people with disabilities in Ireland. However, the NDA indicate a lack of progress with PCP, as they note in their report that any monitoring and evaluation exercise in relation to PCP must be to establish whether its overall aim of good planning is leading to positive changes. To this end, the NDA note that there are two key aspects of PCP which require monitoring and evaluation;

- a) plans (because they are the stated means through which person-centred planning hopes to achieve this aim).
- b) programmes, processes and supporting structures (because these are the means of generating good, workable person-centred plans, and putting them into action).<sup>47</sup>

119. In the *Independent assessment of the implementation of the National Disability Inclusion Strategy* under the theme of joined up policies and public services, the NDA note that person centred service delivery requires co-ordinated provision of access to supports from different sources, co-operation to support effective and smooth, timely transitions and referrals between different service areas, delivered with clear roles of accountability, good communications and continued building of staff capacity in this regard.

120. FEDVOL highlighted how a new range of service delivery models must be developed to accommodate the different stages and levels that people need. Some people have complex medical requirements that will require nursing support, while others require a couple of hours support, for help with, for example, cooking or buying groceries. FEDVOL also noted that the top level of support should not be provided unless that is required because it can impact people's independence. FEDVOL also highlighted that there is need to move to a multiannual funding model to develop these levels of service at the right time in a person's life and to respond to the person's will and preference.

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<sup>47</sup> National Disability Authority, *Guidelines on Person Centred Planning in the Provision of Services for People with Disabilities in Ireland*, pp. 36

121.FEDVOL advised that moving to a multiannual funding framework can consider a lifelong diagnosis of disability which could provide the potential to plan early and provide the resourcing to adequately support individuals. However, current budget and planning cycles are annual in nature, which results in crisis-driven and emergency responses that do not result in the best outcomes for individuals, cause enormous uncertainty for families and may not provide best value for State funding.

122.FEDVOL further highlighted how the collaborative approach undertaken by services together with the HSE during the Covid-19 pandemic provided fertile ground for continued partnership in developing services into the future. FEDVOL stated that an emphasis on partnership would support working and addressing the challenges as highlighted in the Catherine Day Report and the Dialogue Forum would produce outcomes that sustain the recent improvement in that relationship.

123.The Committee believe that the Department of Children, Equality, Disability, Integration and Youth, the Department of Health and the HSE and Disability Service Providers must further develop the partnership approach. This could be supported by a new Memorandum of Understanding on service provision aligned with the UNCRPD which includes multi annual funding allocation and criterion for accessing funding. The HSE must review and agree new Service Level Agreements (SLAs) with Disability Service Providers. These SLAs must include;

- a) targets for service provision aligned with the UNCRPD and Assisted Decision-Making (Capacity) (Amendment) Act 2022
- b) and person-centred planning
- c) a lifecycle approach
- d) training to be provided to all staff and management within the HSE and Disability Service Providers organisations on person centred service delivery and how to ensure the rights of people with disabilities.

124.The HSE noted that their service has been drawn into the provision of public services that was not within the HSEs remit. The Committee believe that this reflects the need for better collaboration across departments in the delivery of Disability Services. All Departments need to collaborate on meeting the needs of people with

disabilities. The Committee recommend that the *UNCRPD Implementation Plan* and the *Disability Action Plan* include additional measures to enable cross-service working with the needs of the individual at the centre.

125. The Committee's report *Ensuring Independent Living and the UNCRPD* calls for development of a national plan, in consultation with DPOs, to support the realisation of the right to independent living and inclusion in communities. This must include support for national service providers and agencies to re-configure their services to be developed to achieve this. A national plan requires collaboration between housing, health, rural and community, education, and social protection to combat social exclusion and segregation of people with disabilities.

126. PCP cannot align with the UNCRPD and provide meaningful choice for people with disabilities, unless there are appropriate individual supports available in line with that choice. In tandem with developing person-centred planning and a wider person-centred support plan of community inclusion, a new range of service delivery models must be developed that respect the individual's independence including personal assistance, home support, supported independent living and, for some with higher support needs, full-time residential care.

## **Residential care and decongregation**

127. The Review notes that residential care forms 64% of the specialist disability budget under Disability Services and approximately 8,300 people with disabilities, 90% of individuals with an intellectual disability, live in residential care. The Review continues that the most common form this takes is a group home, an ordinary house in the community shared ideally by no more than four people, along with support staff.<sup>48</sup> Approximately 2,000 people live in 'congregated settings', which are 'institutions, residential campuses or other living arrangements where ten or more people with a disability live together. The Review highlights that a significant increase in the number of disability residential care/supported housing would be required to deal with the impact of demographic change, and to address the

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<sup>48</sup> *Disability Capacity Review*, pp. 17

substantial accommodation required. An average of approximately 90 new residential places are projected for every year from 2020 to 2032. The Review also notes that a planned response is required to anticipate need and meet it in a cost-effective manner, rather than high-cost crisis placements in an emergency. The Review recommends that 150 settings be transitioned yearly up to 2030 if the State is to move away from decongregation.

128. However, HIQA note in their *Annual Report 2021* that for 2019 and 2020, the Chief Inspector continued to identify that people with disabilities who live in congregated settings are at increased risk of poor-quality standard of care and support and that during 2021, there was an overall reduction of 422 in the number of residential places in congregated settings. HIQA support the national policy to transition people from congregated settings to more appropriate, community-based living arrangements.<sup>49</sup>

129. The Committee are also aware that in adhering to the Mental Health Act 2001 and associated regulations, the HSE closed a centre which was reported as providing residents access to the community, and subsequently placed some of these residents in institutions. The Committee believe that this highlights a regression in the policy of decongregation where these individual's rights, as per UNCRPD, become more significantly impacted as they are placed in institutions which are medicalised and lack access to the community. The Committee recommend more alignment between HIQA, MHC, and the Department of Health and the HSE on a strategic level to deliver decongregation and that the HSE must ensure appropriate accommodation and supports are in place before closing a centre, as well as ensuring that residents rights are upheld in the interim.

130. NAS support people through independent advocacy, living in congregated settings and have worked with many people who have moved to community-based living and have witnessed its positive impact. Evidence from NAS highlighted that a person living in an institution for many years may have a poor quality of life, limited natural

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<sup>49</sup> HIQA, *Annual Report 2021*, pp. 33



supports, limited access to appropriate therapeutic supports and limited access to his or her community, as well as their rights continuing to be impacted in their interaction with the health care sector.

131.NAS told the Committee about the importance of completing decongregation to align future service provision with Article 19 of the UNCPRD and how this will improve the lives of people living in unsuitable placements. However, commissioning residential placements for people far away from their communities and families is not a sustainable solution. The Committee believe that investment must be targeted to developing new community-based service models which would facilitate the acceleration of decongregation.

132.The Minister of State with responsibility for Disability acknowledged that people were living in settings that are not suitable for them and that challenges still exist to complete the decongregation process, and that housing and recruiting extra staff to allow the transitional care piece to take place are key. The Minister acknowledged that more ambition is needed to deliver this policy.

133.HIQA uses the regulatory framework to ensure that people living in designated centres are provided with good quality, safe care and support in an appropriate environment that enables them to live fulfilling lives. ‘Designated centres’, include nursing homes, residential services for people with disabilities, and children’s special care units. HIQA’s 2020/2021 reports found an increased level of non-compliance in situations supporting residents to make their own decisions about their lives in a way that maximises their autonomy and independence. The overall experience of residents in terms of their rights, their possessions and general welfare have the highest level of non-compliance and require improvement.<sup>50</sup>

134.The MHC, 8 December 2022, stated that services in the community are on the basis of the medical model of disability with a lack of supports to deliver care in the

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<sup>50</sup> HIQA, *Overview Report Monitoring and Regulation of Designated Centres For People with Disabilities in 2020* and *Overview Report Monitoring and Regulation Of Designated Centres For People With Disabilities in 2021*

community aligned with the UNCRPD. This is particularly applicable to the lack of community and rehabilitation supports for people with mental health issues. The MHC also stated that they have no powers to regulate community supports and call for change under the Mental Health Act 2001 to provide for this regulation.

135.NAS also highlighted that the regulation of residential service providers does not always consider quality-of-life issues. NAS highlighted how residents' rights, particularly concerning dignity, freedom, choice and equality, must be at the forefront of policy development and advocacy is a critical component of this.

136.The Committee heard from HIQA, 31 March 2022, that the 2013 regulations for residential service providers made under the Health Act 2007, set out the minimum legal requirements for the providers of Disability Services and that they must be reviewed to better reflect new and innovative approaches to meet the needs of people with disabilities. The Committee welcomed hearing, 27 October 2022, that HIQA has invested in training in human rights for all inspectors and are working to translate this training into the inspection process and how HIQA report on the rights of people in designated centres. HIQA has also developed e-learning programmes that staff in centres and providers can access, as well as guidance on human rights. The Committee believe that the 2013 regulations must be reviewed to ensure alignment with the UNCRPD and to deliver quality of life outcomes for residents. Person-centred planning is considered a form of self-advocacy. It needs to be strengthened to uphold individual's rights. Individuals, staff teams and managers, in both private and public residential care settings must also be trained to promote self-advocacy and provide access to a range of supports, including independent advocacy.

137.There is a serious over dependence on the emergency residential placement process, which provides accommodation for people with disabilities, usually with higher support needs, in residential care when a parent/carer passes away. This impacts the availability of places for respite and leads to diminishing resilience and ultimately crisis for families. As highlighted in the Review, respite or home support is also focused on crisis situations, and at the expense of supporting families whose

resilience is diminished significantly. The Committee heard from Down Syndrome Ireland about the experience of parents in their 80s who are looking after children with Down syndrome in their 50s with early onset dementia, and they are being told there is no residential place until somebody dies.

138. The Committee believe that radical change is needed to redistribute the budget from supporting a medical model of disability to one that reflects the social or human rights model of disability. The Committee has repeatedly called for action to disrupt the medical model by redistributing the budget in line with the UNCRPD and developing Equality Budgeting to deliver UNCRPD compliant budgeting.

139. The Committee continue to call for the elimination of the process of placing people in institutions and congregated settings and introducing a right to independent living. The Committee believe that without a national plan to target the development of community-living infrastructure, care and support, including respite and support for agencies to re-configure their services, the State will be locked in a medicalised response of emergency residential placement.

140. There are long waiting lists for assessment and early intervention therapies, as noted in the Review, and reflected in Chapter 3, and this is maintaining the reliance on emergency residential placements. There are increasing numbers of teenagers and young adults with disabilities with significant behaviour and mental health issues. The Committee heard the lived experience from parents of children under 18 as they worry about the impact of regression and that their child will end up in residential care. This cements the Committee's view of the importance of a lifecycle approach to human rights for people with disabilities across all services.

141. The Committee heard from FEDVOL that people with intellectual disabilities need significant adaptations to homes to live in the community. Often the funding, through Local Authorities, from the Capital Assistance Scheme, does not meet the considerable costs for supporting appropriate housing models. The Committee also heard of the need for more joined up thinking between health and housing, and public and private services. The Committee recommend a review of the Capital

Assistance Scheme to ensure that it is being operated to its full potential to deliver housing for disabled people under the *National Housing Strategy for Disabled People 2022 – 2027* as well as inclusion of the principles of universal design.<sup>51</sup>

- 142.NAS provides advocacy to residents in almost 21% of private and 13% of public nursing homes, supporting a total of 90% of people under the age of 65 living in nursing homes. NAS stated that the role of nursing homes in disability service provision is a barrier to the alignment of Disability Services with the UNCRPD. Urgency is required regarding transitioning people under the age of 65 who are still inappropriately placed in nursing homes. The Committee note €1 million was spent out of a total allocation of €7million in 2021 on the transfer of under-65 from nursing homes and decongregation. The Committee recommend that the Department of Children, Equality, Disability, Integration and Youth and the Department of Health and the HSE must ensure that any unspent funding for decongregation and any other UNCRPD initiatives must be rolled over and ring-fenced to support progress the following year.
- 143.A significant amount of private provision is funded directly by the HSE in the form of home support and personal assistance. The HSE and the traditional Section 38 and Section 39 services are also using private providers to provide residential placements. The Committee heard from NAS that there was caution needed with regard to using private providers to provide residential placements as there is greater potential for inconsistency across services.
- 144.NAS noted that their experience of many private providers in residential care, is that private providers are using properties that are very far from people's home locations, their families and communities. NAS concluded that private providers should not be used just for a quick fix and that it is important that private providers are meeting the needs of the people using the service.

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<sup>51</sup> Department of Housing, Local Government and Heritage, Department of Health & Department of Children, Equality, Disability, Integration and Youth, *National Housing Strategy for Disabled People 2022 – 2027*

145. The Committee re-iterate their recommendation to complete a national survey of the current population of people under the age of 65 in nursing homes to determine the level of need and funding, both for supports and housing, and to develop the pathway to appropriate support arrangements must be completed urgently. The Department of Children, Equality, Disability, Integration and Youth and the HSE must collaborate to develop integrated services for these individuals, including access to the range of primary and other supports they may need in the community.
146. The Committee heard that the Minister of State with responsibility for Mental Health and Older Persons is leading the work on the safeguarding legislation, Health (Adult Safeguarding) Bill and the Minister for State for Disability will be focusing on the legislation through the lens of disability. HIQA told the Committee, 31 March 2022, that placing adult safeguarding on a statutory footing acknowledges the State's commitment to adults at risk and the duty of civil society to adopt a zero-tolerance approach to adult abuse. In the absence of safeguarding legislation, HIQA stated that they are committed to using the current regulatory framework to minimise risk for people living in designated centres. However, ensuring people with disabilities are free from exploitation, violence and abuse can only be achieved when all parties understand and exercise their responsibilities. The Committee are aware that the Health (Adult Safeguarding) Bill has priority drafting in Spring 2023 and work is underway.<sup>52</sup>
147. The Committee believe that the Health (Adult Safeguarding) Bill safeguarding must be prioritised further, and the Joint Committee on Health must ensure consultation with people with disabilities and DPOs in their scrutiny on the Bill. The Committee also believe legislation must be further developed through the interaction between largely privately supplied services and CHOs and strengthened as the State moves towards implementation of Sláintecare.
148. The Department of Children, Equality, Disability, Integration and Youth, the HSE, along with Disability Service Providers must act in consultation with DPOs and

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<sup>52</sup> Government of Ireland, *Legislation Programme Spring Session 2023*

private providers, including parent's groups, and move from the unplanned model of residential placements to a model of planned intervention and supports to families. This should include respite, to enhance resilience and capacity to care, and facilitate delayed entry into long-term residential care. This work must include all actors who have responsibility for intervention supports including health, homecare, and education, supported by a multi-annual funding framework. The Committee would support a multiannual approach to planning, budgeting and delivery of service provision that responds to the UNCRPD and the Assisted Decision Making (Capacity) (Amendment) Act 2022.

## Transport to services

149. Gaps in access to healthcare often include issues of inaccessibility or unaffordable means of transport. The Committee heard about the inequity in accessing services, and how some individuals and parents are impacted because they have to travel a significant distance to services. People are further impacted because of inaccessibility of public transport and the lack of access to a personal transport scheme.

150. Under the NDIS in 2017, the Government committed to a review of all Government funded transport and mobility schemes for people with disabilities, to enhance the options for transport to work or employment supports for people with disabilities and to develop proposals for development of a coordinated plan for such provision. In January 2022, the Minister of State with responsibility for Disability initiated an interdepartmental group to examine the transport issues for people with disabilities. The Committee are dismayed with the lack of action and delay by Government in introducing a fair and adequate transport scheme for people with disabilities that ensures equality, accessibility, and a right to transport and subsequent inclusion in communities across all sectors. The Committee published a statement along with a number of recommendations to be considered as part of the ongoing review.<sup>53</sup>

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<sup>53</sup> Joint Committee on Disability Matters, Joint Committee on Disability Matters, Press Release, *Joint Committee on Disability Matters calls on Government to urgently introduce new personal transport scheme for people with disabilities*, 2 December 2022. Accessed 14 February 2023: [Joint Committee on Disability Matters calls on Government to urgently introduce new personal transport scheme for people with disabilities – 2 Dec 2022, 10:33 – Houses of the Oireachtas](#)

151. The Committee heard how school leavers funding is ring-fenced and only includes money for supports for the young person but not for provision of transport and escorts which has to be negotiated separately. The Committee are aware that individuals may have multiple health issues and medical appointments to attend, and they need access to reliable transport. Transport must be embedded within services as a standard along with the development of a stronger link between Irish Rural Link and health and educational services.

152. In response to a parliamentary question, 21 September 2021, the Minister of State with responsibility for Disability highlighted that the HSE has no statutory obligation to provide transport services and no funding is allocated for this. Transport is not considered a core health service and as such Day Service funding does not include transport. The Minister of State continued that some transport supports are provided by the HSE or funded agencies on a discretionary basis, and a variety of transport solutions are pursued in different CHO Areas including travel training to enable public transport to be used upon commencement of a day programme (where applicable), local transport such as Local Link, private bus transport providers and taxis, funded via a combination of service provider, HSE funding, service user contribution, and / or combined funding; and some service providers provide transport where capacity exists.<sup>54</sup>

153. The Department of Children, Equality, Disability, Integration and Youth, the Department of Health and Department of Education must develop a plan in consultation with parents, DPOs and Disability Service Providers that provides equitable access to transport across disability services, health and education to support children with disabilities access to services, as part of the service.

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<sup>54</sup> Houses of Oireachtas, *Disability Services*, Dáil Éireann Debate, Response to Parliamentary Question 629, 21 September 2021, Accessed 14 February 2023: [Disability Services – Tuesday, 21 Sep 2021 – Parliamentary Questions \(33rd Dáil\) – Houses of the Oireachtas](#)



## Home care and support

154. The Committee were informed about the limited assistance provided through homecare services, which often only provides support for getting out of bed, washing, dressing, showering, feeding and being put back to bed (often early evening). The Committee heard that the principal difference between a personal assistant (PA) and a carer, is that a carer provides assistance within the house, while the PA, under the direction of the person with disabilities, supports with everyday tasks as well as work/college. The current provision of the Home Care Service can often reflect a medicalised level of service resulting in low quality of life outcomes similar to the experience of individuals with disabilities who are living in nursing homes, group homes and other congregated settings.
155. The Government is establishing a new, statutory home-support scheme, which will aim to provide equitable and transparent access to high-quality services for people based on their assessed care-needs. The Minister of State with responsibility for Mental Health and Older Persons told the Committee, 17 November 2022, that the development of a statutory scheme for the financing and regulation of home support services is advancing at pace with the development of primary legislation for the licensing of home support providers and of regulations to underpin the new licensing regime. HIQA is also developing national standards that will underpin the ongoing quality enhancement of home support services. The draft of the Health (Amendment) Licensing of Professional Home Support Bill 2020 (the Bill) is underway and when enacted, will provide for the regulation of both public and private home care providers.
156. The Review states that current provision of PA and home support services caters for just a fraction of the people with disabilities who experience difficulties with activities of everyday living.<sup>55</sup> The Review forecast a minimum 120% increase in demand for homecare over the period 2016-2030, this level of demand has already been reached and is expected to increase further.

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<sup>55</sup> *Disability Capacity Review*, pp. 121

157. The Committee note that the implementation of a statutory home-support scheme aligns with the Government commitment to enable people with care needs, at all ages, to live independently in their homes and communities for as long as possible. A re-orientation of the model of care towards primary and community care will support this.

158. It was also highlighted to the Committee that training of home care workers with regard individuals with a chronic illness or long-term disability is very important and must be aligned with the social and human rights model of disability. In cases where home care is provided by a private organisation, there may be no interaction between the private organisation and the CHOs, or Sláintecare. The HSE also stated that the funding is available to recruit personnel to provide homecare support, but it is difficult to recruit workers because it is competing with the private sector.

159. Minister of State with responsibility for Mental Health and Older People, 17 November 2022, also highlighted to the Committee that work is ongoing under Homecare with regard to legislation and to extend and streamline the recruitment process, including better alignment of essential qualifications.

160. The HSE standard assessment tool, InterRAI, is being used in respect of older persons to determine the allocation of care depending on the need of the individual and will enable equity and fairness in service provision for homecare. The assessment is based on will and preference and that the person will be enabled to live at home. However, the Committee are aware how the statutory home-support provision as it exists only refers to people over the age of 65 and needs to be updated to recognise that for a person with disabilities, age-related needs typically impact much earlier. People under 65 years with an assessed need should also be eligible as highlighted by Family Carers Ireland in their Submission to the Department of Health on the Creation of a Statutory Home care Scheme.<sup>56</sup> The HSE highlighted that this tool also applies to some of the people under 65 who are inappropriately placed in nursing homes. Minister of State with responsibility for

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<sup>56</sup> Family Carers Ireland, *Submission to the Department of Health on the Creation of a Statutory Home care Scheme*

Mental Health and Older People, 17 November 2022, confirmed that there are four pilots in operation and that recruitment is underway for InterRAI assessors.

161.As mentioned previously, the Committee emphasise the importance of better integration of services between older persons, disability, private and public service providers which would deliver a more uniform approach to statutory home-support provision.

### **Respite provision**

162.Respite can be residential, home sharing, day breaks, contract families or summer camps. Respite supports families to continue caring for their loved ones. Respite care services, and services with nursing care, are a lifeline to families.

163.The Committee heard that the importance of respite services is underestimated and undervalued. Respite is predominantly provided by charities and in many cases, they are not open for new applications because they are so under-resourced, and demand is so high. Children are also aging out of charity support and respite access is being withdrawn without any transition plans for continuation of support. Overnight respite is very difficult to access because the existing emergency placement process blocks access to planned placement/beds. The Committee heard of one case where there were behaviour issues, and a parent who was looking for respite felt they were steered towards thinking about residential care for their son.

164.The Committee support the Government's policy of keeping individuals in their homes as long as possible. However, in order to achieve this families must be able to access support either in appropriate respite care or in home support.

165.The Committee also heard about other factors impacting respite provision such as the loco parentis rule which requires that there must be another adult in the house with the child when nursing care is provided. This means that even though nursing care is provided a parent may not receive a break or respite.

166. The Committee welcomed hearing that the Minister of State with responsibility for Disability and the HSE are developing an approach for respite provision aligned with the Convention. However, the Committee are aware there is a need to ensure that centres are located in areas with appropriate infrastructure and with appropriate access to public transport. The Minister of State with responsibility for Disability acknowledged the need to create capacity in respite care and that there is a need provide innovative alternatives for people with autism and behavioural challenges.

167. The Minister of State with responsibility for Disability also updated the Committee about a pilot project where the key performance indicator (KPI) in respite provision is not when a parent passes away but is instead a serious emergency, with a view to supporting ageing families. The Committee note that this is still dependent on an emergency response. This indicator sustains the dependence on parents who are ageing to deliver the same level of care to their children with disability that they provided in their younger years.

168. The Committee believe that respite provision is vital given the projections for the ageing population and the number of elderly carers currently providing informal care in the home. There is a requirement to develop a national standard to ensure consistent and equitable approach to accessing respite. The Department of Children, Equality, Disability, Integration and Youth and the Department of Health and HSE must consider innovative solutions and ensure respite provision nationwide with the appropriate resources.

169. Respite is also provided through Summer Provision over the summer holidays. The Committee heard from parent's groups that only 26 special schools of the 126 (data reflected the time of the public meeting), provide Summer Provision. The Committee also heard that there is such low take up of Summer Provision by schools because there are no incentives for staff and that teachers and SNAs received payments late in the past.

170. The Committee believe that a more integrated approach for the provision of respite is needed which aligns with early intervention outcomes across health and education

sectors. The HSE must move away from providing respite as an emergency measure and ensure a more planned approach that prevents people from going into crisis in the first place. Respite services must be developed to support early intervention of children on waiting lists for assessment of needs or early intervention. Summer Provision must be included under an integrated approach that delivers respite and does not lead to regression through non-standard approach and routine disruption.

### **Lack of community and rehabilitation services**

171. As highlighted earlier, current supports in the community are on the basis of the medical model of disability with a lack of supports to deliver care in the community in line with the rights as per UNCRPD.
172. The term neurodisability is used to describe a group of congenital or acquired long-term conditions that are attributed to impairment of the brain and/or neuromuscular system and create functional limitations.<sup>57</sup> Neurodisability is also used to describe patients who acquire a brain injury, like a stroke, or neurological conditions like Motor Neurone Disease.
173. The Neurological Alliance of Ireland explained how the UNCRPD has wide ranging relevance and implications for people living with a neurological disability. Article 26 of the Convention calls on State parties to provide comprehensive rehabilitation services and programmes for people. However, the Review specifically recognises the major shortfall in timely access to rehabilitation for people with a neurodisability and the critical need for investment in neurorehabilitation services.
174. Evidence provided to the Committee highlighted that there was a lack of centrally managed and stand-alone specific brain injury services along with inequity in services nationwide because of the lack of implementation of the *National Strategy and Policy for Neuro Rehabilitation Services*. On a practical level, this means that

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<sup>57</sup> Morris, C. Janssens, A. Tomlinson, R. Williams, J. Logan, S. *Towards a definition of neurodisability: a Delphi survey*, Developmental Medicine & Child Neurology, Vol 55, Issue 12, 1103-1108

one person with an acquired disability might be discharged to a community team and have access to resources, while another person will not have this access. This has a significant impact on the success of rehabilitation.

175. The *National Strategy and Policy for Neuro Rehabilitation Services* was launched in 2011 and acknowledges that neuro-rehabilitation services have been underdeveloped. It also acknowledges that where services have been developed, it has been in an ad hoc manner, primarily by the voluntary sector. Services developed by the statutory health system are focused on medical rehabilitation, which, while most important, is not comprehensive.<sup>58</sup>

176. As discussed in Chapter 1, similarly neuro-rehabilitation services have evolved through a bottom-up approach where individuals or families come together to introduce a service that is not available in the community. A central strategy would support proper integration and co-ordination between services required on discharge from hospital.

177. The Committee heard that voluntary organisations such as Headway, Acquired Brain Injury Ireland and Quest Brain Injury Services are filling the gap in services, and are supporting people with acquired brain injury to return to work. These organisations are supporting people who should have received a year or two of complex neurodisability rehabilitation before accessing their services.

178. Evidence from witnesses highlighted how the lack of implementation of a central strategy has resulted in a lack of progress in establishment of essential community neurorehabilitation teams in each CHO Area and much needed increase in specialist rehabilitation beds in line with population needs. There is also a lack of data on the number of people with these conditions.

179. The Committee are concerned that the lack of roll-out of community neuro-rehabilitation services and teams as envisaged will result in many individuals with

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<sup>58</sup> HSE, *National Strategy & Policy for the Provision of Neuro-Rehabilitation Services in Ireland*, pp. 4

acquired brain injuries being discharged home with no support. An individual discharged from hospital with acquired brain injury can disappear into the community and are often hidden trying to manage their disability with the help of their families because of the lack of supports and continuum of care. Individuals often do not receive a discharge plan on exiting the hospital.

180. In the UK, a discharge plan is part of the entitlement for stroke survivors along with a six-month follow-up and annual appointment. The Committee believe that patients must receive a discharge plan where they are either discharged to a community team or designated a case worker who can follow the person through discharge into the community or transitional living units, along with a six-month follow-up and annual appointment.

181. A discharge plan supports access to a continuum of care, access to family therapy and counselling. Without these supports individuals often return for support to clinics within a year after being discharged and are unable to get back to work or study.

182. The Committee also heard that young people with severe brain injury who need residential care may end up in nursing homes for the elderly without resources of any kind because of the lack of supports in the community. In addition, the absence of a clear pathway from hospital to home has a significant impact on the cost of health care.

183. The Committee heard that international data suggests that 40% of people who are rough sleepers have had a brain injury at some point. Prison populations were also highlighted as having high rates of people with brain injuries. This highlights how a lack of early intervention, not recognising disability, or trauma event can result in the intervention response pushed to other sectors. This impacts an individual's engagement across multiple services, including education and health.

184. Under Article 26 of the UNCRPD, State Parties are required to strengthen and extend comprehensive habilitation and rehabilitation services and programmes, particularly in the areas of health, employment, education, and social services, in



such a way to support participation and inclusion of individuals in the community and all aspects of society and as close as possible to their own communities, including in rural areas.

185. The Committee are concerned that the evidence highlights that the current level of rehabilitation service reflects a medical model of disability where the basic level of support is provided in hospital but there is an absence of the continuum of supports to support an individual live an independent life in the community.

186. The Committee also heard the living experience of parents of an individual who received a brain injury and who was made a Ward of Court. The parents cannot access the compensation that their loved one received on foot of the injury to use for the individual's rehabilitative care. This creates significant worry for parents about what will happen when they pass away or are no longer able to support their loved one. The Courts Service has begun preparatory work for the discharge of Wards of Court on commencement of the Assisted Decision-Making (Capacity) (Amendment) Act 2022.

187. The Committee heard that there are a huge number of stroke survivors whose workplaces cannot, or will not, adapt sufficiently to allow them to return to work. These are people who want to work, contribute to society and move forward in their lives, but are not being given sufficient support and opportunity to do so. The public meeting, 11 November 2021, highlighted the disconnect between recommendations on returning to work from neurological teams for stroke survivors and return to the workplace accommodations. The Committee recommend proper integration of services to remove barriers and introduce more flexibility to allow people who have neurodisability to return to work at their own pace, as recommended by medical experts.

188. The Committee also heard from the Irish Heart Foundation that research on returning to work after stroke shows that employers want to help but they just do not know how.

189. The Committee recommend that the HSE *National Stroke Strategy* is implemented, particularly the commissioning of the Early Supported Discharge teams and 'Stroke Key Worker' so that discharged stroke patients and their families have access to the specific support and advice. The Committee recommend that the Department of Children, Equality, Disability, Integration and Youth and the HSE work together with other applicable Departments to develop rehabilitative services in line with the social and human rights model of disability and across health, employment, education and social services. As part of this work the data on stroke must be developed as well as training and support for employers.
190. Ultimately, there is need for better integration between primary care teams and adult services in communities through Sláintecare as well as developing working relationships between clinicians and staff through a multidisciplinary approach. Early intervention outcomes must be achieved through adult services, and they must be resourced accordingly. Staff transferred to the Assessment of Need (AON) process and early intervention waiting lists must be reinstated.
191. The Committee believe that the lack of adult services, as highlighted by the Review, and evidenced at Committee public meetings, for people with disabilities in local communities is in breach of Article 26 of the UNCRPD. This article requires comprehensive habilitation and rehabilitation services and programmes, particularly in the areas of health, employment, education, and social services, in such a way to support participation and inclusion of individuals in the community. The Government must undertake crisis talks on how to ensure meaningful transformation of Disability Services and provide equitable adult services integrated as part of Sláintecare, as well as agreeing national measures to support transformation and highlight their commitment to the provision of health services to people with disabilities. Children services must also be included under crisis talks as highlighted in Chapter 3 below.

## Re-envisioning day services

192. Adult Day Services are HSE funded programmes to provide day service supports to people aged 18 and over, with intellectual disabilities, autism, or complex physical disabilities. Under this programme, people with disabilities are assisted to make choices and plans, and to be an active, independent member of the community. The HSE note that the needs of a person with disability leaving school may be met by a HSE rehabilitative training programme or HSE adult day service or mainstream education or training services.<sup>59</sup> NCSE highlight in their report, *Review of Education in Adult Day Services*, that data sources differ on the number of day services in operation however analysis of the most recent information (March 2019) from the HSE indicates 953 settings in total.<sup>60</sup>

193. The Disability Capacity Review reported that the provision of day services comprises of 21% of budget. *New Directions, Report of the National Working Group for the Review of Health Service Funded Adult Day Services (2012)* aims to improve day services by focusing on empowering people to make their own decisions about how they spend their day and to access activities in their own community. Day services offer support during the weekday, about three quarters of service users have an intellectual disability.

194. FEDVOL highlighted good examples of transition planning developments for day services where young people began planning two years before they leave school. FEDVOL highlighted the WALK PEER Programme and the Cumiskey Ross Ability Programme where the outcomes from supporting young people at that early stage have been excellent. FEDVOL also highlighted how a person with autism experiences life differently from other people and this often requires the development of bespoke day services or residential buildings to reflect the person's needs.

195. The Committee heard about a vast array of different service providers in day services, but these providers are operating what is almost like an 'educational system without a college, syllabus or training programme'. There is a prevalence of

<sup>59</sup> HSE, *School Leaver Referral HSE Funded Adult Day Service(s)*

<sup>60</sup> NCSE, *Review of Education in Adult Day Services*, pp. 5

issues in relation to staffing, difficulty in knowing what the different agencies offer, day services operating at second level when young adults have exited second level, services located outside local communities in industrial estates and running pre-school hours. Parents of children attending day services highlighted the need for syllabus and training programmes to be developed at organisational level and rolled out for all service providers.

196. In this regard, a main finding from the NCSEs *Review of Education in Adult Day Services* is that policy and funding for adult day service provision traditionally sits within the remit of the Department of Health and the HSE and at present there is no legislative basis for those working in these settings to offer education/learning. Further as there is no legal basis for appropriate education provision post 18 for people with disabilities, young people with disabilities can experience a 'cliff edge' when turning 18 with regard lack of further opportunities, supports and services.
197. Parents highlighted the frustration of every year waiting until the end of August and sometimes into September to see whether their child can access day services. There are no appropriate day or resource services for people with physical and sensory disability services. Witnesses also highlighted that there are no day services for individuals with neurological disabilities and acquired disability that could provide physiotherapy and occupational therapy in local communities. Also, there is a need for consultation with autistic people and their DPOs on day services that meet autistic people's needs.
198. Down Syndrome Ireland highlighted to the Committee that the School Leaver Programme in its current design is maintaining segregated pathways and a medical model of disability.
199. The HSE Occupational Guidance Service will establish the person's support needs, assist in the identification of an appropriate service provider and guide the allocation of funding for their service rehabilitative training courses or tailored adult day support

programmes.<sup>61</sup> Down Syndrome Ireland highlighted that a young adult may have progressed through mainstream school and is in a position to take up further education or maybe employment, however families are not supporting these pathways because of fear that there is no way back into services if required, at a later stage. That acts as a disincentive to individuals to access the community and society and lead independent lives.

200. The Committee believe that individuals leaving school should have choice in what they want to do after school, regarding day services or other types of services that provide after school training.

201. Day services or other types of services that provide after school training must be aligned with the UNCRPD and uphold the rights of people with disabilities. As part of the development of UNCRPD compliant SLAs with Disability Service Providers all Day Services must provide a curriculum that aligns with the National Framework of Qualifications in consultation with people with disabilities.

202. The system must be developed further to support young people with disabilities to have choice and the HSE must ensure that opting out of day services does not lock people out of funding and services that support their rights. It is also crucial that the School Leaver Programme is developed to include access to a personal assistant to deliver improved quality of life outcomes for young adults including additional non-segregated options and increased choices. The Department of Education must ensure career guidance for young people in special schools is introduced so that young adults can be supported that there are other options other than a full-time day service placement.

203. The Committee also believe that, in the short term, the Department of Education must ensure that all young adults with disabilities in special and mainstream schools are provided meaningful choice on what their employment and education opportunities are leaving school. The Committee support FEDVOL's

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<sup>61</sup> NCSE, *Leaving School? Information on some Post-School Options for Rehabilitative Training and Adult Day Services*

recommendation that career guidance for young people in special schools must be introduced so that young adults can be supported to access other options other than a full-time day service placement.

### **Gaps in autism services**

204.As highlighted previously, the Committee heard the lived experience of autistic people about services and supports which are medicalised and result in negative outcomes, as well as impact autistic people's rights. This medicalisation was highlighted further as witnesses told the Committee that the present adult diagnostic manual for autism was written by neurotypical people and does not capture the full range of autistic experience. As a result, many autistic adults find it difficult to access the diagnosis they require.

205.Witnesses highlighted that autistic people have a higher incidence of mental health conditions, self-harm and suicidality. Other issues raised include the lack of diagnostic and post-diagnostic service provision for autistic adults, healthcare professionals having only a basic understanding of autism, the need for routine autism screening of adults with mental health or learning disabilities, the urgent need for autism treatment pathways in mainstream and mental health services and the lack of provision of augmented alternative communication, AAC. These challenges were further exacerbated for people with autism and intellectual disabilities and their families living in remote rural Ireland.

206.The HSE told the Committee that the autism model of service being developed will include representation from Child and Adolescent Mental Health Services (CAMHS). The HSE will consult with National Education Psychological Service (NEPS) as part of the model's development. The HSE also noted that under this model a service improvement board is in place which comprises of people with lived experience, parents, other family members, various clinicians and many other stakeholders from fields such as primary care, mental health, and disability, as required. This board is examining matters such as awareness and pathways for diagnosis and assessment. A knowledge hub and phone line has also been announced as part of these improvements.

207. The HSE highlighted the work being undertaken to develop a new protocol around autism which was due to be trialled in four different CHOs, starting in January 2022. The HSE provided an update to the Joint Committee on Autism and stated that the draft protocol is currently being piloted in two CHO's and its next phase will bring that up to four CHOs.<sup>62</sup>

208. The Committee note the importance of a National Autism Strategy to develop appropriate public pathways of support for autistic adults to access diagnosis and support, including mental health services in a timely manner. The strategy also needs to consider autistic people's difficulties accessing healthcare and maternity services.

## Disability and mental health

209. Evidence from international and Irish studies indicate that people with intellectual disability have a higher overall prevalence of mental health problems (Cooper et al., 2007).<sup>63</sup> These problems are more complex and show differences to the general population, with much higher rates of co-existing autism spectrum<sup>64</sup> and multiple medical and psychiatric conditions occurring together (multi-morbidity).<sup>65</sup> The Committee heard at its public meeting, 4 November 2021, that there is a need to recognise that very few autistic people do not have co-occurring other neurodivergent diagnoses such as ADHD, obsessive-compulsive disorder, OCD, Tourette's syndrome or mental health difficulties.

210. The Committee also heard how the current medical approach to disability can sustain the development of mental health issues for people with disabilities. Segregation and institutionalism can lead to a lower quality of life for people with

<sup>62</sup> Joint Committee on Autism debate, *Autism Policy and Health: Health Service Executive*, 18 Oct 2022, Accessed 14 February 2023: [Joint Committee on Autism debate - Tuesday, 18 Oct 2022 \(oireachtas.ie\)](https://www.oireachtas.ie/en/joint-committee-on-autism/debate-tuesday-18-oct-2022/)

<sup>63</sup> Hughes-McCormack LA, Rydzewska E, Henderson A, MacIntyre C, Rintoul J, Cooper SA. *Prevalence of mental health conditions and relationship with general health in a whole-country population of people with intellectual disabilities compared with the general population*. BJPsych Open. 2017 Sep 29;3(5):243-248. doi: 10.1192/bjpo.bp.117.005462. PMID: 29034100; PMCID: PMC5620469.

<sup>64</sup> Matson, JL, Shoemaker, M. *Intellectual disability and its relationship to autism spectrum disorders*, Research in Developmental Disabilities, Vol. 30, Issue 6, 2009, Pages 1107-1114.

<sup>65</sup> Cooper SA, McLean G, Guthrie B, McConnachie A, Mercer S, Sullivan F, Morrison J. *Multiple physical and mental health comorbidity in adults with intellectual disabilities: population-based cross-sectional analysis*. BMC Fam Pract. 2015 Aug 27;16:110



disabilities. People living at home with their family or independently in the community cannot access formal support structures which can lead to isolation, poverty, social exclusion, unemployment, and mental health issues. Family carers and caregivers in some instances who are not adequately supported may also develop mental health issues.

211. The MHC in relation to their report *Rehabilitation and Recovery Mental Health Services in Ireland 2018/2019* highlights an almost ‘total absence’ of community mental health services including rehabilitation services and that this is sustaining the placement of individuals in mental health settings that can be inappropriate for them. <sup>66</sup>MHC confirmed that the position had not improved significantly, 8 December 2022.

212. In this report, the MHC highlights that the focus regarding rehabilitation mental health services in Ireland had been associated with programmes which sought to resettle individuals in supported community residential homes but lacked an emphasis on active rehabilitation. This has resulted in a large cohort of people with enduring mental illness who did not receive appropriate rehabilitation and who are destined to remain in highly supported institutional type care, either in inpatient units or in supervised residences in the community; in the community but not part of it.

213. The Committee recommend that the HSE ensure that all residents in their centres have access to active rehabilitation services and supports to be meaningfully included in the community. The Committee also recommend the development and implementation of specialist rehabilitation and recovery mental health services as highlighted in *A Vision for Change*.

## **Emerging and chronic disability**

214. Chronic diseases cause significant morbidity and mortality, and result in poorer quality of life for many people and it has been estimated that 70% of the global disease burden in 2030 will be due to chronic diseases, with an increasing number of

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<sup>66</sup> Mental Health Commission, Statement *New review reveals an almost ‘total absence’ of community mental health services*

individuals having multiple chronic conditions in their lifetime.<sup>67</sup> The growing trend for longevity, along with the impact of chronic diseases such as heart disease, diabetes, stroke, lung cancer and chronic obstructive pulmonary disease is one of the leading causes of disability.<sup>68</sup>

215. The Committee heard the living experience of individuals who were experiencing the debilitating impact of a chronic or rare illness, including Early Onset Parkinson's Disease, Ehlers-Danlos Syndrome (EDS), Myalgic Encephalomyelitis/Chronic Fatigue Syndrome, (ME/CFS) and Lupus.

216. Evidence provided by witnesses confirmed that there is a significant lack of awareness of their illness across health services and often there is no care plan provided on receipt of diagnoses. Without a care plan witnesses could not access early intervention, multi-disciplinary or community-based supports. Witnesses were left feeling isolated and overwhelmed having received a life-changing diagnoses. Some witnesses also highlighted the significant time it took to receive the correct diagnosis because of the lack of consultants with the expertise to deal with their disease. This had significant impact on early intervention and patients were at risk of permanent deterioration. Access to diagnosis and treatment in the community was highlighted as crucial to support witnesses to return to work and participate fully in society.

217. As a public patient, an individual can apply for the Treatment Abroad Scheme to cover the cost of treatment in another country in the EU, European Economic Area or Switzerland. To access this scheme, all treatment requested must be within Irish law and either not available in Ireland, or not available within the time normally necessary to get it in Ireland. The scheme should take into account an individual's current health and the likely course of the individual's condition or disease.<sup>69</sup>

<sup>67</sup> Department of Public Health & Primary Care Trinity College Dublin, A National Survey of Chronic Disease Management by Irish Hospital based Consultants, pp. 11

<sup>68</sup> World Health Organisation, News Release, *WHO reveals leading causes of death and disability worldwide: 2000-2019*, Accessed 14 February 2023: [WHO reveals leading causes of death and disability worldwide: 2000-2019](#)

<sup>69</sup> HSE, *Treatment abroad scheme*, Accessed 14 February 2023: [About the Treatment Abroad Scheme - HSE.ie](#)

218. Witnesses with rare diseases like EDS, were impacted more significantly because of the lack of expertise as there are no EDS Specialists in Ireland. EDS patients are forced to travel abroad for assessment and treatment however this is not covered under the Treatment Abroad Scheme. The Committee also heard from Thalidomide survivors how some survivors had to receive treatment abroad because the expertise was not available in Ireland for their treatment, however this was not covered under the Treatment Abroad Scheme.

219. The Committee heard evidence from witnesses with chronic disease highlighting the importance of wrap around accessible services to delay the progressive nature of these conditions.

220. The Committee believe that the Department of Health and HSE must ensure a more joined up approach to emerging disability and chronic illnesses. If a pathway of care has not being developed in Ireland, people must be supported to access care abroad. The Department of Health and HSE, as part of the work under the European Reference Networks, must review eligibility and expand access to the Treatment Abroad Scheme in this regard.

221. The Committee heard how EDS is a multi-systemic disorder of which there are many subtypes. However, the response in the health sector is not multi-systemic. To access medical and physical therapies in the Irish healthcare system, patients with EDS generally must be referred individually for each body or brain part and explain the disorder from the beginning each time. Although awareness has increased, currently this lengthy process could be avoided by multi-systemic overviews, saving families time on travel to and from appointments. Gaps in provision of care means that many people access care privately which has significant costs.

222. The Committee also heard that the HSE currently has no pathway to care for ME patients and no official ME consultants. Many consultants and GPs dismiss ME or have no knowledge of it. The result is that many patients do not receive a diagnosis or treatment. In some cases, patients are unable to access healthcare as they cannot leave their beds or houses and home visits are not available. Without early

and correct diagnosis, patients risk permanent deterioration. A consultant is essential to access relevant mobility aids which ensure the patients continued independence and quality of life.<sup>70</sup> Individuals with ME also highlighted the lack of access to the Housing Adaptation Scheme to make adaptations to their house to ensure accessibility. It was also highlighted that the social welfare system is designed assuming that disabled people who do not own their homes, live in social housing, and therefore those who are renting often live in houses that are not adapted to the individual's needs.

223. The Committee heard that Parkinson's is one of the fastest growing neurological diseases and its incidence is expected to double by 2032 and that people with early onset Parkinson's disease are not receiving the care they need to help manage the disease and are deteriorating as a result. A care plan on the day of diagnosis that includes physiotherapy, nutrition advice and voice and occupational therapy is essential. Counselling is also essential to deal with the shock and ongoing challenges following the diagnosis of a disease or life changing condition. Early intervention with a multidisciplinary approach is crucial to live well with Parkinson's. Patients need access to intensive therapies and assessment but also to be able to return after a period (two years) for reassessment.

224. In Ireland, where a patient has a medical condition that is long term and chronic, it may be covered by the Long-Term Illness Scheme which was established under Section 59(3) of the Health Act 1970. Under this scheme, a patient can receive drugs, medicines, and medical and surgical appliances directly related to the treatment of their illness, free of charge. A witness to the Committee who suffered from Lupus highlighted that even though Lupus is a long-term autoimmune disease, it is not included under the Long-Term Illness Scheme. In April 2021, the Minister of Health stated that there are no plans to extend the list of conditions covered by the Scheme.<sup>71</sup> The Committee recommend that a review is undertaken of the list of

<sup>70</sup> Irish Wheelchair Association, *Am I entitled to mobility aids and appliances free of charge?* Accessed 14 February 2023: [Am I entitled to mobility aids and appliances free of charge? - Irish Wheelchair Association \(iwa.ie\)](https://www.iwa.ie/entitled-to-mobility-aids-and-appliances-free-of-charge/)

<sup>71</sup> Houses of Oireachtas, Dáil Éireann Debate, 29 April 2021, Response to Parliamentary Question 135, *Long-Term Illness Scheme*. Accessed 14 February 2023: [Long-Term Illness Scheme – Thursday, 29 Apr 2021 – Parliamentary Questions \(33rd Dáil\) – Houses of the Oireachtas](https://www.oireachtas.ie/en/debates/doc/long-term-illness-scheme/)

conditions as well as including consideration of conditions specific to different ethnic groups with a view to extending eligible illnesses for the Long-Term Illness Scheme.

225. The healthcare, financial and social impact of chronic diseases is recognised widely as well as the need to invest appropriate time and resources in the treatment of the chronic condition. The *National Survey of Chronic Disease Management by Irish Hospital based Consultants undertaken in 2014* highlighted that only a quarter of hospital consultant respondents use a register to identify and track patient care. 63% indicated that they do not routinely use electronic patient medical records in their practice, which places the Irish system at a disadvantage in delivering effective Chronic Disease Management. Good information technology systems are internationally recognised as a cornerstone of modern quality healthcare delivery.<sup>72</sup>

226. The *National Framework for the Integrated Prevention and Management of Chronic Disease in Ireland 2020-2025* outlines an integrated approach using a whole-system approach encompassing population health and wellbeing, preventive, acute, non-acute and community-based services to provide a person-centred service so that individuals can receive “the right care, at the right time, by the right team and in the right place.”<sup>73</sup> It was developed to support decision-making in relation to the management of the four major chronic diseases (cardiovascular disease, chronic obstructive pulmonary disease (COPD), asthma and type 2 diabetes mellitus) at the national, regional and local levels. The roll out of a Chronic Disease Management (CDM) programme for General Medical Services (GMS) patients is central to the implementation of Sláintecare. The Committee believe that the National Framework must be updated to expand the management of chronic disease beyond the four major chronic diseases.

227. This National Framework also highlights that the Covid-19 pandemic has emphasised the need to focus services primarily in the community to an even greater extent than previously recognised. The Framework continues that it is now essential

<sup>72</sup> A *National Survey of Chronic Disease Management by Irish Hospital based Consultants*, pp. 9.

<sup>73</sup> HSE, *National Framework for the Integrated Prevention and Management of Chronic Disease in Ireland 2020-2025*

that congregated settings for older people or people with chronic disease are avoided as much as possible and that these individuals are cared for in their own homes to the greatest extent.<sup>74</sup>

228. Research also highlights the need to develop an optimal process for the introduction of National Rare Disease Care pathways into the Irish Healthcare System in the absence of a commonly recognised best practice methodology. Research also highlights challenges in mapping adult Irish clinical experts for lifelong, childhood-onset neurodevelopmental conditions, such as NF1, 22q11 deletion syndrome and Angelman syndrome, revealed significant gaps in adult service provision due to a lack of clear transition pathways.<sup>75</sup>

229. Healthcare providers across the EU use virtual European Reference Networks (ERNs) to facilitate discussion on complex or rare diseases and conditions that require highly specialised treatment, and concentrated knowledge and resources.

230. Research also highlights registries are recognised as an invaluable resource for capturing epidemiological disease information and natural history, identifying patient cohorts available for clinical research, assessing therapeutic outcomes, generating evidence and monitoring CoEs (Centre of Excellence) for disease specific key performance indicators that can be used to gauge European Reference Networks activity and impact.<sup>76</sup>

231. The Committee note the work undertaken on existing rare disease registries under the *National Rare Disease Plan for Ireland*. The Department of Health and the HSE must develop central registries for capturing epidemiological disease information and natural history and introduce a standard process for the introduction of national rare disease care pathways. Lessons learnt and innovation gained from the Covid-19 Response, as well as national rare disease care pathways for diseases which have

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<sup>74</sup> *National Framework for the Integrated Prevention and Management of Chronic Disease in Ireland 2020-2025*, pp. 30

<sup>75</sup> Ward et al. Orphanet Journal of Rare Diseases (2022) 17:162 *Designing rare disease care pathways in the Republic of Ireland: a co-operative model*

<sup>76</sup> *Designing rare disease care pathways in the Republic of Ireland: a co-operative model*

no dedicated care pathways should also be considered. The Department of Health and the HSE must also consult with people with rare disease as part of this work. The National Framework must also be updated to include this standard process for the introduction of national rare disease care pathways.

## Priority recommendations

### 2.1. National Framework for person-centred planning in Services for Persons with Disabilities:

The Department of Health, Department of Children, Equality, Disability, Integration and Youth and the HSE, in consultation with people with disabilities and their DPOs, must update the National Framework for Person-Centred Planning in Services for Persons with a Disability in line with the UNCRPD.

Accountability in person centred planning must be developed by establishing formal monitoring processes for implementation in line with the UNCRPD and include external monitoring mechanisms to ensure the process is strengthened and further ensures that;

- a) the process is implemented as a standard across all services to determine and record how people with disabilities are being provided choice in line with the UNCRPD and the Assisted Decision-Making (Capacity) (Amendment) Act 2022
- b) develop a personalised model of supports for people with disabilities to access diagnosis and support
- c) all services must urgently roll out the education and training programmes to support staff on how human rights principles can be achieved into day-to-day practice and service delivery and ensure positive outcomes for residents including training to promote self-advocacy and independent advocacy

**2.2. Partnership approach:** The Department of Children, Equality, Disability, Integration and Youth, the Department of Health, HSE and Disability Service Providers must further develop the partnership approach supported by a new Memorandum of Understanding on service provision in compliance with the UNCRPD which includes multi annual funding allocation and criterion for accessing funding.



**2.3 Congregated Settings:** The Committee continue to call on the Government to eliminate the process of placing people in institutions and congregated settings and introducing a right to independent living.

**2.4. Respite:** The Department of Children, Equality, Disability, Integration and Youth, the Department of Health and HSE must further develop modelling for respite provision to deliver a more integrated nationwide respite provision that aligns with early intervention outcomes across health and education sectors, including resourcing the service to provide in-home respite, respite support for autism and co-location of respite with day services

**2.5. Day Services:** The Committee recommend that day services or other types of services that provide after school training must be aligned with the UNCRPD and uphold the rights of people with disabilities. As part of the development of UNCRPD compliant SLAs with Disability Service Providers, all Day Services must provide a curriculum that aligns with the National Framework of Qualifications in consultation with people with disabilities. The HSE must introduce a mechanism when a person opts out of day services so they can access funding for other services that support their rights.

**2.6. Transport:** The Department of Children, Equality, Disability, Integration and Youth, the Department of Health and Department of Education must develop a plan in consultation with people with disabilities, DPOs and Disability Service Providers that provides collaboration and equitable access to transport across disability services, health and education to support children with disabilities access to services as part of the service

**2.7. Adult services:** The Department of Health and the HSE must ensure adult services are mainstreamed and integrated under Sláintecare, including mental health for people with disabilities. Better integration between primary care teams and adult services must be developed including working relationships between clinicians and staff through a multidisciplinary approach.

**2.8. National Framework for the Integrated Prevention and Management of Chronic Disease:** The Department of Health and HSE must ensure the development of the National Framework for the Integrated Prevention and

Management of Chronic Disease in line with the UNCRPD and reflect a response to chronic disease as the leading cause of disability including;

- a) updating the National Framework to support decision-making in relation to the management of chronic disease outside the four major chronic diseases
- b) expanding individualised, wrap-around services in communities to support patients with chronic disease
- c) developing a programme for psychotherapy and/or counselling that can be offered to people who receive any lifechanging diagnoses, including when a person attends a GP
- d) reviewing the National Framework and List of Long-Term Illnesses to ensure that individuals with all chronic conditions are sufficiently recognised and supported in implementation of the National Framework.
- e) undertaking a capacity review, informed by an up-to-date understanding of the links between Long Covid and chronic conditions, to ensure that there is sufficient capacity to meet projected demand in the years to come.

**2.9. National Rare Disease Plan for Ireland:** As part of the work under the European Reference Networks, the Department of Health and HSE must develop the National Rare Disease Plan for Ireland and central registries to include a standard process for the introduction of national rare disease care pathways and consult with people with rare disease as part of this work and undertake a review of the list of conditions including consideration of conditions specific to different ethnic groups, under the Long-Term Illness Scheme with a view to extending eligibility; and review the eligibility to the Treatment Abroad Scheme and expand where appropriate.

**2.10. Capital Assistance Scheme:** Housing, Local Government and Heritage must review of the Capital Assistance Scheme to ensure that it is being operated to its full potential to deliver community infrastructure and appropriate housing for disabled people.

**2.11. Community-based supports:** The Department of Children, Equality, Disability, Integration and Youth, the Department of Housing, Local Government and Heritage, the Department of Health, the Department of Rural and Community

Development, County and City Management Association and Local Authorities must work together to strengthen the provision of community-based supports aligned with the UNCRPD. The NDIS steering group must consider the inclusion of Local Authorities representation.

## Chapter 3: Children's Disability Services

### Introduction

232. The Committee held a series of public meetings to examine Children's Disability Services and the new Progressing Disability Services for Children and Young People model (PDS model).

233. Similar to other services, Children's Disability Services developed in Ireland through a bottom-up *ad hoc* manner where Section 38 and 39 organisations delivered services for specific diagnoses, age groups and geographical areas. This level of service provision is considered inequitable as some children received a service and others received none. Children's Disability Services are currently being reformed under the PDS model where services will be centralised under Children's Disability Network Teams (CDNTs). The aim is to deliver a more equitable service which will provide a clear pathway and fairer access to services for all children with disabilities based on their needs. The HSE highlighted that the PDS model is a family-centred model supported through an individual family service plan (IFSP) outlining agreed goals with the child and how best the teams can support the child and his or her family in achieving these goals.

234. The Review highlights that the demographic demand for children's therapy services, at current use rate, will be broadly stable up to 2027, as fewer young children will be counterbalanced by larger numbers of teenagers. By 2032, the total number of children will fall, lowering demand for children's therapy services by 10%. However, the combined impact of addressing the unmet need and the demographic change will raise overall demand for therapy services by about two thirds in 2032. Also, the Review notes that the 2016 Census recorded a measurable increase in the

prevalence of certain forms of childhood disability, intellectual disability, and emotional/psychological disability.

235. The Committee are aware that there have been significant challenges with the roll out of the PDS model and as a result, considerable impact on parents with children with disabilities. Down Syndrome Ireland, AslAm, Inclusion Ireland and other representative groups have made comprehensive reports highlighting an overall situation of significant regional service variations, lack of early intervention due to lengthy waiting lists, as well as a complete absence of communication.

236. Evidence from parents of children with disabilities under 18 and parent's groups using the PDS services highlighted that the lack of access to services and early intervention and lengthy CDNT waiting lists, is considered a breach of children's fundamental human rights. This lack of access to early intervention continues to impact and is causing further regression.

### **Children's Disability Network Teams**

237. The new PDS model centralises Children's Disability Services into interdisciplinary teams under ninety-one CDNTs each with a network manager, all of whom are clinicians by profession. The CDNTs are coterminous with the primary care teams. The Committee welcomed hearing that the configuration of these teams aligns with the UNCRPD, and services are delivered in the community. The PDS model provides interdisciplinary supports for children with complex disability needs as far as possible in the child's natural environments, their home, school, and community. The services are centralised, and the Early Intervention (0-5) and School Age (6-18) Teams integrated under CDNTs (0-18). In this regard, criteria to access CDNT services include the age of the child, their home address and their needs.<sup>77</sup>

238. The Committee are concerned because many of the CDNT teams are not fully operationalised as there are issues with recruitment. There are significant gaps in therapist roles across a whole range of different specialties, including nursing

<sup>77</sup> HSE, *National Policy on Access to Services for Children & Young People with Disability & Developmental Delay*. Accessed 14 February 2023: [Introduction \(hse.ie\)](https://www.hse.ie/eng/health/children/childrens_disability_services/national_policy_on_access_to_services_for_children_and_young_people_with_disability_and_developmental_delay.pdf)

support. The HSE confirmed that on average a 28% gap exists in respect of vacant positions across CDNTs, and the three largest areas of vacancy included occupational therapy, speech and language therapy and physiotherapy. Further, there is difficulty in recruiting for short-term placements to cover maternity leave, parental leave, and other types of leave. Recruitment to CDNTs is severely impacted because primary care, private practice, disability services, services for older people and acute services are all drawing from the same pool of people.

239. As well as a high level of staff vacancies, the HSE also acknowledged other challenges in CDNTs, including large caseloads and long waiting lists and the legislative focus on assessment rather than intervention. The Committee heard that a million children are seen each year through CDNTs. The high demand and low retention and recruitment rates in CDNTs are leading to significant caseloads for staff that are retained. The HSE recognised that these difficulties have created additional stress for families. Recruitment is a major challenge across the general health system including in Disability Services and that the service is progressing all available options to secure the necessary staff.

240. The HSE also told the Committee that the service is developing a new management information tool to replace the paper-based system that is currently in place. The new system will be developed around outcomes for children and families.

241. The Committee welcomed hearing from the Minister of State with responsibility for Disability how the PDS roll-out has abolished the ageing-out aspect, where wait times were so lengthy that a child aged out of one waiting list, only to be placed on the bottom of the next age group waiting list. The Minister highlighted that this was one of the gaps that was identified to be removed and is an integral part of the PDS. However, considering parents highlighted wait lists for CDNTs up to four years, the Committee believe that aging out is still present in the system as a child may not receive early intervention in the optimal years 0-5 years to produce quality of life outcomes.

242. The Committee heard that to support the pipeline for recruitment for CDNTs, there is a need to develop the education pipeline for therapists, and this will require significant change in work practices among the various clinicians. The Minister of State with responsibility for Disability noted that conversations were ongoing with the leads in the specialist areas, CORU and the universities.

243. Professor Malcolm MacLachlan from Maynooth University, highlighted to the Committee, 6 October 2022, that to address the need to recruit more speech and language therapists, in particular Maynooth University suggests the introduction of two new postgraduate entry-level master's courses to more rapidly train people coming in at graduate level. At this meeting, Irish Association of Speech and Language Therapists (IASLT) also noted that there is currently a crisis in student placements as colleges that are producing speech and language therapists have a real problem finding the placements for students. Therapists do not have enough capacity to take on students and help them develop their clinical competencies in Disability Services.

244. The Committee heard that therapists have been transitioned from one part of the service to another to tackle backlogs, creating further gaps in service provision. Therapists were moved from Disability Services to work on the Covid-19 Response and then moved from adult services to work on backlogs under children's services in the PDS model. When they were moved to work on children's services and assessments backlogs, backlogs developed in early intervention. This has a significant impact on the sustainability of service provision across both children's and adult's services.

245. Parent groups reported that the recruitment issues in the PDS model have a significant impact and CDNTs communicate this as an excuse for the delay and lack of services, with no coherent plan to improve this trend and impact to the relationship formed with children who thrive on familiarity and routine.

246. Cavan Monaghan Parents Committee highlighted that there is a need to increase the number of places in third level education for therapists along with recognition of a

drop-down qualification such as that of a therapist assistant who could work under the direction of the therapist to bridge the gap for children who have been waiting for a service. Additional grants or even final year pay for student therapists would make the career option more attractive. Cavan Monaghan Parents Committee noted that Magee Campus of Ulster University produces speech and language therapists, and these therapists cannot transition from the North to the South of Ireland because they have not completed a dysphasia course (feeding, eating, drinking, swallowing, FEDs). The need to develop a pipeline and lead in for recruitment to align with universities was also highlighted. At the public meeting, 26 January 2023, the HSE explained that UK qualifications do not include FEDs and these therapists must complete FEDs training to work in Ireland.

247. The Committee also heard how some parents are undertaking innovative initiatives to bring intervention therapies to Ireland. A parent told the Committee how she and six other mothers came together and set up a six-week programme to provide an intervention service for children in Ireland. The group put a proposal to the Neurological and Physical Abilitation (NAPA) Centre in Boston to come and work with the children in Ireland. The programme was oversubscribed as more than 500 applications were received for 18 places on the six-week programme.

248. Down Syndrome Ireland provided some insights on the recruitment crisis highlighting that some therapists were leaving Children's Disability Services because the service provided does not line up with their professional ethics. Down Syndrome Ireland noted that the State has a responsibility to provide effective therapy to children with disabilities to support development and to prevent regression under Article 25(b) of the UNCPRD. Similar ethical concerns were raised by therapists regarding the revised Assessment of Need, Standard Operating Procedure.

249. On 6 October 2022, the Committee heard similar concerns from IASLT. Many speech and language therapists are firefighting trying to manage waiting lists and informing families they cannot have the service, which is demoralising for the therapists. IASLT highlighted therapists are not going to stay in posts where they cannot do their job. IASLT stated that waiting lists must be the first issue addressed,



and then the issue of retention. IASLT further noted that therapists needed proper clinical supervision and mentoring and support within clinical specialist areas as well as access to continuing professional development to let therapists build their skills and then use those skills to their best ability to help people to achieve their potential.

250. Similar insights were conveyed by a father of a child with complex disability. It was highlighted that a lot of Irish therapists living in Australia, the US and the UK are extremely specialised and want to move home, but the health system is too immature for them, and they would not have the same job satisfaction in the Irish Health Service. It is the same for the medical profession and if Irish schools and facilities can be made more attractive for therapists, more people will return to Ireland.

251. It is also noted that in relation to the Hospital Doctor Retention and Motivation Project, the Royal College of Surgeons in Ireland highlighted to the Joint Committee on Health, 23 March 2022, that hospital doctors (like many health workers) do not always feel safe to speak up about the challenges they face at work and that among emigrant doctors in Australia, there was a sense that exit (via emigration) was a less risky option than speaking up.<sup>78</sup>

252. The Minister of State with responsibility for Disability acknowledged that the transition to the CDNTs, has not been smooth and recruitment issues has made it difficult to achieve the equity of service the PDS programme aims for. The Minister continued that all parties are working to fix the policy through the development of the PDS Roadmap. The Committee welcomed hearing that the PDS Roadmap will be communicated to all stakeholders, especially families, so they know exactly what they can expect from the services over the next year. The Committee are advised that the PDS Roadmap will be published in early 2023.

253. The Minister of State with responsibility for Disability and the HSE also highlighted the importance of interdisciplinary training. The HSE noted that there is a need to

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<sup>78</sup> Joint Committee on Health, Public Meeting 23 March 2022, *Opening Statement from Dr Niamh Humphries to the Oireachtas Joint Committee on Health in relation to the Hospital Doctor Retention and Motivation Project*. Accessed 14 February 2023: [2022-03-23\\_opening-statement-dr-niamh-humphries-senior-lecturer-rCSI-graduate-school-of-healthcare-management\\_en.pdf](https://www.oireachtas.ie/publications/2022-03-23/opening-statement-dr-niamh-humphries-senior-lecturer-rCSI-graduate-school-of-healthcare-management_en.pdf) (oireachtas.ie)

adopt a radically new approach to training individuals which would ensure that those training to be occupational therapists, speech and language therapists and psychologists would all train together from the beginning so that when they graduate, they could hit the ground running and know how to interact effectively. There also may be opportunities for direct placements in the final stage of training to support CDNTs, more effectively. The Committee recommend that the Department of Children, Equality, Disability, Integration and Youth and the HSE urgently develop interdisciplinary training along with updating training paths to enable direct placements aligned with the UNCRPD. A recruitment campaign which conveys the benefits of working in Disability Services must also be considered.

254. It is proposed that the CDNTs will have access to further specialised support on a tiered level to in-reach, to allow CDNTs to be as effective as possible. The National Clinical Programme will support CDNTs when they are experiencing particularly challenging issues, for example, when full expertise may not be available on the teams, that expertise is going to in-reach to the teams, rather than referring a child out of the teams and creating a waiting list elsewhere. The Committee heard from the HSE at the public meeting, 26 January 2023, that this has been delayed.

255. The HSE advised that under the *National Access Policy*, integrated children's services forums will be set up in each area comprised of primary care, social care, mental health services, the acute sectors, Tusla and many other stakeholders. It will cover decision-making and involve all participants reviewing the needs of children and their families and how to work together to best meet those needs. The Committee believe that each CHO must be resourced adequately to implement the policy and that it is tracked and monitored in terms of its effectiveness.

256. The Committee further believe that the HSE, including the National Clinical Programme for People with Disability, must drive a culture change in its service through extensive consultation. Representation of disability must be included on the Sláintecare Implementation Advisory Council. An international campaign, along with additional incentives must be rolled out to encourage therapists to return to work in Ireland.

## Parents of children under 18

257. The Committee heard evidence from two parent's groups for children with disabilities who were set up due to frustration with the lack of services for children with disabilities. Overall, the evidence highlighted that the delay with the reconfiguration of the PDS model left families with nowhere to turn for support or help which led to additional stress.

258. Dublin 12 Campaign for Autism Inclusion shared results of their survey of parents on waiting lists in April 2022 which highlighted significant inconsistencies in CDNTs service provision and access as a new case takes two and half years with no access to respite or home help during this wait time.

259. Cavan Monaghan Parents Committee also shared the results of a poll they recently undertook which also highlighted significant inconsistencies, wait times of up to two years or more for services. It was reported that children were falling through the service gaps as a child's needs were being deemed not complex enough for a CDNT but too complex for primary care.

260. Down Syndrome Ireland also stated that every year around 150 babies join the population of people with Down syndrome living in Ireland and recent research by their organisation highlighted that almost half of all children with Down syndrome had no therapy in 2021. Even when children receive therapy, it is not at the intensity required. Down syndrome is diagnosed before or immediately after birth and early diagnosis means there is no need to wait for babies to start showing developmental delays and there is the opportunity to provide targeted therapy from birth, with potentially life-changing results.

261. As early intervention is critically important, some parents have had to find ways to fund therapy services privately. However, private services also have waiting lists, and parents highlighted that many are over-subscribed and waiting lists are often closed to new clients. The Committee heard how Dublin 12 Campaign for Autism Inclusion are trying to fill the gap in accessing support and direct therapies as they highlighted that they source experts such as OTs, SLTs and psychologists and

negotiate a fee with them to talk to parents, which can cost on average €4,000 for a single child in a year. Cavan Monaghan Parents Committee also reported that if a family accesses private services for an AON the child does not get a service statement.

262. Other issues highlighted by parents include lack of access to early intervention preschool, individual SNAs, overnight respite, physiotherapy, occupational and speech and language therapy including in schools. In some circumstances, occupational therapists only had time to provide medicalised supports such as a wheelchair assessment.

263. Family-Centred Practice (FCP) is the accepted model of the PDS programme<sup>79</sup> and as part of this, CDNTs utilise IFSPs to set out the goals for the child and how the family and team are going to work towards them. CDNTs can also provide parent training to empower families to take ownership of their IFSP. Parents completing IFSP for children with complex needs highlighted that they did not have the expertise or knowledge to be able to decide which three priority areas in relation to their child that the CDNTs should work on.

264. Parents also highlighted that there was a significant lack of communication as services transitioned to CDNTs. Initial communication was infrequent between the HSE and families with little detail regarding dates for reconfiguration of services. Communication was inconsistent as some families received correspondence while others did not. Families struggled with uncertainty. The HSE told the Committee that they are very conscious that when letters issue to families it is not reflective of the direction and model of service which the HSE is working very hard to implement.

265. Inconsistencies were reported across CDNT's, some parents were allocated key workers and attended an initial meeting while other parents did not get this service. Some parents were asked to bring their children to these initial meetings, others were advised to leave their children at home. Some of the CDNTs offered play

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<sup>79</sup> HSE, Progressing Disability Services for Children and Young People, *Progressing Towards Outcomes-Focused Family-Centred Practice an Operational Framework*

therapy and interventions for children and some were more focused on giving parent training. Dublin 12 Campaign reported that there were instances where parents received last-minute cancellations from a CDNT when they were waiting in a reception for their appointment. Other CDNTs have a messaging system in place for appointments and reminders.

266. The Committee were concerned to hear that the inconsistent levels of service being provided is causing disruption to many children. The Committee are aware that service levels can drop when services transition from decentralised to centralised services, however the transition could have been better planned, better communicated to key stakeholders, with a phase-by-phase approach to ensure standard and consistent service levels across CDNTs.

267. Dublin 12 Campaign also reported that the family forums, as recommended by PDS, to be used to discuss issues within the CDNTs, were still not established. The HSE stated that the work on implementing the final family forums is commencing, with the expectation that all family forums will be in place and active by the end of 2022. However, the HSE confirmed at the public meeting, 26 January 2023, that two CHO Areas have active family forums and work is underway to commence the remainder of the forums.

268. Witnesses also highlighted the impact of transitioning to the new consultancy and parent-training model that is included in the PDS and that most families are being offered indirect therapy, such as parent training. This model is family centred and is a needs-based process where a parent attends a meeting to learn methods to support the child while at home. However, Down Syndrome Ireland stated that there is no evidence that this model supports outcomes such as improvements in speech and language skills for children with Down syndrome. Parents also reported that they are being steered away from requesting any occupational therapy or speech and language intervention directly. Down Syndrome Ireland also noted that coaching parents to help their child is not a once-off event and support to the family needs to be consistent at least weekly to provide adequate support.

269. Parents also highlighted the benefit of direct therapies where therapists demonstrated what would work in different scenarios and parents could bring that knowledge to apply at home. This specifically helped parents with challenging behavioural issues at home. However, parents reported being told that direct therapies and intervention will only be given if they are part of the IFSP.

270. Down Syndrome Ireland highlighted children with developmental speech and language disorders who do not have intellectual disabilities are offered direct therapy, with no suggestion of moving to a less direct model for those children. However, children with a speech and language disorder associated with Down Syndrome face much longer waiting lists, which may be triaged based on a phone call. They are extremely unlikely to be offered therapy. Down Syndrome Ireland stated that this was State-designed discrimination and a breach of Article 25(a) of the UNCRPD.

271. Cavan Monaghan Parents Committee also highlighted how the current provision of services impact the States fulfilment of Article 25(c) of the UNCRPD which requires State Parties to provide health services as close as possible to people's own communities, including in rural areas. As highlighted earlier, some families have transportation difficulties accessing services, they may not have a car and public transport is often not accessible.

272. The Committee were concerned to hear that due to the lack of early intervention parents worry and suffer anxiety about the prospect of their child being placed in residential care and that the way the current system is set up, is leading to this and maintaining segregation and institutionalism.

## Developing early intervention pathways

273. One of the metrics to identify if a rights-based service for children with disabilities is being delivered is early intervention. Article 25 (b) has a specific focus on early intervention in that it requires State Parties to provide ‘those health services needed by persons with disabilities specifically because of their disabilities, including early identification and intervention as appropriate, and services designed to minimise and prevent further disabilities, including among children and older persons’.
274. The Disability Act 2005 (the Act) legally requires the HSE to carry out an AON within 3 months of receiving an application and finish the assessment within a further 3 months. The Act outlines how the AON shall determine whether a child has a disability, shall determine the nature and extent of disability, shall state the health and education needs, shall state the services the child needs and shall state when and for how long the services should be provided. Based on the AON, the HSE must prepare a service statement which sets out the health service intervention the child will receive and identifies the educational needs of the child but will not identify the educational supports required to meet that need.<sup>80</sup> CDNTs are completing AONs.
275. The HSE states that as the Act does not define this assessment, the process is not standardised. In addition, the AON, being an accumulative process, has resulted in resources being targeted almost exclusively towards assessment with some children receiving very limited intervention.<sup>81</sup> The HSE state that the reduction in ability of the service to undertake interventions in how the Act is implemented results in increased clinical risk.
276. Down Syndrome Ireland stated that research highlights that even delaying therapy for three months has a negative impact on outcomes, yet there are children on waiting lists for two and three years. Some of these children were also born during Covid-19 Pandemic and did not get the benefit of mother and toddler groups and early interaction and were already at a disadvantage. Down Syndrome Ireland

<sup>80</sup> Inclusion Ireland, (2021). *Step 1 Assessment of Need, Diagnosis and Professional Reports*

<sup>81</sup> HSE, Response to Parliamentary Question 23328/18, 23329/18, *The Assessment of Need Process*. Accessed 14 February 2023: [West Cork Community Services, \(hse.ie\)](https://www.hse.ie/eng/press/2023/02/14/2023021401.htm)



continued that because of a lack of early intervention these children cannot communicate in any other way than through behaviour and this causes significant challenges for families. In the long term, this results in problems being stored up and pushed into education, social integration etc. These issues will be more costly to solve in the long-term.

277. The current level of service provision is not delivering early intervention for children with disabilities as some waiting lists for these services can cover up to four years. This is not only leading to a continuation of behavioural regression from the loss of services during the Covid-19 Pandemic and low quality of life outcomes for these children, but it is sustaining the medical approach to disability. The Committee are concerned regarding the significant stress, anxiety and burden that is being placed on parents and families, as children regress further, and at present the new service does not provide the adequate support to families.

278. NAS highlighted that there is an issue in how Ireland currently defines disability and HSE service provision. A move towards a definition of disability which is defined by how people access services must be considered. NAS commented that the Australian system, and the definition of advocacy that applies in terms of accessing services is broader, as it is not based on assessment like in the HSE services, with a distinction between mild and moderate disability defining whether individuals can access services.

279. Sections 3 to 13, inclusive, of the Education for Persons with Special Educational Needs Act (EPSEN Act) 2004 have never been commenced. The sections provide for an individual right to assessment, individual education plans, the designation of schools, appeals processes and co-operation between the education and health services.<sup>82</sup>

280. The Committee heard that in the absence of an amendment to the Disability Act 2005 to legally oblige the HSE to provide therapies for children, the only recourse

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<sup>82</sup> Inclusion Ireland, *The Right to Education*. Accessed 14 February 2023: [The Right to Education - Inclusion Ireland](#)

parents have is legal recourse. The Committee are aware of the increase in litigation against the HSE and that parents who have exhausted domestic mechanisms this way will not be able to bring their complaint to the UN Committee, because Ireland has not ratified the Optional Protocol.

281. The NDA note that the original intention was that the EPSEN Act and the Disability Act would operate in tandem and provide people with disabilities and special educational needs with a joined-up approach to assessment and support provision.<sup>83</sup> The Committee note that the EPSEN Act has opened for public consultation in November 2022.

282. In January 2020, the HSE introduced a new Standard Operating Procedure (SOP) for AON to help standardise the AON and make it quicker. The SOP has a two-stage process, which aimed to ensure that children have access to early intervention immediately rather than waiting long periods for diagnosis assessments and potentially aging out of the service. The stages included a desktop assessment and a preliminary team assessment, which consisted of a 30-minute conversation with the parent and an hour observation of the child at play.

283. A recent High Court ruling<sup>84</sup> held that the HSE failed to properly assess potentially disabled children in accordance with the Disability Act 2005. As a result, the HSE is currently reviewing the judgement and has stopped using the SOP.<sup>85</sup>

284. The Committee note that the Chief Commissioner of the Irish Human Rights and Equality Commission highlighted concern that the HSE's SOP sidesteps the need for a formal diagnosis in needs assessments and therefore risks becoming the exact type of societal barrier that the UNCRPD sets out to avoid, with real impacts on individual's lives in terms of access to essential services. The Chief Commissioner continued that an initial formal diagnosis is crucial in providing necessary and life

<sup>83</sup> National Disability Authority, *NDA Independent Assessment of Implementation of the National Disability Inclusion Strategy for 2021*, (2022), pp. 26

<sup>84</sup> Irish Legal News, *High Court: HSE failed to properly assess disabled children under Disability Act 2005*, 15 March 2022. Accessed 14 February 2023. [High Court: HSE failed to properly assess disabled children under Disability Act 2005 | Irish Legal News](#)

<sup>85</sup> *NDA Independent Assessment of Implementation of the National Disability Inclusion Strategy for 2021*, pp. 34

changing supports for a person's health, educational, workplace, social and other needs.<sup>86</sup>

285. The HSE have not been reporting annually on the aggregate unmet need as required by Section 13 of the Disability Act 2005. The HSE noted that with regard to Section 13 reports that a number of reports up to the period of 2014 were recently published and the service had an agreement to complete and publish all outstanding reports no later than the end of 2022. From there onwards, the HSE noted that the service will be in full compliance with the requirements of the Act in terms of their provision to the Minister and their publication within six months of the end of a year.

286. The Committee note that the evidence indicates that the Disability Act 2005 impacts the rights of children to early intervention as per Article 25(b) of the UNCRPD. The Disability Act 2005 provides a legal entitlement to an assessment but no entitlement to an intervention. The Committee agree with the HSE that there should be a legal entitlement to intervention, which is of primary importance. The Committee believe that waiting lists for people that have been appropriately assessed and need continuing support is ineffective.

287. The Committee are aware that the current definition of disability under the Disability Act 2005 may be insufficient in its provisions to promote the inclusion and participation of people with disabilities in society, for example to determine the extent of disability or human need or ensure that the significant costs arising from disability are based on an assessment of the individual's support needs rather than on a degree of impairment assessed. Focusing on impairment rather than needs, reflects a medical model of disability, where, as highlighted by the UN committee, persons with disabilities are not recognised as rights holders but are instead "reduced" to their impairments. The UN committee also express concern that the laws and policies of States parties still approach disability through charity and/or medical models, despite the incompatibility of those models with the Convention. The

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<sup>86</sup> Irish Human Rights and Equality Commission, Press Release, *HSE's Interpretation of Disability Act Undermines Rather Than Upholds Disability Rights*, 25 January 2022. Accessed 14 February 2023. [HSE's Interpretation of Disability Act Undermines Rather Than Upholds Disability Rights - IHREC - Irish Human Rights and Equality Commission](#)

persistent use of such paradigms fails to acknowledge persons with disabilities as full subjects of rights and as rights holders.<sup>87</sup>

288. The HSE acknowledge the need for transformation in the system where there has been a tradition of seeing diagnoses as an end point of a process instead of it being a continuing process. The Committee agree with IHREC that a review of this legislation is necessary to consider what reform is required in order that disability legislation is aligned to UNCRPD.<sup>88</sup> Please see recommendations under Chapter 1.
289. The Committee heard from the HSE on 13 May 2021 as well as at a site visit on 14 March 2022 that the AON is one of the ways in which children can access services but is not the only way and the HSEs preference is for children to access services directly through the CDNTs.
290. Integrated and standard early intervention service including summer programmes, day services, respite should be used in tandem with managing waiting lists to effectively tackle regression. The HSE advised that the new model has enabled children who were not included previously, to be included on waiting lists and therefore to be 'on the radar' to receive services. In one of the CHOs, 40% of the children on the waiting list were previously, prior to reconfiguration, not on any waiting lists.
291. The Committee welcome that children who were not previously identified are now included on waiting lists, however the Committee believe that the system must be developed to ensure that all children who need support are identified and receive services. This includes better coordination and collaboration between health and education as outlined further in this report. Currently, Children's Disability Services are not fit for purpose as services are failing to deliver standard early intervention and the HSE must develop the model to align it with the UNCRPD. The Government must include under crisis talks on how to transform Disability Services, how to

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<sup>87</sup> Committee on the Rights of Persons with Disabilities, *General Comment on Equality and Non-discrimination (Article 5)*

<sup>88</sup> *Consultation on Terms of Reference and Work Programme for the Joint Oireachtas Committee on Disability Matters Submission by the Irish Human Rights and Equality Commission (2020)*

ensure better coordination between health and education to support the early intervention of children and support parents.

## **Supporting school-based health services**

292. As the new PDS service is rolling out and services are being centralised in CDNTs, some schools were informed that they were to lose their on-site provisions such as speech and language therapy. This caused significant distress because of the impact on children who were receiving therapies as part of their school day.

293. The Committee welcomed that the Minister of State with responsibility for Disability ordered the HSE in April 2021 to stop removing specialists from special needs schools. At the public meeting, 13 May 2021, the HSE also confirmed that existing supports provided to the small number of special schools will remain in place and resources will not be removed. The HSE also stated that their service, Section 38 and 39 agency partners are mindful to reassure parents with children attending special schools of their commitment to build the capacity of these teams to give greater levels of interdisciplinary supports.

294. At the public meeting, 13 May 2021, the HSE told the Committee that there are 136 special schools across the country, of which 33 have an on-site health-funded service provision, which equates to approximately 85 whole-time equivalent staff working in the area, at an approximate cost in excess of €6 million. The HSE stated that the level of service available in these schools varies and on-site services, where they exist, generally provide a unidisciplinary model of service. Staff can be working in silos and in isolation in school settings without the benefit of their peers working with them in an interdisciplinary team. Many children with equally complex needs attend mainstream schools or special schools that do not have dedicated on-site services. The HSE further noted that it is fundamental for SLT professionals to work jointly with the teaching profession around language acquisition and curriculum attainment.

295. The HSE also highlighted to the Committee how the CDNTs, when fully resourced, bedded down and working well, can complement the full inclusion of children with

disabilities in mainstream education settings by working conjointly with education partners. CDNTs will work with schools more generally under the *National Access Policy* as it facilitates the education sector, parents and CHOs, which are responsible, with the lead agencies, for agreeing how best to deliver the services. There are also local structures for implementation which include staff as well as parents.

296. The Committee believe that there is a need to further develop integration and coordination between health and education sectors and align the *National Access Policy* and the *National Clinical Programme for People with Disabilities*. The HSE must consider including representation from Educations' National Access Policy Group under the National Clinical Programme for People with Disabilities to strengthen integration.
297. The NDA note that the lack of inclusive policy position and subsequent legislation (EPSEN Act, 2004) in Ireland has meant that the number of children not educated in mainstream classes in mainstream schools continues to rise. The Irish statutory education system is likely to be considered a 'dual system' by the UN Committee on the CRPD which it says are not compatible with inclusive education.<sup>89</sup>
298. Down Syndrome Ireland highlighted that employing therapists in education can develop and support pathways where children and young adults can be steered towards further education. This highlights to the Committee how inclusive education can be designed and deliver inclusion in society for children with disabilities.
299. In some CDNTs, parents were not able to obtain an updated educational placement recommendation in time from their CDNT team in order to enrol a child in a special class or in a unit in a secondary school. The Committee note that this is another example of the need for more coordination and integration between health and education.

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<sup>89</sup> National Disability Authority, *Overview of UNCRPD Article 24 in Ireland Education*, pp. 50

300. The HSE highlighted, 25 November 2021, that it is important to note that neither the Disability Act 2005 or the EPSEN 2004 use the word “diagnosis” anywhere and that a convention has been developed where schools have requested a diagnosis so that they can make a stronger case for getting an SNA. It is important to note that SNAs can be appointed without a diagnosis.

301. Following a legal judgement in 2021, the NCSE now has the responsibility to nominate an appropriate person to carry out an assessment of education needs on behalf of the HSE under the AON process. As noted previously, the service statement completed by the HSE sets out the health service intervention the child will receive and identifies the educational needs of the child but will not identify the educational supports required to meet that need.

302. If the HSE Assessment Officer forms the opinion that there may be a need for an education service to be provided to an applicant under Section 8 (3) of the Disability Act (2005), she/he will request the NCSE to nominate a person with the appropriate expertise to assist in carrying out the assessment of education needs.<sup>90</sup>

303. The Committee believe that a high level of engagement with schools, including parents, on the trialling of this new initiative is needed and schools must be provided with additional resources to ensure that the education needs of all students, including those with disabilities or other special educational needs, are identified and supported. There must also be engagement and coordination between the HSE and the Department of Education.

304. The Committee heard how a CDNT became aware of a child that needed support only because of the existing on-site services schools. This highlights the importance of on-site services and the requirement to develop an integrated system with better coordination between health and education sectors where the child is placed at the

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<sup>90</sup> Department of Education, (2022). *Report of Education Needs for the purpose of Assessment of Need (Disability Act 2005)*



centre of the service so that early intervention and inclusion in education and society can be realised.

305. The Committee heard that the health model is a needs-based delivery programme for children who wish to access various levels of education, whether at a national school or when transitioning from national to secondary school. The education system on the other hand, is based on assessment and diagnosis that provides an SNA or access to a special class or special unit. However, the Committee note that the reform of special education in Ireland has moved away from a medicalised diagnostic model for resource allocation to a more equitable model of assessment and allocation.<sup>91</sup>

306. The Committee believe that the HSE must ensure that the capacity of teams and services that are being delivered on-site at schools are built up to give greater levels of interdisciplinary supports and that additional measures are introduced to ensure cross sectoral working under the *National Access Policy* between the education sector, parents and the CHOs and the lead agencies. The Committee recommend that the Department of Education develop a national strategy to transition Ireland to an inclusive education system, in line with the UNCRPD and in conjunction with the Department of Children, Equality, Disability, Integration and Youth, the Department of Health and HSE.

## **Mental health supports for children**

307. The mental health of young people is a growing concern with a worldwide prevalence of 13% of young people experiencing mental health issues. Accessibility to mental health services in Ireland is poor with the HSE not meeting many of its own targets. The available evidence indicates that the transition process from child to adult mental health services in Ireland is often haphazard and does not meet best practice guidelines.<sup>92</sup>

<sup>91</sup> Kenny, N. McCoy, S. & Mihut, G. (2020) *Special education reforms in Ireland: changing systems, changing schools*, *International Journal of Inclusive Education*, DOI:10.1080/13603116.2020.1821447

<sup>92</sup> Heery, E. Oireachtas Library & Research Service (2019). *Youth Mental Health: Is there a need for a specialist service?*

308. The Committee are concerned about the access to mental health and behavioural management supports for children with disabilities. The Committee are aware that some children have regressed during the Covid-19 pandemic and continue to regress because of the lack of access to services. The non-standard delivery of services as services transition to CDNTs and in delivery of day and overnight respite and summer programmes also impact the child's progress.
309. The HSE told the Committee how the *National Access Policy* helps to determine how children are assessed and streamed into the right service including access to behavioural supports under CAMHS. Behavioural management supports will be a key part of what the CDNTs do, and children will have access to psychology services through these teams.
310. The Committee are aware that a medical card holder attending a GP can access low threshold psychological care such as counselling (maximum of six sessions per year), however, this not available to people under 18 years.
311. In January 2023, the MHC published Interim Report arising from an *Independent Review of the Provision of Child and Adolescent Mental Health Services (CAMHS) in the State*. This report reflected the MHC's serious concerns and consequent risks for some patients, considering that children and young people accessing child and mental health services with open cases have been "lost" to follow-up care. The report also reflected the impact of the resourcing crisis on staff.<sup>93</sup> The Committee are concerned, as reflected in this report, that there is evidence that some teams were not monitoring antipsychotic medication, in accordance with international standards (there are currently no Irish national standards). Consequently, some children were taking medication without appropriate blood tests and physical monitoring, which is essential when on this medication.
312. The Committee believe that an accessible integrated health care service with joined up mental, physical, and social care services, ideally in one location may potentially

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<sup>93</sup> Mental Health Commission, (2023). *Independent Review of the provision of Child and Adolescent Mental Health Services (CAMHS) in the State by the Inspector of Mental Health Services Interim Report*

address common mental health issues, while operating a specialist level service for young people with severe and complex disorders. The Committee support the MHCs recommendations that there should be an immediate clinical review of all open cases in all CAMHS Teams and immediate regulation of CAMHS under the Mental Health Act 2001 should be a priority.

## Priority Recommendations

**3.1. Government must undertake crisis talks:** The Government must undertake crisis talks on national measures to support transformation of Disability Services to ensure the delivery of early intervention across health services for people with disabilities including;

- a) a targeted focus on ensuring human rights to individuals living in residential settings,
- b) integration of adult services as part of Sláintecare and standard access to services in the community including mental health services
- c) access to early intervention in Children's Disability Services and mental health including better coordination between health and education
- d) development of recruitment and retention of staff in Disability Services

**3.2. Disability Capacity Review and Progressing Disability Services:** The Minister for Health and the Minister of State with responsibility for Disability must implement the Disability Capacity Review with regard the PDS model for the full operationalisation, capacity building and filling of the therapy posts for all 91 CDNTs. The Department of Health and the HSE must develop the PDS model to fully align with the UNCRPD, particularly Article 25 (b). Implementation of the Review that focuses on timely intervention must also be ensured and supported by;

- a) identifying what is required for AON to deliver diagnostic services and early intervention and resource accordingly
- b) ensuring waiting lists for AON and early intervention are eliminated and introduce a scheme to deal with existing backlogs such as the National Treatment Purchase Fund

- c) ensuring access to mainstream primary care therapy services under Sláintecare's integrated health service
- d) developing mental health supports through CAMHS or other mental health services once a child has a diagnosis of disability

**3.3. Children Disability Network Teams:** The Department of Health and the HSE must develop consistent levels of service provision across CDNTs and primary care services for children with disabilities and;

- a) develop a management information system and case management system that allows metrics on the outcomes for families that will measure all the way through the process
- b) allow all outreach and home-sharing agreements to continue until CDNTs are fully operational
- c) ensure case-coordinators are assigned to families to provide up to date information and support, websites, and information pathways
- d) introduce flexibility to the system which takes into consideration that children may not be able to access their local school and may have to attend a school outside their county and consider access to therapists who service the school in that county

**3.4. Disability Act 2005:** The Department of Children, Equality, Disability, Integration and Youth must undertake a review of the Disability Act 2005 to consider what reform is required in order that disability legislation is aligned to UNCRPD and as part of this review consider;

- a) alignment with requirements of Article 25(b) of the Convention and include a legal entitlement to intervention and provision of services
- b) developing the lifecycle approach to diagnoses and identification of people's needs across transitions and lifecycle
- c) ensuring a holistic and multidisciplinary approach to the assessment and identification of a child's development needs
- d) appropriate assessment and access for Assistive Technology and ongoing maintenance (please see Chapter 4 for further detail)

**3.5 Integrating disability into Sláintecare:** The Department of Health and the HSE must ensure better integration between *Sláintecare*, the *National Clinical Programme for People with Disability* and the *National Access Policy*. Representation of disability must be included on the Sláintecare Implementation Advisory Council.

**3.6. National Access Policy:** The *National Access Policy* must be tracked and monitored in terms of its effectiveness. The Minister of State with responsibility for Special Education and Minister of State with responsibility for Disability must consider forming a working group on the *National Access Policy* that includes HSE officials to consider the alignment of the PDS model and the School Inclusion Model (SIM) and ensure needs-based delivery across sectors.

**3.7. National strategy for inclusive education:** The Department of Education must develop a national strategy to transition Ireland to an inclusive education system in line with the UNCRPD and in conjunction with the Department of Children, Equality, Disability, Integration and Youth and the Department of Health and HSE.

## Chapter 4: Future innovation

### Introduction

313. Innovative, inclusive, and multi-stakeholder initiatives and partnerships focused on researching, developing, and facilitating access to health technologies have the power to support the transformation of Disability Services. The Committee heard from Aoife O'Toole how Ireland is on the cusp of this transformation, especially with the transfer of disability from the Department of Health, the ratification of the UNCRPD and the knowledge and expertise that exists in Ireland in partnering with individuals and their families.

314. Ms. O'Toole stated that there are three areas that need to be considered when thinking about innovation in Disability Services. First, investing in a social movement campaign that shifts mindsets and can bring about the societal change needed to achieve equality and non-discrimination. The Committee have considered and reported previously on the cultural shift that is needed in parallel with implementation

of the UNCRPD and have made several recommendations (Chapter 1). Second, investing in how Ireland grows and scales approaches in designing and delivering services in partnership with people and their families. Third, investing in the digital transformation of Disability Services in a way that keeps relationships at the heart of service provision.

315. Throughout public meetings, witnesses highlighted further the need for cultural change, and the need to move from away from delivering a medical model of disability to delivering a social or human rights model of disability as per UNCRPD.

### **Service delivery model transformation**

316. The *National Framework for Person-Centred Planning in Services for Persons with a Disability* notes that it can be difficult to step outside service models and imagine futures with approaches that do not follow conventional service design and practices. Many organisations start with a service model in mind rather than asking questions about what is most needed by the person.<sup>94</sup> The Committee believe that as recommended in *Supporting the Implementation of the National Framework for Person-Centred Planning in Services for Persons with a Disability* there is a need for a national strategy to engage persons using services, families and community members in *New Directions* and the *National Framework for Person-Centred Planning in Services for Persons with a Disability*.

317. FEDVOL, the national umbrella body of not-for-profit organisations providing direct supports and services to people with intellectual disability, stated to the Committee, 2 December 2021, that the sustainability of the voluntary sector and the relationship-based support provided to people by Disability Service Providers is very challenged when there is a large turnover in the volume of staff. There are challenges for the entire sector with recruitment an acute challenge for all organisations.

318. FEDVOL recommend a workforce planning stream within the *Disability Capacity Review Action Plan* that would take account of the entirety of the sector, regardless

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<sup>94</sup> A *National Framework for Person-Centred Planning in Services for Persons with a Disability*, pp. 85

of which funding arrangement is in place with the State. Other issues highlighted that particularly impacted Section 39 organisations include the escalating cost of insurance and the need for access to the clinical indemnity scheme.

319. The scale of the transformation needed to align Disability Services with the UNCRPD was also highlighted by FEDVOL who recommended a range of service delivery models that respect the individual's independence including personal assistance, home support, supported independent living and, for some with higher support needs, full-time residential care. These supports need to be planned, rather than providing solutions in a crisis when a family carer becomes ill or passes away.

320. The Committee heard how members of FEDVOL have been working to transform services and supports with several initiatives. These include the development of individualised supports in day services under the New Directions programme, collaborative work with Local Authorities to deliver housing and supports, supporting people to move from congregated settings to the community and the establishment of programmes that re-enforce the value of transition planning and tailored employment supports. Further work is underway through the Next Steps Community of Practice and the Immersion Programme, the person-led research of the Inclusive Research Network and work with the older persons working group which will support strongly individualised, person-centred and person driven approaches.

321. A central aim of the Next Steps Project is to collate the learning of organisations who are developing individualised and self-directed supports and provide leadership and practical help to the wider intellectual disability sector as it progresses with this movement for the people who use services. The *Next Steps the Journey so Far* report included positive outcomes such as increased independence and ownership within the person's own life, enhanced connection with the individual's own family, and the development of meaningful roles in the community.

322. FEDVOL highlighted that an essential element in availing of opportunities under the Transforming Lives process and decongregation is the management of the transitions to new service options that promote community participation and



inclusion and that change had to be paced at a rate that people can cope with. FEDVOL also highlighted how the requirement to register houses with HIQA before moving in (due to supports provided) is causing significant delays, lost opportunities for accommodation options and distress for people moving.<sup>95</sup>

## Advocacy and culture

323. The word ‘advocate’ comes from the Latin *advocare*, to “add” a “voice” and is a person who represents another person’s interests. In this regard, to advocate is to simply add a voice of support to a cause or person.<sup>96</sup> NAS provides an independent, confidential, and free advocacy service to adults with disabilities, aged 18 years and over, and highlight that advocacy is representing the person’s views ‘as if they were the advocate’s own’. In this regard, advocacy work is crucial to ensuring the rights of people with disabilities.

324. Self-advocacy started in the 1960s where individuals with intellectual disabilities formed self-advocacy groups. In this regard, self-advocacy would mean that individually or in groups, people with intellectual disabilities speak or act on behalf of themselves or others or on behalf of issues that affect them directly.<sup>97</sup>

325. The Committee heard about the vital work undertaken by NAS in representing the lived experience of people who are still living in congregated settings or inappropriate placements, such as nursing homes for those who are under 65. NAS also highlighted that some individuals have lived in institutional settings for more than 30 years and have never experienced choice or made their own decision on options available. These individuals need to be given appropriate supports in line with the supported decision-making set out in the UNCRPD and the Assisted Decision-Making (Capacity) (Amendment) Act 2022 and to be empowered to be able to make informed decisions of their own free will.

<sup>95</sup> National Federation of Voluntary Bodies Providing Services to People with Intellectual Disability, *Next Steps, The Journey so far, Sharing learning to inform the movement to individualised supports*, pp. 20

<sup>96</sup> Advocate, Vocabulary.com. Accessed 14 February 2023. [Advocate Definition, Meaning & Synonyms | Vocabulary.com](#)

<sup>97</sup> Self-Advocate Net, *History of the Self-Advocate Movement*. Accessed 14 February 2023. [History of the Self-Advocate Movement – SelfAdvocateNet.com](#)

326.NAS also highlighted that they have growing waiting lists, and that they anticipate that when the Assisted Decision-Making (Capacity) (Amendment) Act 2022 is commenced, there will be an increased demand for advocacy, as people seek to implement the provisions of the Act in terms of their own decision-making. The Committee support the NAS recommendation that access to advocacy services must continue to be promoted in future service design to safeguard human rights and in particular independent advocacy should be adequately resourced and aligned with the UNCRPD.

327.NAS continued that when many disabled people are given the opportunity to make decisions or exercise choice, they find it extremely challenging due to the disempowerment they have experienced from a young age. A lot of support is required and much of the work of NAS is on building people's confidence and autonomy to voice their concerns about decisions in respect of fundamental rights regarding where one lives and how one spends one's time.

328.Advocacy will play a significant role in giving voice to people's experiences and improve their quality of life in conjunction with the community, appropriate therapeutic supports, personalised budgets and other options within the community.

329.The Committee also heard from NAS that they host the patient advocacy service, which was commissioned by the Department of Health and that this service provides independent, free and confidential advocacy for people who wish to make complaints about patient safety incidents in HSE-funded public acute hospitals or nursing homes and it will play an integral role in protecting the rights of people in receipt of healthcare into the future.

330.Ms. O'Toole highlighted how the reform of disability services in Australia under *Every Australian Counts* campaign fought for the introduction of the national disability insurance scheme and is very instructive for Ireland. The Committee agree with Ms O'Toole that there is need for investment in a social movement campaign that shifts mindsets and believe that this can be achieved through a comprehensive national

disability awareness strategy led by people with disabilities and highlighting the issues they experience.

331. The Committee are also aware how advocacy is particularly important in the case of those who are marginalised in society. For example, there many marginalised women who experience more significant barriers to accessing services as there is a bias that arises as a result of where they are from, where they live or the experiences they have had in life. These parents may experience fear of judgment or stigma in trying to access services. The Committee believe that individuals must be informed about disability advocate supports when they are accessing services.

332. The Committee heard from Peter Broadhead about the implementation of the UNCRPD in Australia. Australia ratified the UNCRPD in 2008 and the Optional Protocol to the Convention in 2009. Australia is delivering a National Disability Insurance Scheme (NDIS). The design of NDIS is based on the social or human rights model of disability and eligibility recognises that disability results from the interaction between persons with impairments and the environmental barriers that hinder their participation in society.

333. The Committee heard how civil society and non-governmental organisations mounted *Every Australian Counts Campaign* for the introduction of the NDIS, where families told their stories in a way that resonated with the Australian population. The Committee heard that the public in Australia were not aware of the lived reality for people with disabilities, and they were quite shocked by it to the extent that 80% of the population voted for a 0.5% increase in their taxes in order that a system could be developed that was fair and equitable. The National Disability Insurance Scheme Act 2013 to establish the NDIS was passed with cross party support in 2013 and the articles of the UNCRPD were built into the design of the scheme from the outset.

334. The NDIS sits under Australia's *Disability Strategy 2021-2031* and is a tax-funded social insurance scheme that delivers funding to eligible persons with significant and permanent disabilities, known as participants, to purchase the disability supports they need. It is a major change to the way people with significant disability are

supported in Australia. At its core, the NDIS takes an individualised and rights-based approach to disability support, empowering eligible participants to exercise choice and control in accessing support. It provides access to individualised funding to help participants realise their aspirations and to participate in the social and economic life of the community. The NDIS is not means tested and provides its participants with funding for supports to help them live an ordinary life. The NDIS does not provide income support, which for those who require it is provided through a separate tax-funded social security system. Eligibility for the scheme is not based on a person's diagnosis or specific medical details, rather the scheme focuses on how a person's functional capacity to undertake the activities of daily living is affected by their disability.

335. The Committee heard that the NDIS also includes provision of early intervention supports for eligible people with disability and children with significant developmental delay. The NDIS includes needs led cost of disability in that a participant receives a NDIS plan and associated funding developed through assessment of what supports are reasonable and necessary given a person's level of functional capacity and circumstances, and current access to formal and informal supports. It is the realisation of an insurance scheme that takes a lifetime approach, investing in people with disability early to improve individuals' outcomes later in life.

336. Examples of the supports included in plans under the NDIS include therapy, home and vehicle modifications, assistive technology devices and equipment, assistance with household tasks, personal care and transport, and assistance for family and carers. Funds can be included for capacity building supports and supports for community participation.

337. Peter Broadhead also highlighted the impact of the transition from funding service providers to funding individuals and from block-funded set of arrangements to a market for provision of services. Mr. Broadhead highlighted that it was very painful for organisations, to change from an organisation that had certainty of funding to provide a level of services to having to compete to secure payment from the people

with disability for the services they provided. Many made the transformation successfully, however, some did not.

338. The Committee believe it is time for action and for the Government to examine how the current system can transition to a rights-based, person-centred service that takes a lifetime approach, is inclusive and enables access to services and supports. The Committee believe that there is significant opportunity to transition to a new system of long-term care for people with disability in Ireland that is based on early intervention, equity of provision as well as equality. A new system could include digitalisation at its core and align with systems already in place, such as PDS.

339. The Committee recommend that the Department of Children, Equality, Disability, Integration and Youth examine the development of a National Disability Long-term Care and Support Scheme in line with the social or human rights model of disability to determine the feasibility of undertaking something similar in Ireland and to consider the legislative needs. Supports must include a coordinated package of care services such as home and vehicle modifications, assistive technology devices and equipment, assistance with household tasks, personal care, accommodation support, respite, transport and a range of community participation, day programs and employment available for a person's lifetime.

## **Equality and non-discrimination**

340. On the 3 February 2022 the Committee held a public meeting on Equality and Non-discrimination and heard from LightAware and the Irish Thalidomide Association. Both witnesses experience challenges in being acknowledged by health services.

341. LightAware represent light sensitive people who experience pain and ill health when exposed to the newer forms of lighting, with symptoms including eye pain, headaches and migraines, skin rashes, burning, dizziness and nausea. These individuals are considered light-disabled and are unable to work, socialise, access education or healthcare or really participate in society. The Committee heard the lived experience of the disabling effects of light-emitting diode (LED) lighting on

individuals with light sensitivity and its significant impact on health as well as access to the community.

342. Research highlights how information about environmental electromagnetic fields (EMF) is of increasing importance as more and more people are developing electromagnetic sensitivities.<sup>98</sup> Reactions can occur when an affected individual is near transformers, LED or fluorescent lights, microwave ovens, refrigerators, and other appliances. The World Health Organisation (WHO) notes that this reputed sensitivity to EMF has been generally termed “electromagnetic hypersensitivity”. Affected individuals describe multiple symptoms, and it has been difficult for medical specialists to create a reproducible set of diagnostic criteria that could be applied to this group of individuals to diagnose a specific malady or group of maladies related to electromagnetic hypersensitivity.

343. The European Commission Regulation (EU) 2019/2020 outlines requirements for energy efficient lighting and introduces an exemption from using LED lighting in homes for individuals with a specific condition causing photosensitive symptoms.<sup>99</sup> However, the Committee heard that this provides only lighting at home, leaving light-sensitive people at risk of social isolation and unable to access essential services or employment.

344. The Scientific Committee on Emerging and Newly Identified Health Risks (SCENIHR) found that while for some conditions either flicker and/or UV/blue light could exacerbate symptoms, there is no reliable evidence that the use of fluorescent tubes was a significant contributor. Of all compact fluorescent lamps properties, only UV/blue light radiation was identified as a potential risk factor for the aggravation of the light-sensitive symptoms in some patients with such diseases as chronic actinic dermatitis and solar urticaria.<sup>100</sup>

<sup>98</sup> Salvatore, J.R., *Electromagnetic Fields*, Encyclopaedia of Toxicology (Third Edition), Academic Press, 2014, pp. 316-319

<sup>99</sup> European Commission, *Commission Regulation (EU) 2019/2020 of 1 October 2019 laying down ecodesign requirements for light sources and separate control gears*

<sup>100</sup> Scientific Committee on Emerging and Newly Identified Health Risks SCENIHR, (2008). *Light Sensitivity*, pp. 4

345. SCENIHR also states that the use of double-envelope energy saving bulbs or similar technology would largely or entirely mitigate both the risk of approaching workplace limits on UV emissions in extreme conditions and the risk of aggravating the symptoms of light-sensitive individuals.

346. The Committee agree with LightAware that employers and service providers should be able to make reasonable adjustments to allow light sensitive people to access employment and essential services. Before the installation of new external LED lighting, such as street lighting or traffic lights, Local Authorities have a duty of care to find out who may be affected and the measures that must be taken to minimise the health impacts on sensitive individuals. There is also a need for consideration of the impact of LED and fluorescent lightning on autistic individuals<sup>101</sup> and that LED streetlights are leading to biodiversity loss.<sup>102</sup> It is important that Local Authorities undertake Disability Impact Assessments on the impact of legacy and future LED retrofitting projects to identify in their local areas individuals that may be affected. On the basis of this, double-envelope energy saving bulbs or similar technology that is recommended to mitigate the risk with regard to light sensitive individuals must be introduced in areas along with the development of 'lifeline routes' free from LEDs.

347. The WHO has conducted workshops on electromagnetic hypersensitivity and has published information on what is known about this potential medical condition. The WHO advise Governments to provide appropriately targeted and balanced information about potential health hazards of EMF to electromagnetic hypersensitive individuals, health-care professionals and employers. The information should include a clear statement that no scientific basis currently exists for a connection between electromagnetic hypersensitivity and exposure to EMF.<sup>103</sup>

348. However, in 2011, the International Agency for Research on Cancer, a branch of the WHO, classified radiofrequency electromagnetic fields as possibly carcinogenic

<sup>101</sup> National Development Team for Inclusion, *Sensory Friendly LED Lighting for Healthcare Environments*.

Accessed 14 February 2023: [Sensory Friendly LED Lighting for Healthcare Environments - NDTi](#)

<sup>102</sup> Neill, P. 1 September 2021, Environment Journal, *LED streetlights are leading to biodiversity loss*. Accessed

14 February 2023: [LED streetlights are leading to biodiversity loss - EnvironmentJournal](#)

<sup>103</sup> World Health Organisation, *Electromagnetic hypersensitivity*. Accessed 14 February 2023: [Radiation and health \(who.int\)](#)



(cancer-causing) to humans. The European Union defined basic restrictions for limiting exposure to electromagnetic fields in Council Recommendation 1999/519/EC, setting maximum values that should not be exceeded. Moreover, in view of the scientific uncertainty, the European Environment Agency advises taking a precautionary approach.<sup>104</sup> The WHO will conduct a formal risk assessment of all studied health outcomes from radiofrequency fields exposure.<sup>105</sup>

349. The International Commission on Non-Ionising Radiation Protection (ICNIRP) recommends exposure limits for non-ionising radiation (NIR), which include radio waves emitted from mobile networks, infrared radiation and visible light, in areas accessible by the public. As part of its spectrum management function, every year ComReg measures NIR levels in public areas at a minimum of 80 different sites, located throughout Ireland which are chosen based on demographic and geographic factors. To date, over 1400 sites have been surveyed and NIR levels at all sites have been found, without exception, to fall well below the international limits for public exposure set by ICNIRP.<sup>106</sup>

350. The Government's position is that, even though there is general consensus that children are more vulnerable to radiation from mobile phones than adults, given the scientific uncertainty regarding mobile phone related cancer risks, to adopt a precautionary approach, rather than wait to have the risks confirmed, along with many other countries including Germany, France, Austria, United Kingdom and Russia who have also taken a precautionary stance regarding cell phone use.<sup>107</sup>

351. Research suggests that radiofrequency electromagnetic fields may have adverse effects on the development of memory performance of specific brain regions exposed during mobile phone use.<sup>108</sup> The Government's position is based on the

<sup>104</sup> European Parliament, (2019). *Briefing: Mobile phones and health: Where do we stand?*

<sup>105</sup> World Health Organization, *Radiation and health*. Accessed 14 February 2023: [Radiation and health \(who.int\)](https://www.who.int/news-room/fact-sheets/detail/electromagnetic-fields-and-low-frequency-electromagnetic-fields)

<sup>106</sup> Commission for Communications Regulations, *Non-Ionising Radiation Information*. Accessed 14 February 2023: [Non-Ionising Radiation Information | Commission for Communications Regulation \(comreg.ie\)](https://www.comreg.ie/non-ionising-radiation-information)

<sup>107</sup> Department of Health, Press Release, *Advice from the Chief Medical Officer on Mobile Phone Use*. Accessed 14 February 2023: [gov.ie - Advice from the Chief Medical Officer on Mobile Phone Use \(www.gov.ie\)](https://www.gov.ie/en/news/2023-02-14-advice-from-the-chief-medical-officer-on-mobile-phone-use/)

<sup>108</sup> Swiss Tropical and Public Health Institute, 19 July 2018, *Mobile Phone Radiation May Affect Memory Performance in Adolescents*. Accessed 14 February 2023: [Mobile Phone Radiation may Affect Memory Performance in Adolescents \(swisstph.ch\)](https://www.swisstph.ch/en/news/mobile-phone-radiation-may-affect-memory-performance-in-adolescents)

*Report of an Expert Group on the Health Effects of Electromagnetic Fields* which was commissioned by the Department of Environment, Community and Local Government in 2007, 16 years ago.

352. The Committee believe that, even though research findings are inconclusive, radiofrequency electromagnetic fields are classified as possibly carcinogenic (cancer-causing) to humans and the Government must consider the issue further. Also, considering the impact of EMF on individuals and biodiversity there is a need to reflect in local planning and development, through meaningful disability proofing and disability impact assessment.

353. The Irish Thalidomide Association represents the majority of about 40 survivors of the pharmaceutical tragedy that occurred in Ireland when pregnant women took the drug thalidomide for morning sickness, which damaged the baby in the womb. Thalidomide was removed from world markets in 1961 however, an investigation by RTÉ PrimeTime in 2013, revealed that thalidomide was not removed from the Irish market until nine months later in 1962.<sup>109</sup>

354. Thalidomide survivors told the Committee that medical knowledge of impact of thalidomide has improved since the Irish Thalidomide Medical Assessment Board undertook their review in the 1960s. The Committee also heard that the criteria that the special Contergan Foundation in Germany uses for assessment of thalidomide survivors has not been updated and is based on 1960s criteria.

355. The Committee heard about the inequity of access to health services and reasonable accommodation that thalidomide survivors experience along with the significant cost of disability and the need for full access to a medical card. The Committee were concerned to hear that one of the most painful things that a thalidomide survivor undergoes is giving blood samples considering survivors may have no arms or have shortened arms. The Irish Thalidomide Association stated that survivors have been

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<sup>109</sup> The Irish Times, 6 December 2021, *Ireland's thalidomide survivors: 'The State is only waiting for us to die'*. Accessed 14 February 2023: [Ireland's thalidomide survivors: 'The State is only waiting for us to die' – The Irish Times](#)

refused blood tests because staff in some public hospitals are not insured to take it from other parts of their bodies, such as legs. Similar issues have arisen in relation to blood pressure and other medical devices to assess survivors' health.

## **Developing data**

356. The Committee continue to hear the impact of the lack of data with regard certain groups of disability and how this impacts the delivery of services and supports.

357. The Committee heard how the inclusion of a question on the census on autism could ensure that the data is not personalised and therefore avoid concerns with regard the use of an autism register.

358. With regard the lack of data on stroke survivors in Ireland, the Irish Heart Foundation told the Committee that the figure of 30,000 stroke survivors it uses comes from an estimate based on international studies that are a quarter of a century old. Studies by the Institute of Public Health and UK comparisons suggest the real figure is approximately 90,000 people.

359. The Committee continue to recommend that data on disability should be disaggregated by age, gender, ethnicity, in line with developing and harmonising definitions of disability across sectors in line with the UNCPRD. The National Census of Ireland must also be updated in line with the UNCPRD, and new census questions must be introduced regarding autism.

360. There is also a need to develop safeguarding data, decongregation data, chronic illness/conditions data.

## **Personal assistance**

361. The Personalised Budgets Demonstration Project is one of the ways to progress disability service provision. The report of the *Task Force on Personalised Budgets (Towards Personalised Budgets for People with a Disability in Ireland)* was published in 2018 and recommended that Personalised Budgets would be piloted and evaluated in an Irish context over a two-year period. The HSE has established the

Personalised Budget Demonstration Projects in 2019 and the evaluation of the project has not yet completed. The NDA is managing the evaluation of the Demonstration Project.

362. The Minister of State for Disability has sighted the Covid-19 pandemic, challenges in recruiting HSE staff and the cyber-attack on the HSE as reasons for the delay with the evaluation of the project.<sup>110</sup> The Minister further stated a key output of the evaluation process will be a report capturing learning about the experiences and outcomes for persons with disabilities participating in the Demonstration Project, as well as consideration of the costs of administering the system. This will inform Department of Health considerations for any future programme of Personalised Budgets.

363. The Committee continue to hear how securing a direct payment and employing a personal assistant enables people with disabilities to live independent lives as envisaged by the implementation of the UNCRPD.

364. The Committee made priority recommendations to develop the position on Personal Assistance in Ireland through introducing a National Personal Assistance service (PAS) in their report '*Ensuring Independent Living and the UNCRPD*'. In many of its public meetings on Aligning Disability Services with the UNCRPD, the Committee continued to hear how PAS is a gamechanger with regards delivering the social and human based model of disability, in that PAS enables people with disabilities to live their lives independently, and participate meaningfully in education, employment and social activities.

365. The UNCRPD is unique in that it includes provisions for the consultation of people with disabilities in issues that affect their lives, yet the Committee heard people with disabilities want to be involved in organisations or consultations, but they cannot sacrifice their Personal Assistance hours and they cannot do it without the support.

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<sup>110</sup> Houses of Oireachtas, Response to Parliamentary Question, 685, 28 September 2021 *Disability Services*, Dáil Éireann Debate. Accessed 14 February 2023. [Disability Services – Tuesday, 28 Sep 2021 – Parliamentary Questions \(33rd Dáil\) – Houses of the Oireachtas](#)

366. The Committee heard that to receive access to a Personal Assistant (PA), an individual would have to negotiate with not-for-profit organisation to determine if they were in a position to administer PA hours that had been allocated by the HSE. However, it is not economically viable for these organisations to administer this service due to the fact that when the administration costs were taken from the PA budget, the remaining budget for hours can be insufficient.

367. The Committee also heard that PAs are not available to people with an autism diagnosis unless they have a co-occurring diagnosis.

368. The Committee are aware that PA services in Ireland are not regulated and there is no legal right to a personal assistance service and people currently negotiate access to this service on a piecemeal basis directly with the HSE. Further inconsistencies were evident as there is a different system in each CHO Area, and it is up to each disability manager to design a service, which creates inefficiency. PAS in Ireland must be developed through introducing mechanisms to develop the market for PA service and incentivise service providers to offer this service. Disability managers in every CHO Area must introduce a service for people with disabilities in their area that is needs-based not diagnosis-based provision. Service providers must also consult with people with disabilities and DPOs on what people with disabilities require from this type of service.

### **Developing a market in service provision**

369. On the 9 December 2021, the Committee heard from Peter Broadband, Group Manager, NDIS Participants and Performance, Department of Social Services in Australia on the transition to a market model of services where an individual with disability had meaningful choice in services available. However, the Australian Government had to develop and expand the services available to maintain this model and had challenges, similar to Ireland, with regard to workforce shortages.

370. To begin this transition to a market model of services, the Australian Government developed software that collected data on people participating in small local areas that anticipated the funding from the State and the services they would require. The

software mapped small areas and predicted how many workers were expected to be required in that area. As it is a market-based model, it provides service providers with sight of where they have opportunities to expand. The Committee are aware of the potential of applicability of geographic information system (GIS) to undertake a similar initiative in Ireland in a health and social care setting.<sup>111</sup>

371. The Committee are aware that an individual may have to apply to multiple services and schemes across different Departments in Ireland to access support and this creates a significant burden, including administrative and financial, on individuals and parents. The Committee believe that the individual must be placed at the centre of an integrated service across departments, so that this burden can be diminished.

372. The Minister of State with responsibility for Disability, 25 November 2021, confirmed that the Department was working on a pilot for a 'one-stop-shop' where people can get information on what services are nearest to them, what suits them, and who they can contact. The Minister noted that as part of this work a mapping of services is being completed, that includes Disability Service Providers, respite, day services, adult education and employability programmes, but does not include HSE service providers.

373. The Committee also heard that the Neurological Alliance of Ireland, along with the Disability Federation of Ireland, were embarking on a project in 2022 to map where community neurorehabilitation services exist and where they do not, but this project has been impacted by the lack of implementation of the neurorehabilitation strategy.

374. The Committee believe that this one-stop-shop service must take a whole-of-person, and lifecycle approach model that includes employment, housing, education and health into account, an information service that covers all Departments schemes and supports related to disability to support a person to live in the community. The Minister of State with responsibility for Disability must also include neurorehabilitation services under this service.

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<sup>111</sup> Foley, R. *Assessing the applicability of GIS in a health and social care setting: planning services for informal carers in East Sussex, England*, Social Science & Medicine 55 (2002) 79–96.

375.Ms. O'Toole highlighted compelling examples of co-creation, collaboration and good lives being realised by individuals and their families throughout Ireland and that a new ecosystem is emerging, where social enterprises, networks, entrepreneurs, coaches, mentors are partnering with people with disabilities and their families and achieving the kinds of change, support and outcomes people want. These initiatives include the Inclusive Living Network; Positive Pathways and the In Conversation series; Blossom Ireland; In Charge; Humankind Coaching; Future Solutions; and Codie: Communities Driving Ireland.

376.The Committee believe that for Ireland to begin to move to a market model like Australia's NDIS, where a person with disabilities receives funding to buy the services that are in line with his/her needs, there is a need to develop the market and the service ecosystem as described above. There needs to be choice for an individual with disabilities in the services available.

### **Assistive technology and digitalisation of services**

377.The Committee held a public meeting on Assistive Technology (AT), 6 October 2022, and heard from Professor Malcolm MacLachlan, co-director of the Assisting Living and Learning Institute (ALL), Maynooth College and Muireann McCleary and Dr. Yvonne Lynch from the IASLT.

378.AT is any technological device or service that assists an individual in some way, particularly people with disabilities or the elderly. Augmentative and Alternative Communication (ACC) is an assistive technology that aids in communication meaning it is an effective means for individuals to communicate when they do not have the physical ability to use verbal speech or writing.<sup>112</sup>

379.The Committee heard from Professor MacLachlan how important language is to allow individuals a way of being part of, and belonging to others, being able to commune and be a part of a community and how AT can be used to enable individuals with no language, communicate with others. Professor MacLachlan

<sup>112</sup> *Difference Between Assistive Technology and AAC*, differenceBetween.net. Accessed 14 February 2023: [Difference Between Assistive Technology and AAC | Difference Between](https://www.differencebetween.net/technology/difference-between-assistive-technology-and-aac/)



stated that AT is necessary to equitably achieving each of the substantive articles of the UNCRPD. ACC can have significant impact in improving the lives of non-verbal children.

380.IASLT highlighted that there is a need to think about how a speaking child learns language and learns to communicate, a child says something, and someone interacts back, and that is how a child learns. Their school attainment is all through that interaction. If a child does not have that opportunity, much of the time they can only communicate through their behaviour. As time goes on, the child's chances of moving on to higher education, or of securing employment and independent living is being reduced because they do not have this basic ability to communicate with the supports, they need. The Committee agree with IASLT, this highlight's lost opportunities around education and recommend that the Department of Education and the Department of Health must work together and develop speech and language therapy supports in schools.

381.IASLT also highlighted how communication is a fundamental feature of humanity and a fundamental human right and how many people with severe speech or language impairments experience communication difficulties across their lifespans, their natural abilities may not be sufficient to meet their communication needs, and they may rely on AAC to communicate. These modes include communication boards, manual signs such as Lámh and electronic devices with voice output.

382.Communication impairments may arise from a developmental disability, such as cerebral palsy or an intellectual disability, or from an acquired disability such as Parkinson's disease, motor neuron disease or stroke. Based on UK data which estimate that 0.5% of the population has a communication impairment resulting in a need to use AAC, IASLT estimate that approximately 25,000 Irish people who have a significant communication disability may benefit from AAC.

383.The Committee heard that universal design must be targeted more broadly at societal level so that products are designed to ensure that a broad range of people can use them without adaptations or reasonable accommodations. The UNCRPD

requires countries to provide technologies that are necessary to allow people to participate effectively in society.

384.The Committee heard that AT can be used to transform Disability Services and create a step change, empower service users, and open new markets as well as enabling equity in service provision. However, in Ireland there is significant inequity in service provision. There is a huge gap in the timelines across the country between when a person comes for an assessment and a device is recommended for loan. There is no national process for funding of devices so the timeline depends on where you live.

385.The Committee were concerned to hear further from IASLT about the impact of the lack of communication on children. IASLT undertook research where they interviewed parents who spoke about the anxiety their children were feeling. Parents are aware their children's communication skills are not meeting their needs. Parents know people do not understand their child, so the child withdraws and loses their confidence. Once they lose the confidence to be able to communicate, they miss out on multiple opportunities. This is called negative participation. Children withdraw from the situation, and they do not get the learning and social skills they need. The ramifications are significant across their lives in terms of social development, not participating in school and the academic learning that is lost.

386.IASLT noted that in March 2020, community-funded prescription guidelines on aids and appliances were launched by the HSE on foot of work completed over several years. There was due to be a roadshow to provide guidelines around prescribing to clinicians but, unfortunately, momentum on that stopped with Covid-19 and it has not gathered momentum again.

387.The *Global Report on Assistive Technology* (the global report) formally launched by Micheál Martin, Taoiseach, 16 of May 2022, mandates governments to act, embracing a rights-based approach, through putting AT users first, embracing co-design and the maker movement, and radically democratising access to and the development of services.

388. Professor MacLachlan highlighted to the Committee that the global report makes several recommendations, some of which are particularly salient to Ireland. These include having an integrated or stand-alone policy on AT, with an associated budget; enlarging, diversifying, and improving workforce capacity on AT; increasing public awareness of AT; investing in data and evidence-based policy; investing in research and enabling ecosystems; and actively involving users of AT and their families. It also recommends AT being key in humanitarian responses and inter-national co-operation, pointing to the priority the Department of Foreign Affairs and Irish Aid should give to AT.

389. The Committee also heard how, in Ireland, the response to Covid-19 has produced a bounce in digital literacy with the game-changing potential to extend the reach of services and the participation of service users. It has also reinforced the value of direct human contact and of being together in one space.

390. The Committee welcomed hearing that the ALL Institute at Maynooth University is leading the largest European Commission-funded project called Smart and Healthy Ageing through People Engaging in Supportive Systems, SHAPES. This project involves work across 14 European countries, with funding of €21 million. The project starts with lived experience and then explores how an open-source platform can provide access to individualised technologies that meet personal needs, maintain people in their communities and keep them out of hospital. By adopting the principles of universal design and being sensitive to individuals' needs for reasonable accommodations in the context of AAC and AT, this project can ensure that many more people can be included.

391. Professor MacLachlan highlighted recommendations to include more minority difficulties under this project including;

- a) new legislation on AT and AAC which recognises them as cross-cutting mediators of human rights and ensures a more systematic and appropriately funded approach across sectors;
- b) the development of an assistive product list (APL), for Ireland;

- c) and supporting a centre of excellence in this area which would bring together service users, service providers, researchers, educators, and representatives of industry

392. Professor MacLachlan told the Committee that the Disability Act 2005 entitles an individual to an assessment but not to an intervention. However, there is a real danger in Ireland that assessments will increasingly be moved into the private sector and people will have less access to them. It will be important to have legislation that establishes not only that people should have an appropriate assessment for AT but also that they should be entitled to the appropriate intervention, namely the technology itself and the ongoing maintenance. Please see recommendation 3.4 (e).

393. IASLT also raised the issue with regard the inequitable access to speech and language therapy supports and funding pathways to help individuals access the most appropriate AAC systems. Waiting lists for speech and language therapy and other team supports are critical issues. Addressing the long waiting times is a crucial resourcing issue requiring urgent action.

394. IASLT highlighted that a UK report calculated that an appropriately prescribed and implemented AAC system that resulted in a young person taking up employment could lead to a benefit of £500,000 accruing to the economy over a lifetime.

395. IASLT highlighted that specialist support pathways for AAC were to be established as part of the roll-out of the PDS programme. These services had previously been provided by specific, client cohort-focused services, or the agencies with staff skilled in these areas who could provide the relevant supervision, support, and training. Reconfiguration to the PDS dismantled this structure. The promised specialist supports have not been consistently developed and, in some cases, there is no local access to specialist supports for children and families.

396. IASLT stated that Article 21 of the UNCRPD protects the right of all people to communicate by whatever means, modes or formats of communication are most

appropriate to them, but lack of access to AAC and SLT means that this right is not currently being upheld. In this regard, IASLT recommend;

- a) changes in the provision of services, with equitable access to speech and language therapy supports, including specialist supports and pathways for AAC;
- b) a national framework for funding prescribing and funding of communication devices;
- c) urgent action on staffing to address the long waiting times;
- d) provision of public services which are fully accessible to people with communication disabilities;
- e) social and attitudinal change, with training required for those in service industries and community organisations to ensure communication accessible communities and;
- f) a mass media campaign to raise awareness and advocate for communication accessibility

397. IASLT also highlighted the model used in the UK to recommend communication aids.

The UK have developed a hub and spoke model where they have set hubs all over the country to which a person can be referred and get the specialist knowledge, try out the technology and use their loan bank. Each hub has a dedicated fund, and they immediately finance the device once a person has gone through that comprehensive assessment process. The hubs also provide training and support for the local teams, so the intervention process is supported. IASLT highlighted the need for a network like this in Ireland so that people can get specialist help and then work with their local team in their community within the PDS model. The Committee also heard how Specsavers is leading in this space as it is centralised and offers a whole range of services, where there may be no need to have an audiologist on the staff as certain resources are trained very specifically to do that sort of assessment.

398. The Committee welcomed hearing further from Aoife O' Toole how digitisation can positively support the transformation of Disability Services as online platforms are also being used to help with the challenges in recruiting and retaining staff which enable people with disabilities and support workers to connect based on needs,

interests and location, and offer choice of who to work with. The platforms also have the potential to connect people with other supports, such as community co-ordinators, mentors and natural supports in the community. They work successfully in other countries and are starting to emerge in Ireland.

## Envisioning the way forward

399. Disability Services in Ireland are in crisis as the system is not delivering individuals rights, not achieving early intervention, and, in some cases, breaching individuals' rights. Ireland is also considered the worst country in western Europe for a person with disabilities.<sup>113</sup> As highlighted previously, a root cause of the crisis is due to the fragmented organisational structure of Disability Services which has evolved over the decades in Ireland where voluntary organisations and semi-independent Section 38s and Section 39s reflect a third world configuration.
400. The Committee heard that there is evidence that a culture of mistrust and lack of communication pervaded between the HSE and service providers that stifled any real service transformation. A recruitment crisis added to this paradigm. In this regard, Disability Services are not fit for purpose.
401. From the evidence presented to the Committee, Disability Services in their current configuration reflects a medical model of disability. Services are maintaining the institutionalism of people with disabilities in Ireland through the provision of segregated pathways and services. The Committee welcome the transition to a social and human rights-based approach to disability under the PDS model for children's services. However, the lack of operationalisation of the teams to achieve early intervention and the lack of a standard roll out of teams means that children continue to age out of early intervention and are placed on a pathway to institutionalism and residential placements. Adult's services, including Mental Health services, as highlighted by the Review, need to be developed and resourced to meet

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<sup>113</sup> The Irish Times, 9 January 2020, *Joanne McCarthy: Ireland worst country in western Europe to have a disability*. Accessed 14 February 2023: [Joanne McCarthy: Ireland worst country in western Europe to have a disability – The Irish Times](#)

unmet need and align with the UNCRPD, as well as achieving early intervention and deliver meaningful quality of life outcomes.

402. There is hope that when the transfer of functions is completed and the responsibility for disability policy moves to the Department of Children, Equality, Disability, Integration and Youth, there is an opportunity to develop services through the lens of equality and ensure rights-based service provision. Two Ministers will have oversight of the function and have the opportunity to establish a market model of services where people with disabilities have access and a choice of services within a rights-based provision.

403. As part of the mapping exercise of services, the Minister of State with responsibility for Disability must undertake a comprehensive review of all services in local communities including new and emerging services. In conjunction, the Department of Children, Equality, Disability, Integration and Youth must provide grant aid funding to these organisations to develop the market and choice in services for individuals with disability, as well as supporting people with disabilities to access these services.

404. The Committee believe that developing a market of service providers along with UNCRPD compliant SLAs and continuing multi annual funding will align with the Convention and establish the groundwork for transitioning from block funding to individualised funding directly to people with disabilities.

## **Priority recommendations**

**4.1. National person-centred support plan for community inclusion:** The Department of Children, Equality, Disability, Integration and Youth and Department of Health and HSE must develop a national person-centred support plan for community inclusion to progress collaboration, action and funding on delivery of specialist community-based disability services and supports for people with disabilities to target the development of community-living infrastructure, care and support, including respite and support for agencies to re-configure their services and in this plan ensure;



- a) integration with Sláintecare to support mainstream access to services and enable strengthened safeguarding through the interaction between privately supplied services and CHOs
- b) inclusion of a strategy to engage persons using services, families and community members in New Directions and the National Framework for Person-Centred Planning in Services for Persons with a Disability
- c) additional measures to enable cross-service working with the needs of the child or individual at the centre
- d) the development and implementation of specialist rehabilitation and recovery mental health services as highlighted in *A Vision for Change* and the HSE must ensure that all residents in their centres have access to active rehabilitation services and supports to be meaningfully included in the community as well as advocacy supports
- e) more investment is targeted to develop new community-based service models which would facilitate the acceleration of de-congregation along with additional measures targeting joined up thinking and integration between MHC, HIQA, Department of Children, Equality, Disability, Integration and Youth, Department of Health and HSE and Disability Service Providers regarding implementation of decongregation
- f) measures to ensure implementation of the *National Strategy and Policy for Neuro Rehabilitation Services*, the *HSE National Stroke Strategy* support and rehabilitative services

**4.2. Centralised service for disability supports:** The centralised service that the Minister of State with responsibility for Disability is developing must take a whole-of-person, and lifecycle approach model that includes employment, housing, education and health into account, an information service that covers all Departments schemes and supports related to disability to support a person to live in the community.

**4.3. Personal Assistance Service:** PAS in Ireland must be developed through introducing mechanisms to encourage the market for PA service and incentivise service providers to offer this service and every CHO Area must introduce a service for people with disabilities in their area that is needs-based not diagnosis-based provision and;

- a) service providers must also consult with people with disabilities and DPOs on what people with disabilities require from this type of service;
- b) consider a section within Disability Services that can provide administrative support for personal assistant services such as organising payroll, sourcing insurance, support in recruitment, HR, etc

**4.4. Statutory entitlement to independent advocacy:** The wishes, choices and preferences of all people with disabilities should be respected and promoted through a statutory entitlement to independent advocacy including;

- a) informing individuals about disability advocate supports when they are accessing services
- b) disability awareness training for all staff who are dealing with people with disabilities,

**4.5. Disability proofing:** The Department of the Taoiseach (central) and the Department of Housing, Local Government and Heritage (local) must ensure that disability proofing and Disability Impact Assessments are undertaken on all policy and legislation, across all public bodies to identify the impact on people with disabilities, and in line with the UNCRPD including consultation with people with disabilities. Local Authorities must undertake a Disability Impact Assessment to identify and improve the consequences of a policy or development on people with disabilities in their local area, and consult all stakeholders, with an understanding of the area, to identify how groups in the population could be affected.

**4.6. Thalidomide survivors:** The Government must immediately introduce a mechanism for unacknowledged survivors to come forward to be evaluated and ensure that all survivors have access to national as well as international funding. The Support for Irish Survivors of Thalidomide Bill must be prioritised and enacted within this session of Dáil Éireann and must include measures to ensure full accessibility to health services for survivors.

**4.7. National Disability Long-term Care and Support scheme:** The Department of Children, Equality, Disability, Integration and Youth must undertake an examination into the development of a National Disability Long-term Care and Support scheme that would replace the existing system funding for the eligible population in line with

the social or human rights model of disability as well as considering the legislative needs.

**4.8. Assistive Technology:** The Department of Children, Equality, Disability, Integration and Youth must develop an integrated policy on AT, with an associated budget along with new legislation which recognises AT and AAC as cross-cutting mediators of human rights and;

- a) develop the use of AT in humanitarian responses and international co-operation
- b) develop an assistive product list (APL), for Ireland along with supporting a centre of excellence bringing together service users, service providers, researchers, educators, and representatives of industry
- c) introduce specialist support pathways for AAC as part of PDS and ensure local access to specialist supports for children and families and specifically target long waiting times
- d) introduce clinical specialist speech and language therapy roles
- e) deliver training for those in service industries and community organisations to ensure communication accessible communities as well as communication accessibility for service providers
- f) the Department of Education and the Department of Health must work together and develop speech and language therapy supports in schools
- g) the HSE must introduce community-funded prescription guidelines on aids and appliances

## APPENDIX

Meeting No./ Date	Topic	Witnesses
J27. 13/05/2021	Progressing Disability Services Model and the withdrawal of occupational therapies from Schools	<ul style="list-style-type: none"> <li>Representatives from Health Service Executive (HSE) Dr Cathal Morgan, Head of Operations, Disability Services, Prof Malcolm MacLachlan, Clinical Lead for People with Disabilities, Breda Crehan-Roche, Chief Officer, CHO West, &amp; Angela O' Neill, National Disability Specialist, Community Operation</li> </ul>
J44. 21/10/2021	Aligning Disability Services with the UNCRPD in consideration of physical and sensory disability	<ul style="list-style-type: none"> <li>Damien O'Reilly</li> <li>Samantha Kenny</li> </ul>
J45. 04/11/2021	Aligning Disability Services with the UNCRPD in consideration of Autism and Intellectual Disability	<ul style="list-style-type: none"> <li>Representatives from AsIAM, Adam Harris, Founder and CEO</li> <li>Representatives from Autistic Paddies Gillian Kearns &amp; Marja-Kristina Akinsha,</li> <li>Jean Mullan</li> <li>David Doyle</li> <li>Tom McLoughlin</li> </ul>
J46. 11/11/2021	Aligning Disability Services with the UNCRPD in consideration of acquired disability	<ul style="list-style-type: none"> <li>Representatives from Irish Heart Foundation, Chris Macey, Head of Advocacy and Patient Support &amp; Fiona Bardon</li> <li>Mary Farrell</li> </ul>
J47. 18/11/2021	Aligning Disability Services with the UNCRPD in consideration of chronic disease	<ul style="list-style-type: none"> <li>Olga Wehrly</li> <li>Lorna McGreehan</li> <li>Anna-Karin Ulpe</li> <li>Representatives from Early Onset Parkinson's Disease (EOPD), Mary Casserly, Chairperson</li> </ul>

J48. 25/11/2021	Aligning Disability Services with the UNCRPD and in particular an update on progress regarding Disability Services	<ul style="list-style-type: none"> <li>• Anne Rabbitte, Minister of State at the Department of Children, Equality, Disability, Integration and Youth and at Officials from the Department of Health</li> <li>• Officials from the Department of Health Patsy Carr, Principal Officer, Audrey Hagerty, Principal Officer, Bernard O'Regan, Head of Disability Strategy and Reform, Breda Crehan Roche, Chief Officer, Community Health Organisation, West &amp; Professor Malcolm MacLachlan, Clinical Lead for People with Disabilities</li> <li>• Officials from Department of Children, Equality, Disability, Integration and Youth Niall Brunell, Principal Officer</li> </ul>
J49. 02/12/2021	Aligning Disability Services with the UNCRPD and considering the future system and innovation of Service provision	<ul style="list-style-type: none"> <li>• Representatives from Neurological Alliance of Ireland, Magdalen Rogers, Executive Director, Dr. Niall Pender, Board member and Principal Clinical Neuropsychologist and Head of Psychology, National Neuroscience Centre Beaumont Hospital</li> <li>• Representatives from National Federation of Voluntary Service Providers Dr. Alison Harnett, CEO, Michael Hennessy, Chair of National Federation and CEO of Brothers of Charity Services Ireland Natalya Jackson, Board Member of the National Federation and CEO of the Daughters of Charity Disability Support Services.</li> </ul>
J51. 09/12/2021	Aligning Disability Services with the UNCRPD and considering the future system and innovation of Service provision (resumed)	<ul style="list-style-type: none"> <li>• Representatives from National Advocacy Service, Louise Loughlin, National Manager, Joanne Condon, Southern Regional Manager</li> <li>• Representatives from Australian National Disability Insurance Scheme Peter Broadhead, Group Manager, Department of Social Services</li> <li>• Dr. Simon Walsh</li> <li>• Fiona Walsh</li> <li>• Aoife O'Toole</li> </ul>
J55. 03/02/2022	Equality and Non-Discrimination	<ul style="list-style-type: none"> <li>• Representatives from Irish Thalidomide Association, Finola Cassidy, Survivor and Spokesperson &amp; Jacqui Browne, Survivor and Committee member</li> <li>• Elaine Dennehy &amp; Representative from LightAware Anna Levin</li> </ul>

J72. 26/05/2022	Progressing Disability Services (resumed)	<ul style="list-style-type: none"> <li>Representatives from D12 Campaign for Inclusion, Helen Holmes</li> <li>Representatives from Down Syndrome Ireland, Nicola Hart, Member Support Team Leader</li> <li>Representatives from Cavan Monaghan Parents Committee, Linda Whitmarsh, Co-Chairperson</li> </ul>
J73. 02/06/2022	Progressing Disability Services	<ul style="list-style-type: none"> <li>Anne Rabbitte, Minister of State at the Department of Children, Equality, Disability, Integration and Youth and at the Department of Health</li> <li>Officials from Dept. of Health, Siobhan McArdle, Assistant Secretary, Social Care Division, Deirdre Comiskey, Principal Officer, Disability Services Unit, Audrey Hagerty Principal Officer, Social Care Integration Unit, Jason Doran Assistant Principal, Disability Services Unit, Thomas Morrin, Assistant Principal, Disability Services Unit</li> <li>Representatives from Health Service Executive (HSE), Paul Reid, Chief Executive Officer, Yvonne O'Neill, National Director, Community Operations, Bernard O'Regan, Head of Operations, Disability Services &amp; Breda Crehan-Roche, Chief Officer Community</li> </ul>
J84. 06/10/2022	Accessibility – Assistive Technology	<ul style="list-style-type: none"> <li>Representatives from Maynooth University, Malcolm MacLachlan, Professor of Psychology &amp; Social Inclusion and Co-Director, ALL Institute, Research &amp; Innovation Co-Ordinator WHO GATE Programme</li> <li>Representatives from Irish Association of Speech &amp; Language Therapists (IASLT), Muireann McCleary, Speech and Language Therapy and Adult Clinical Services Manager CRC &amp; Dr. Yvonne Lynch, Assistant Professor in Speech and Language Therapy, TCD</li> </ul>
J106. 26/01/2023	Consideration of Family Centered Practice and Parent Training Interventions	<ul style="list-style-type: none"> <li>Representatives from Triple P – Positive Parenting Program, Matt Buttery, Chief Executive Officer</li> <li>Representatives from Parents Plus Charity, Cherie Tyner, Chief Executive Officer, Ciara Ni Raghallaigh, Special Needs Programme Co-Ordinator, Niamh Kerrigan, Parent &amp; Wayne Mc Sweeney, Parent</li> <li>Representatives from Health Service Executive (HSE), Bernard O'Regan, Head of Operations,</li> </ul>

Disability Services, Professor Malcolm MacLachlan, Clinical Lead for National Clinical Programme for People with Disability, Caroline Canton, National Programme Co-Ordinator, Progressing Disability Services for Children and Young People & Angela O'Neill, National Disability Specialist, Community Operations





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