National Federation of Voluntary Service Providers
Supporting people with intellectual disability (CLG)

Submission on the Draft Initial State Report under the United Nations Convention on the Rights of Persons with Disabilities

April 2021

1.0 Introduction

Over two thirds of disability services in Ireland are provided on behalf of the State by the voluntary sector[i] . The National Federation of Voluntary Service Providers Supporting People with Intellectual Disability is the national umbrella organisation of not-for-profit agencies providing direct supports and services to people with intellectual disability in Ireland[ii]. Across almost 60 organisations, our members support more than 26,000 children and adults with intellectual disabilities and their families, providing services and supports throughout the lifespan. National Federation member organisations have community presence and connection across large urban centres and small villages throughout Ireland.

The National Federation warmly welcomes the opportunity to participate in consultation on the ***Draft Initial State Report under the United Nations Convention on the Rights of Persons with Disabilities*** (the Draft State Report)***.*** As the largest umbrella body of service providers supporting people with intellectual disability in Ireland, we believe that this submission presents a broad insight into views from the service provider perspective. We also believe that we have a shared responsibility together with State agencies and Departments to reflect on the implementation of the CRPD to date, to listen closely to the views of people with lived experience, and to progressively work together to achieve further implementation of the Convention and the further realisation of the rights of people with disabilities.

In order to prepare this submission, the National Federation has consulted widely with our membership. This included the convening of three national workshops, each dealing with a different range of the CRPD articles. At each, there was a broad representation from across the Federation's membership; and the facilitation of these workshops was provided by Dr Noelín Fox, Programme Director for Social Care with the Open Training College in St. Michael's House. We acknowledge the contribution of all of our members, and in particular those who prepared presentations on individual articles to facilitate discussion at the workshops. Following the workshops, members then also prepared written submissions. The written submissions and notes from the workshops were collated and edited into a draft submission which was then considered in detail, and signed off by the Board of the National Federation of Voluntary Service Providers.

2.0 Overarching themes

Whilst this submission will comment in detail on the Draft State Report and the views and experience of our members in relation to the *individual Articles* of the CRPD; a number of cross-cutting themes became evident through our consultation. These are outlined below and form an important overarching aspect of our feedback.

2.1 Positive framework of policy and legislation

The past decade has seen the development in Ireland of a highly positive framework of policy, legislation and practice programmes across the lifespan for people with disabilities. These include the *Progressing Disability Services for Children and Young People* programme (2009-onwards); the *Housing Strategy for People with a Disability* (2011-2016, extended to 2020); the *Time to Move on from Congregated Settings Report* (2011); and *New Directions Personal Support Services for Adults with Disabilities* (2012).
The recent establishment of the Oireachtas Joint Committee on Disability Matters is a positive step in terms of confirming parliamentary priority and oversight of the Government's progress in terms of realising the rights of people with disabilities. The *Assistive Decision-Making (Capacity) Act* (2015) will bring an important legislative underpinning in terms of a focus on rights and on the person's will and preference, when fully commenced. The National Federation welcomes these developments and participates in many of the steering committees and national groups set up to progress their implementation.

The most important development of the past decade in terms of the State's response to people with disabilities, however, came with the ratification by Ireland in March 2018 of the *United Nations Convention on the Rights of Persons with Disabilities,* a defining moment in the journey towards the realisation of the rights of people with disabilities in Ireland. The Convention provides the blueprint for State parties to uphold the rights of individuals with disabilities as equal citizens and sets out in its Articles the responsibilities of State parties in order to achieve this.

2.2 Implementation challenges

Unfortunately, the establishment of the positive framework of policy and legislation – underpinned by the ratification of the CRPD - has not been matched over the past decade with all of the necessary requirements, including sufficient investment and legislative commencement, to implement the vision held within these progressive policies, laws and programmes. There has also been a lack of co-ordination where responsibility crosses between Departments; which has often left the citizen without an adequate State response to accessing rights and needs.

As a result of gaps between Departments in relation to responsibilities towards people with disabilities, and due to the lack of sufficient or appropriate supports, thousands of individuals with disabilities are not currently being supported to live lives of their choosing, nor to maximise their potential to live as independently as possible, as contributing active citizens. In addition to the personal cost to the individual, this leaves significant challenges to the State's compliance with the requirements of the United Nations Convention on the Rights of Persons with Disabilities. These deficits will require focused attention on behalf of the State and all relevant stakeholders, to ensure that progress is achieved. We outline in this submission some key areas in which the rights of people with disabilities are not being realised and areas in which there is a need for change to effect progress in implementation of the CRPD.

There are some signs of hope. The most recent national budget has brought about significant investment into disability services and supports. Whilst not sufficient to address the magnitude of the difficulties facing people with disabilities, nonetheless this investment is at a scale not seen for over a decade. It will need to be continued over a number of years to achieve sufficient progress to address challenges outlined in this submission and in other sources [iii]. The HSE's Corporate Plan 2021-2024 includes as one of its six key priorities, the objective to *"Work to reimagine disability services, to be the most responsive, person-centred model achievable with greater flexibility and choice for the service user"*[iv]. This plan also commits for the first time to the multi-annual funding of disability supports, which will be essential to making a lasting impact. The establishment of the Decision Support Service and the repeal of the 1811 Marriage of Lunatics Act, similarly offer hope in relation to the implementation of key reforms. These welcome first steps must be continued over the coming years to have a sustained effect.

2.3 Progressive realisation and measurable targets

In point 7 of the Draft State Report, it is noted that the Government has adopted a 'progressive realisation' approach to the implementation of CRPD rights. However, the lack of progress in the implementation of existing policy and legislation to further the rights of people with disabilities (referenced above and described in further detail throughout this submission), demonstrates an urgent imperative to ensure that the targets for implementation of the CRPD in Ireland are made clear, measurable and achievable within a specified timeframe.

The Draft State Report indicates that the *National Disability Inclusion Strategy 2017-2021* addresses broader equality and inclusion issues such as the need for joined up public services to meet the needs of people with disabilities. Unfortunately, the implementation of this Strategy has not succeeded in securing change at a sufficient pace to ensure that many people with disabilities are enabled to live lives of their choosing. In fact, the mid-term review of the National Disability Inclusion Strategy concluded that:

> *"for most indicators there are no targets in the current strategy against which to measure any incremental changes. There were also some indicators for which there were little or no data available".*
>
> April 2020, P. 72

It is our view that to implement the CRPD, a clear set of measurable targets should form the cornerstone of the Government's overarching approach to meeting its obligations under the Convention, and that a new approach will be required to ensure greater momentum.

There is an urgent need to fully implement existing legislation and, in some cases, to develop new legislation to enable the implementation of the articles of the CRPD. Examples include the long-awaited commencement of parts of the EPSEN Act (2004), the Assisted Decision Making (Capacity) Act (2015) and to develop new legislation in relation to Article 14.

This submission will highlight many instances in which the gaps in responsibilities between Departments and lack of resources leave the citizen without access to their rights and their needs unmet. In the approaches developed to further progress implementation following on from the *National Disability Inclusion Strategy*, there is a need to consider how a more coordinated approach to the CRPD can be achieved at both national and local levels; and how the architecture and structures required can be put in place to ensure and support cross-Government and inter-Departmental cooperation in developing and implementing legislation and policy arising from the CRPD.

2.4 Article 19 – A comprehensive plan for Independent Living

One of the cross-cutting themes identified in the National Federation's consultation was the central importance of two articles: Article 19 and Article 12. The Committee on the Rights of Persons with Disabilities; the body of independent experts which monitors implementation of the Convention by the States Parties, has described Article 19 in its General Comment No. 5 (2017), as:

> *" one of the widest ranging and most intersectional articles of the Convention and has to be considered as integral to the full implementation of the Convention".*

It was clear in the consultation for this submission with members of the National Federation, that addressing the current challenges for supporting individuals into independent living options and inclusion in their communities, as set out in Article 19, are essential – but not currently achieved for a very significant amount of people with disabilities. Without the progression of implementation of this Article, the aims of many of the other Articles cannot be achieved.

Consequently, this submission calls for a coherent national plan for the realisation of the right to independent living and inclusion in communities, including support for agencies to re-configure their services to achieve this. Further detail is set out under the detailed feedback to Article 19, below.

2.5 Article 12- Supporting capacity and decision-making

The second Article that holds the most significant potential change for citizens with disabilities in Ireland is Article 12. The Committee on the Rights of Persons with Disabilities speaks to this importance also, and its interdependence with Article 19:

> *"Legal personality and legal agency are the bases for the realization of independent living within the community for persons with disabilities. Article 19 is, therefore, linked to the recognition and exercise of legal personality and legal capacity as enshrined in article 12 of the Convention".* [General Comment No. 5, 2017]

Through this consultation, members of the National Federation indicated that the full commencement and implementation of the Assisted Decision Making (Capacity) Act (2015) and the inclusion of its principles in all policy and legislation that will impact on people with a disability, are fundamental to the programme of work required to progress implementation of the CRPD in Ireland.

There is a sense of frustration that the roll-out of this Act has been very slow and that the existing Ward of Court system continues to be highly restrictive to those subject to it. Indeed, in the absence of an alternative, individuals continue to be brought into this process. Further feedback is provided under the specific Article 12 section of this submission, however along with the focus Article 19, **the National Federation stresses as a priority the urgency removing any remaining impediments to commencement of the Assisted Decision Making (Capacity) Act, in order to support implementation of Article 12.**

2.6 Inclusive Communities

A key theme that emerged from the consultation with National Federation members for this submission was that our shared focus together with Government and key stakeholders, should be building the capacity of communities to be **fully inclusive of all groups and individuals**. Accessing disability rights must not be understood to be in some way 'in competition' with the rights of marginalised groups. Instead, accessibility in the physical environment; Governmental systems; communications; and services **benefits all citizens**. The focus on the implementation of the CRPD in this way can and should be seen as having intersectional benefits for society as a whole.

In building supportive communities, it is important that the inclusion of people with disabilities is factored into all mainstream policy and legislative developments from the outset. There is a need to move away from reliance only upon separately funded structures or *pilot schemes*, many of which remain simply a local story, never to be implemented more widely (and sometimes discontinued due to once-off funding) in spite of significant success and positive outcomes. **Instead, the National Federation calls for communities to be supported and capacity built on the assumption that the needs and aspirations of people with disabilities are considered from the outset and form part of coherent policy which is inclusive of all citizens. To assist in planning, the Government should be guided by the steps outlined in the 'General Comments' issued by the Committee on the Rights of Persons with Disabilities regarding *'Implementation at the national level'.***

2.7 Listening to the Voice of People with Disabilities

All processes of consultation and practice relevant to people with disabilities should proactively seek to include the voice of people with lived experience of disability. At an individual level, it is essential that independent advocacy is made available to all people with disability who require it, especially at times when the person is considering important issues in their lives. The principles of 'will and preference' that underpin the Assisted Decision Making (Capacity) Act must be the guiding framework for listening and responding to the voice of the individual with a disability.

At the broader national level, to ensure the lived experience of people with intellectual disabilities in particular is fully included, consultation processes must allow sufficient time to allow for people with intellectual disabilities to be supported to understand documentation, deliberate on the information they would like to put forward, and formulate and submit their responses. **This means that all national consultation processes should include a substantial time frame for response and materials seeking submissions should be provided in accessible formats.** The consultation process for this State Report, and the current consultation on the development of the next *Housing Strategy for People with a Disability* are positive examples of highly inclusive processes. The materials for the Housing Strategy consultation have been made available in plain English, Easy to Read format and have been read out in a video presentation. This helps people for whom written communication is challenging. As with all universal design processes, the provision of accessible options for participation in consultation processes is of benefit to many more individuals than just those with disabilities, and there are many citizens for whom accessible communication is welcome and essential. Individuals with disabilities have indicated that video summaries of key content with Irish Sign Language (ISL), as well as Easy-to-Read and Plain English formats are helpful.

There is a particular need to ensure that the voices of children with disabilities are included and listened to. The recently commissioned report by the Ombudsman for Children's Office; '*Mind the Gap: Barriers to the realisation of the rights of children with disabilities in Ireland'* [v](2021) found that consideration of the needs and experiences of children with disabilities is often missing in mainstream policies and legislation for children; and that children with disabilities are often not asked what they think about laws, policies and services that affect them. In the case of children with disabilities and for adults where family members are providing significant support, it is also important that the voice of families is listened to where appropriate in key consultations (whilst respecting the primacy of the voice of the individual).

There is a specific need to ensure that self-advocacy on the part of people with intellectual disabilities is supported and funded. A key challenge is the need for self-advocacy DPOs of people with intellectual disabilities to be supported around the governance required to access Government funding. It is likely that innovative approaches will be required to achieve this goal, however if this issue is not addressed there is a risk that the independent voice of people with *intellectual* disabilities will be absent from decision-making processes.

2.8 Unmet Need/Equality

Ultimately, plans for the implementation of the CRPD without sufficient resourcing for essential supports will not make a real difference in the lives of people with disabilities. A fundamental thread throughout our feedback to the Draft State Report is that a lack of investment for over ten years has left people with disabilities in Ireland at this time with severely challenging unmet needs.

There is a need for sustained investment and focus to address the significant unmet needs presenting, to ensure that people with disabilities are supported and enabled to live life in the community on a equal basis with others. While the issues as set out below are addressed in greater detail throughout this submission, via feedback on specific CRPD articles, the following key issues require an urgent response:

- There are significant waiting lists for children with a disability to both assessment of needs (AON) and to required services including multi-disciplinary supports; with serious implications for children's quality of life and development.
- The significant difficulties being experienced by both children and adults with intellectual disabilities in relation to accessing adequate multi-disciplinary supports can lead to avoidable deterioration in the conditions of the individual, with consequent effects on quality of life and on the future costs to the State for supporting the person in the activities of daily living.
- The pace of movement from congregated settings to community settings has been unacceptably slow. The timeline envisaged for completion of the work under the *Time to Move On from Congregated Settings Report* (2011) has already passed, with close to 3,000 people remaining in congregated settings.
- There is a lack of new planned residential supports, which leaves many people with intellectual disabilities living in unsuitable settings with people that they have not chosen to live with.
- While there has been very positive work undertaken on the development of respite and alternative models of short-break support that focus on opportunities for personal development and community connection for the individual, there is a need for the implementation of an overarching policy to guide the provision of respite or short breaks to people with disabilities. It is essential that the positive models available are considered and brought together in the development of a new policy that responds to the requirements of the UNCPRD.
- Overall employment levels of people with disabilities in Ireland remain very low; and in particular employment opportunities for people with intellectual disabilities needs to be addressed. There is an urgent need for cross-Departmental working to address the provision of supported employment to people with ID and to ensure local and national structures are in place and fit-for-purpose, including maintaining the expertise built up over many decades of supported employment through disability service providers.
- There remain very significant unmet needs in relation to transport services required by people with disabilities, including the long-standing need for the Motorised Transport Grant and Mobility Allowance to be reinstated. Particular challenges facing those living in remote, rural communities also need to be addressed.

- There has been substantial work undertaken on the model of support to be provided through adult day services, with the introduction of the *New Directions Personal Support Services for Adults with Disabilities* programme. Voluntary disability services have worked closely with the HSE to ensure that services have been provided to all new entrants, including through the worst years of austerity. However, the implementation of the New Directions person-centred approach to both new and existing users of adult day services is significantly challenged in several ways e.g. limited capital investment into the locations in which adult disability day services are delivered and the need for therapeutic supports for adults with ID. Increased allocation in the School Leaver funding in 2021 is very welcome, however increased resources will be needed on a multi-annual basis, and should also be targeted to those who have been using day services in the longer term.
- As the lifespan of people with intellectual disabilities has increased – which is a hugely positive trend, there is a rise in the number of older adults with ID who have significant support needs and changes in their support needs. The incidence rates for dementia in people with Down syndrome for instance, are multiple times higher than in the general population. Other areas of health that influence changes and increases in the support requirements of people with disabilities include mobility challenges, bone health and emotional health. The State has a significant ongoing role in ensuring appropriate supports to facilitate individuals to experience ageing in a positive manner, however service providers report significant difficulties in securing funding for supports for changing needs. **Planning must be in place to respond to the resource requirements brought about through the changing needs of older adults, which result in cost requirements in day, residential and respite services.**

The National Federation calls for the publication, without delay of the long- awaited Capacity Review of Disability Services to provide an evidence base to underpin the response to the substantial unmet needs requiring investment.

2.9 Model of Service Provision going forward:

In seeking to implement the articles of the CRPD there is a need for clarity in relation to the overall model of service provision going forward. Over two-thirds of disability services are provided by the not-for-profit / non-statutory sector in Ireland. This reliance on voluntary organisations should be acknowledged by the State with real engagement in relation to the future model of service provision. Voluntary organisations wish to work in partnership with relevant Government departments in realising the vision as set out in the UNCRPD and making it a reality for people with a disability in Ireland.

2.10 Optional Protocol

The challenges facing Ireland in implementing the CRPD are evident, and together, all sectors with influence must work to ensure that progress is based on an ambitious, coherent, cross-Governmental plan, and that citizens have the right to bring petitions where they believe that there has been a breach of their rights. It is positive to note that the Programme for Government reiterates the commitment to ratify the Optional Protocol after the first reporting cycle.

To support transparent and accountable progress on implementation of the CRPD, the National Federation calls for the ratification of the Optional Protocol to proceed without delay.

3.0 Feedback on individual Articles of the Convention

National Federation members recognise the importance of all articles and this submission therefore in Section 4.0 provides feedback on the Draft State Report across a wide range of these articles. This section of the submission sets out the National Federation's response in relation to a number of specific articles of the CRPD as it was highlighted during our consultation process that there are articles of particular concern or importance in our members' experience, and these will be commented on first. These include the following:

- Article 19 - Independent Living and Inclusion in Community
- Article 12 - Legal Capacity;
- Article 9 - Accessibility
- Article 7 - Children
- Article 24 - Education
- Article 27 - Work and Employment
- Article 25 - Health
- Articles 1- 4 - General obligations

This submission will first present the feedback in relation to these specific articles, followed by feedback on the Draft States Report in relation to the remaining articles in numerical order.

3.1 Article 19 - Independent Living & Inclusion in Community

Positive progress

The development of the first *National Housing Strategy for People with a Disability* (which is now in its final year), and the consultation currently taking place for its successor, is a positive, cross-Departmental response to the importance of access to housing and the required supports for people with disabilities to live in the community. One of the key positive achievements of the Strategy has been the introduction of a new Assessment of Housing Need process – which explicitly underpins the State's approach that a person '*shall not be deemed adequately housed*'[vi] when they live in a congregated setting, group home, or in the family home if they no longer wish to do so. In this way the Assessment process recognises individual choice in a very tangible manner. As set out in the Draft State Report (Item 234), the Strategy has also overseen the setting up of Housing and Disability Steering Committees in each Local Authority, with the aim of putting in place strategic planning for the housing process for individuals with disabilities. For those individuals who have been supported to move from institutional settings to homes of their choice in the community; with the appropriate supports, it has been a transformative process[vii].

Issues of concern

Whilst recognising these successes **it is also essential for the Draft State Report to acknowledge the very significant deficits in relation to Article 19 that persist**. The target set out for completion of the work under the State's own policy *Time to Move on from Congregated Settings* (2011) was due to be completed by 2019, and yet close to 3,000 people remain living in these settings. Further emphasis is required on ensuring that the pathway to community living avoids creating smaller mini-institutions; and a pathway to planned living supports outside of emergency provision is created.

The National Federation calls for the Government to use the extensive clarifications set out in the Committee on the Rights of Persons with Disabilities' General Comment No. 5 (2017)[viii] in setting forth its plans for the next housing strategy for people with a disability, and its strategy under Article 19. The adoption of a rights-based approach and the presumption of capacity will be key drivers of success in this area.

The CRPD states, in Article 19, that people with disabilities must:

> *"have access to a range of in-home, residential and other community support services, including personal assistance necessary to support living and inclusion in the community, and to prevent isolation or segregation from the community".*

However, there is ample evidence, in numerous reports, of these needs not being met due to a lack of investment of the required resources by the State. For instance:

- The *Annual Overview Report* on the inspection and regulation of disability services published by HIQA in September 2020 identifies that 2914 people with disabilities remain living in congregated settings[ix]. The impact for people living in these settings is considerable: the report references the fact that quality of life outcomes for people living in these settings is poorer and safeguarding issues significantly more prevalent than for those living in appropriate settings;
- 1300 younger people with disabilities under the age of 65 are inappropriately accommodated in nursing homes[x]
- The National Federation's own research has indicated that more than 1250 people are supported in the family home by a primary carer who is over the age of 70, at least 400 of whom are over the age of 80[xi];
- At this time resources are so scarce that for adults living in the family home there is no pathway to apply to access supports to live apart from their family of origin in the community, other than through an emergency.

Although funding has been provided over the past decade to support a proportion of the cohort of people living in congregated settings to move to the community, the pace has fundamentally been too slow, leaving many people remaining in these settings. This is having a significant impact on individuals' lived experience[xii], (as evidenced in HIQA's Annual Overview Report, 2019) and breaches their basic human rights on a daily basis. The report presents evidence of individuals living in over-crowded living environments; lack of privacy as individuals are sharing bedrooms; and individuals being exposed to peer-to-peer assaults due to living in living environments where people sharing are not compatible and never choose to live with each other. In many cases, individuals are living in environments very removed from the life of the community, as they are situated in very rural areas with little or no public transport infrastructure – which exacerbates ongoing isolation and segregation;

> *"Providers of congregated settings were challenged in their ability to provide a dependable service that promoted and protected the rights, safety and quality of life of residents"*
>
> [Annual overview report on the inspection and regulation of disability services in 2019, p.9]

Over the past decade there has been a lack of funding for *new planned residential supports*, leading to significant built-up unmet need[xiii]. Funding cuts over the past ten years[xiv] and the lack of new funding to meet demographic need means that those residential supports that have been put in place have often been met on an emergency basis [xv] [xvi]. This means that many citizens living in the community continue to live in situations that are not of their choosing or where families are experiencing significant unsustainable care responsibilities [xvii].

Simultaneously, the (appropriate) closure of those congregated settings or places which have been discontinued, means that previously available residential support options are no longer available as new need comes on-stream. Congregated settings have not been replaced with a sufficient pipeline of new, funded community-based supports for those coming into adulthood, or whose needs (or those of their carers) change and who now require residential support. In the period 2009-2014 there was a net reduction in the number of residential places provided [xviii] contributing to a continually growing and urgent level of unmet need.

While mainstream housing options have been made increasingly accessible to people with disabilities via the *Housing Strategy for People with a Disability* [xix], [xx], these options cannot be accessed without corresponding health and social care supports. With a lack of new support packages, the potential benefits of mainstream housing allocation have not yet been fully realised for people with intellectual disabilities in terms of the numbers of allocations, in spite of the success and considerable quality of life benefits for those individuals who have been able to secure tenancy [xxi]. In addition to the stress of having the transition to living outside the family home met in an emergency rather than in a planned and individually chosen way, meeting residential support need in an emergency model is more expensive than planning and maintaining vital natural supports which can then be supported with the required level of paid resources needed for an individual.

Given that the pace of movement from congregated settings to community settings remains gravely behind schedule [xxii], and together with the lack of new planned residential supports, this leaves many people with intellectual disabilities living in unsuitable settings with people that they have not chosen to live with.

In summary:

- It is still fundamentally the case that contrary to Article 19 of the UNCPRD, adults with intellectual disabilities ***do not have a pathway to planned residential support.*** Instead, it is the experience of our members that most individuals with intellectual disability who begin accessing residential supports currently do so under distressing emergency circumstances, often when an elderly parent who has been providing primary support passes away or when significantly complex needs are not possible to meet within a family's circumstance and this leads to an urgent requirement for residential placement.
- This has consequences not only for the person themselves but often for their family too. Older family members are trapped in unsustainable caring roles in the community as a consequence of a decade in which there has been a lack of investment in planned supports. Many parents are currently providing significant support as primary carers into their 70's, 80's and beyond, with no visibility or security in terms of planning for the future of their loved one. The impact of Covid-19 has in particular further tested the resilience of these individuals and their families.
- Ten years on from the publication of the *Time to Move On from Congregated Settings* report, there remains a substantial number of people living in congregated settings, with significant impact on individual lives as outlined above.
- Due to the lack of availability of planned residential supports as outlined above, many individuals and their families have an urgent need for respite based on their underlying unmet needs. For many services, the reality presenting now is that a significant proportion of their capacity for planned short breaks/respite is taken up with providing full-time support to individuals and their families who are in crisis, when family arrangements break down or acute emergencies present; thus reducing service providers' capacity to support the wider range of individuals and families who need to access this service.
- Covid-19 has pushed the resilience of many people with disabilities and their families to breaking point, as the quantum of service usually provided has been reduced for social distancing and in line with HSPC guidance. There is therefore a need for immediate capacity building within respite services, and more strategic policy development and implementation to achieve a vision that is person-centred and UNCRPD compliant in the provision of short break services.
- Planned residential supports that respond to the individual's choice, and support independence can be provided in a wide range of models including supported independent living; PA and home support; and full-time residential support. Currently there is an over-reliance on the group home model as an alternative to congregated living arrangements. There is a need for planned access to the full range of potential residential supports.
- To facilitate the needed change, substantial multi-annual, planned funding will be required, and agencies must be supported in unbundling funding from group arrangements/bridging funding and provided with particular support at transition times to ensure that the individual can plan their access to a living arrangement that is in line with their will and preference.

- The Draft State Report notes the development of Universal Design Guidance (Item 238). However, measurable targets for the development of housing using Universal Design are essential to ensuring meaningful implementation so that the future stock of housing includes a pipeline of accessible homes for individuals with disabilities.
- In order for the individual to secure their rights under Article 19, there is a complex interaction required between State provision of housing, disability supports and other mainstream supports such as access to Primary Care, transport and community facilities. **To navigate this complex landscape and achieve real progress in the implementation of Article 19, a national, cross Governmental plan on progressing the rights of persons with disabilities to independent living, should be developed and implemented and should be informed by the Committee on the Rights of Persons with Disabilities' General Comment No. 5 (2017).**

3.2 Article 12 - Legal Capacity

As outlined above, Article 12, similarly to Article 19; is an article with enormous intersectional implications, the implementation of which affects the rights accessed throughout the rest of the CRPD. As a result, in our response to the Draft State Report, the National Federation considers feedback to Article 12 to be a priority.

Positive progress

The Enactment of the Assisted Decision Making (Capacity) Act in 2015 (ADM) was a significant, positive milestone in the State's progress towards ensuring the individuals with disabilities enjoy equal legal capacity in all aspects of life as envisaged in Article 12 of the CPRD. As a consequence, there have already been some fundamental shifts in legislation; for instance; Section 7.1 of the ADM Act, commenced in 2021, repealed the Marriage of Lunatics Act 1811. With the full commencement of the ADM Act in the future, the right to marry will be based on capacity.

The incorporation of the principles of the Act in more recent policy and legislative proposals is also becoming evident e.g., in the HSE's *National Consent Policy*. The National Federation notes the transfer of responsibility for the ADM Act to the Department of Children, Equality, Disability, Integration and Youth, and is hopeful that the focus on equality of this Department will be a driving force of momentum to ensure continued progress on its full commencement. The establishment of the Decision Support Service is very welcome. It will be essential that sufficient resources are provided by Government to ensure that this service can fully implement its responsibilities as set out under the Act.

Issues of concern

The Draft State Report outlines (Item 142) that:

> *"Ireland has declared its understanding that the Convention permits supported and substituted decision-making arrangements which provide for decisions to be made on behalf of a person, where such arrangements are necessary, in accordance with the law, and subject to appropriate and effective safeguards.*

> *To the extent Article 12 may be interpreted as requiring the elimination of all substitute decision-making arrangements, Ireland reserves the right to permit such arrangements in appropriate circumstances and subject to appropriate and effective safeguards."*
>
> Draft State Report, p.20

However, despite the decision of the State to enter this declaration, the Committee on the Rights of Persons with Disabilities clarifies in *Disabilities General Comment No. 1* (CRPD /C/GC/1 2018) that

> *'The development of supported decision-making systems in parallel with the maintenance of substitute decision-making regimes* ***is not sufficient to comply with article 12 of the Convention****. The role of the court in situations where a person is deemed to lack capacity, is not to substitute the person's decision-making, but rather to ensure that the supports the person needs to exercise their capacity are in place and are free from any conflict of interest'.* [Paragraph 8].

Nonetheless the passing of the ADM Act represents a major and welcome shift in thinking nationally about the legal capacity of people with disabilities. The feedback of the National Federation in relation to the Draft State Report in relation to Article 12 is summarised below:

1. As noted in section 2.5 above, there is considerable concern at the pace of commencement of the ADM Act. Full commencement of all parts of the Act is required without delay – and there is a need for a targeted implementation plan within a reasonable timeframe. The current commitment to fully commence the ADM Act in 2022 must now be adhered to.
2. Due to the delay in commencing all parts of the ADM Act, adults are still being taken into Wardship in the absence of an alternative, removing them from all decision-making rights contrary to the approach of the Act in relation to the presumption of capacity being issue and time specific. (Item 147 of the Draft State Report). This is a significant deviation from the principles of Article 12. These individuals will need to be transitioned from Wardship when the new Decision Support Service is operational. All stakeholders will need information as soon as possible on how the winding up of Wardship will work in practice.
3. Publication of the Draft Codes of Practice (Item 151) and national guidance is required as soon as possible, with adequate time provided for people with disabilities and all key stakeholders to be involved in meaningful consultation before finalising.
4. There is a need for the development and implementation without delay of a plan for the implementation of the Act at local level. Supports will need to be provided and resourced; including training and awareness raising.
5. There is a need to ensure the full accessibility of the Disability Support Services to all people with disability. The National Federation is concerned that there is a danger of over-reliance of online access which could disadvantage people experiencing a digital divide - including those with disabilities and many family members who, as outlined above, continue to provide significant support for their loved ones well into older age.
6. The delay in fully implementing the ADM Act has left people with disabilities, their families and support services in a very difficult situation as highlighted by recent experience of Covid-19 vaccination consent.

The HSE National Consent Policy (2019) indicates as its first principle that:

> *'No other person such as a family member, friend or carer and no organisation can give or refuse consent to a health or social care service on behalf of an adult service user who lacks capacity to consent unless they have specific legal authority to do so.'*

In the absence of the decision-supports provided for under the ADM Act, people with disabilities currently do not have the opportunity to formally nominate a family member or any other person to assist them in making decisions – and so are left in limbo.

7. The ADM Act appears to preclude people who have formal decision-making supports in place from at the same time being co-decision makers or decision-making assistants. This is a blanket exclusion and should be reviewed.
8. More work is required by the State to address the interface of the ADM Act and existing legislation and national policies such as the Safeguarding Policy, Consent Policy. Other areas where the ADM Act needs to be incorporated include The Mental Health Act 2001, The Nursing Homes Scheme, Persons detained without consent in residential services, Hospitals and Mental health services.

3.3 Article 9 – Accessibility

The Disability Act (2005) provides a statutory basis for making public services fully accessible, placing obligations on public bodies to make public buildings, services, and information accessible to persons with disabilities. However, much remains to be achieved in this regard. The key issues arising for people with a disability supported by members of the National Federation are set out below.

Transport:

Recent improvements in transport measures for people with disabilities as reported in the *Midterm Review of the National Disability Inclusion Strategy 2017-2021* - such as reduced notice periods for use of the Dart and train users; and increased accessibility on buses, are welcome. However, there remain very significant unmet needs in relation to transport services required by people with disabilities and these include:

- The long-standing need for the Motorised Transport Grant and Mobility Allowance to be reinstated;
- Our members report many practical / day-to-day challenges associated with the availability of and use of transport for people with a disability which include:
    - A requirement to phone train stations when a wheelchair user needs a ramp and this facility only being available during office hours;
    - The gap being too wide at train stations - this affects the blind and the visually impaired;
    - Insufficient time to board / exit the LUAS when using a wheelchair or other mobility device;
    - Lifts at train stations regularly being out of order;
    - Having to ask for the ramp on buses / and reports of some staff being unsupportive of individuals to want to use a ramp;
    - Bus stops or times changing without notice or information which can cause problems for people when changing route. The Travel Assistance Scheme operated by Dublin Bus is good service which needs to be further developed and resourced.

- In order to access a service, there are many individuals with intellectual disabilities for whom mainstream transport does not yet provide an accessible option or for whom rural isolation means there is no access to a mainstream route. This can impede people with a disability in all areas of life including access to work and educational opportunities.
- There are significant gaps relating to the transport needs of people supported by funded disability services, and these difficulties have been made more visible by the social distancing requirements of Covid-19 which has further reduced capacity on transport services.
- HSE does not consider the funding for transport to support adults to access their day service as part of its core role and funding provision. Thus, shortfalls in funding are reducing the opportunities to young people leaving school to access their newly arranged day services whilst the Department of Transport has not taken up this responsibility. Plans to provide additional accessible public transport have not advanced and consequently there has been a failure to address the issues for adults with an intellectual disability who require door to door transport to access day supports.
- Across intellectual disability service provider organisations there is an ageing fleet of vehicles which pose a safety risk, and for which no funding has been provided for replacement. Research undertaken by National Federation members in 2019 indicated that across a sample of just 33 member organisations, transport was provided to 6384 people to attend their service and community activities. The survey found that across these services there were 532 vehicles which were over 10 years old, and which required replacement. However, nationally there is no agreement on the Departmental responsibility for transport for people attending disability services and consequently no plan in place to deal with the urgent and potentially dangerous transport deficiencies presenting.
- Funding restrictions currently prevent the allocation of monies from Section 38 organisations to purchase fixed assets such as vehicles and the borrowing of money to lease or hire vehicles, further constraining the ability of voluntary disability services to resolve the issues facing people who need transport to access their service.
- The Health (Transport Support) Bill which had been on the list of priority legislation for publication in the Spring/Summer session 2018[xxiii] has not progressed and is not currently included on the list of priority legislation in the Spring programme.

Information and Communication Technology (ICT):

- The State is obliged to promote access to ICT systems for people with disabilities, however while the Government announcement in 2020 of funding for ICT equipment for Further Education and Training (FET) Colleges was welcome, the funding is insufficient to cater for all affected by the digital divide. This provision should be revisited, with the State addressing the increasing need for both access to ICT equipment and supports to individuals who wish to learn / increase use of ICT supports.
- Furthermore, the move to remote and blended learning in response to Covid-19 restrictions has disproportionately affected students with disabilities, as some students do not have access to IT equipment at home and may not be able to successfully access public services/buildings to use IT equipment.

Public Facilities:

- As outlined above in relation to Article 19, living in the community on an equal basis requires access to community spaces and facilities. However, basic public facilities are not available in many locations for people with disabilities who want to move around or travel within their own community, including at the most basic necessity of accessible public toilets. Initiatives such as 'Changing Places', pioneered by Inclusion Ireland over recent years and resulting in the installation of a number of universally accessible facilities in Ireland, should be further promoted and developed.

Accessible Information/Hearing the Voice of People with a Disability:

- There is a need for increased investment in accessible public communication and resource materials. The National Federation has supported the National Cancer Screening Service in working with member organisations in developing accessible resource materials to support and encourage women's uptake of screening services. Initiatives such as this are key in encouraging women's participation in national health programmes and promoting positive health outcomes for women with a disability - and should be expanded across all areas of public health.
- There are several strategies in place setting out how children and adults with a disability should be consulted with, however, there is a need for increased resources to support such consultation processes, including training to support capacity building and engagement. Involving people with a disability at the outset of any strategy or policy development is key.
- Facilitating the participation of people with a disability in political and public life is essential – and within this supporting capacity building of role models as politicians and community activists is important.

Finance and Banking

- Better access to banking supports is essential to ensuring that people with disabilities – particularly those with an intellectual disability can have control over their finance, which in turn provides access to choice in daily life decisions. Some banks have recently set up specific units to make supports available and this should be encouraged further. Measures should be introduced to make access to opening a bank account easier for people with disabilities

3.4 Article 7 – Children

Article 7 of the UN Convention focuses on ensuring the full enjoyment by children with disabilities of all human rights and fundamental freedoms on an equal basis with other children. It also indicates that in all actions concerning children with disabilities, the best interests of the child shall be the primary consideration - with children having the right to express their views freely on all matters affecting them and provided with age / disability appropriate assistance to realise that right. Key feedback points from National Federation members in relation to Article 7 are set out below:

Progressing Disabilities Services for Children and Young People (PDSCYP):

The PDSCYP Programme provides a positive, family-centred approach to supporting children with disabilities and their families. However, implementation of this programme has progressed at a slower pace than required. **Consequently, children are currently on long waiting lists for services with some even aging out of early intervention before receiving supports**; **and there are delays in accessing the**

Assessment of Need Process. The system is currently prioritising assessment over the required support. This leaves children and their families experiencing significant distress and inequality – with some families seeking private diagnostic and therapeutic supports and others unable to afford to do so. Recent investment is very welcome, however **there is a need for sustained funding and focus to address the significant needs presenting and ensure that children with disabilities are supported to reach their best potential.**

- Overall there is a lack of sufficient multidisciplinary resources to adequately meet with the needs of children with disabilities.
- Delays in accessing guidance from therapists to support their child, leaves many parents feeling isolated and stressed. Children with communication difficulties may find it difficult to express their needs which can translate into challenging behaviours, including self-harm. Where children are provided with the necessary supports, including speech and language / occupational / physiotherapy this can help regulate and support children to communicate their needs.
- In some school settings, there are children on reduced timetables without access to the necessary therapeutic supports, including speech and language and occupational therapy.
- The commitment as outlined in *HSE Service Plan 2021*[xxiv] to the provide 100 additional posts to the network teams to improve assessment of need and support is a very welcome development, as is the move towards the completion of reconfiguration under PDSCYP. There is a need for continued multidisciplinary support allocations in future years to support the full implementation of the PDSCYP programme.
- Assessments of Need (AON) must be provided to all children requiring same within a timely manner, with the required support provisions being put in place so children can live their best life and meet key developmental milestones.
- The Education for Persons with Special Educational Needs Act 2004 has yet to be fully commenced. This Act contains a 'best interests' principle' regarding the placement of children with special educational needs (SEN) in inclusive environments. *Further feedback on the educational needs of children with a disability is outlined in this submission under Article 24; section 3.7 of this submission, below.*
- A high percentage of children are successfully accessing supports under the Access and Inclusion Model (AIM), which is very positive. However, some children with complex medical needs require nursing supports and this is proving a difficult barrier to inclusive access for this cohort of children. It is essential that the required supports are provided to ensure all children with disabilities can access the Early Childhood Care and Education (ECCE) Programme with its important goal of empowering pre-school providers to deliver an inclusive pre-school experience, ensuring that every eligible child can meaningfully participate and reap the benefits of quality early years care and education[xxv].
- *'Sharing the Vision: A mental health policy for everyone'* (2020)[xxvi] should be fully implemented and resourced. While the establishment of the CAMHS ID Teams is of vital importance to support children and adolescents with mental health challenges, the resourcing of posts to enable these teams to meet their objectives is key. There remain significant gaps in services for children with complex needs in accessing mental health supports.
- The 2017 *Joint Protocol for Inter-Agency collaboration between the HSE and the Tusla*[xxvii] is key in supporting joint working between the agencies to support the provision of life long care for children/adults with complex needs who require specialist services. The development of individual pathways to support such children and families whose needs cross between the HSE and Tusla is critical. A key commitment is outlined in *HSE Service Plan 2021,* to prioritise co-funding the placement

of 33 children and supporting the transition of a number of young adults from Tusla to adult disability services; through dedicated joint working sessions across child and adolescent meant health services (CAHMS), primary care and disability services. This provision is very welcome, as is the stated commitment to progress the full implementation of the agreed joint protocol.

- The implementation of recommendations of significant reports of the Ombudsman for Children in this regard is essential, such as '*Jack's Case: How the HSE and Tusla, the child and family agency, provided for and managed the care of a child with profound disabilities'* (2020)[xxviii].
- A recently published report commissioned by the Ombudsman for Children's Office (OCO); '*Mind the Gap: Barriers to the realisation of the rights of children with disabilities in Ireland'* (2021)[xxix], sought to address two key questions: (1) What are the key barriers to the realisation of the rights of children with disabilities in Ireland? and (2) What measures are required to address these barriers appropriately and effectively? The findings and learning from this research should be reviewed with the aim of ensuring an increased focus on the realisation of children's rights.

3.5 Article 24 – Education

Positive progress

The significant investment in education for students with special educational need as outlined in the Draft State Report is a welcome acknowledgement of the essential place of education in levelling inequalities experienced by people with disabilities, and is a sign of the commitment of the State to support students with a disability. The National Federation welcomes a range of positive initiatives, including the commencement in 2020 of the Education (Admission to Schools) Act, 2018; which precludes discrimination against an applicant with a disability to enrolment in a school; highly positive outcomes from a number of *pilot* initiatives to support people with intellectual disabilities in 3rd level settings; and the inclusion of children with special educational needs through the AIM programme.

Issues of concern

However, there are stark inequalities for young people with disabilities in relation to education which must be addressed as a matter of priority in order for students with intellectual disabilities and ASD in particular to be fully included in the progressive realisation of Article 24. For instance, pupils in special schools have **no access to guidance counselling services,** thereby reinforcing a negative cycle of low expectations and limited options for young adults attending these school settings. Outside of a number of very positive pilot initiatives, students with intellectual disabilities do not have the same access to the supports provided to students with other disabilities in order to access 3rd level education and are not included in targets or tracking within the current system. Key issues identified by National Federation members in relation to education are summarised below:

- Throughout the Draft State Report there are references to the Education for Persons with Special Education Needs Act, 2004 (EPSEN Act), and in Item 289 it is identified as '*the primary piece of legislation dealing with education for persons with disabilities'.* However, it is of significant concern that in 2021 this 2004 Act has not been fully commenced, and the report is silent on the reasons for this delay.

- Item 286 of the Draft State Report states that;

  > *"Persons with disabilities in Ireland have equal rights of access to education. The Equality Acts prohibit discrimination against persons with a disability in the areas of admission, access, participation and expulsion and sanction. Ireland's anti-discrimination legislation protects teachers and other education staff with a disability."*

  In this regard the absence of provision of guidance counselling services to students in special schools (routinely available to students in mainstream settings) is an unacceptable contravention of Article 24.
- Members report long waiting lists to access assessments for children in educational settings.
- Our members have highlighted a need for more opportunities for change to be implemented for students with disabilities in special education schools - as some students remain in the same class with the same teacher for a longer period of time than children in mainstream.
- Inclusion of students with disabilities in third level education requires significant development in Ireland, in particular for people with intellectual disabilities and ASD, who currently experience an inequity of access. The implementation of the Department of Education and Skill's *National Access Plan* is designed to ensure that the student body in post-secondary education is reflective of the diversity of Irish society. However, intellectual disability/ASD data is not included in the figures presented, nor are they reflected in the *National Disability Inclusion Strategy Midterm Review*. It is very disappointing that the Draft State Report, in Item 300, speaks about the achievement of targets in respect of '*the three categories of disability'* (physical or mobility; deaf or hard of hearing; blind or vision impairment) without referencing the absence of targets or reporting for students with intellectual disability and /or ASD.
- **A fundamental difficulty identified by the consultation to develop this submission is a lack of meaningful transition planning to support young people with intellectual disabilities/ASD to consider their options for the future and to plan for their post-school life. A system of transition planning that begins several years before the student finishes school and includes career guidance, educational planning, career preparation and work experience should be resourced for all students with disabilities as a matter of urgency.**
- There is a requirement for the system to take account of the differing needs of students with intellectual disabilities – for instance to ensure that students can attend on a part time basis whilst accessing supports, and to have accommodations made with regards to accreditation level. Where these accommodations have been made in a small number of 3rd level institutions there have been hugely positive experiences reported both for students with intellectual disabilities. The inclusion of students with intellectual disabilities was also noted as bringing positive outcomes for their non-disabled peers.
- It is internationally recognised that lifelong learning is an essential requirement if the full participation and inclusion of people with disabilities is to be achieved. With regards to education in Ireland for people with ASD, a recent report found 54% of students with ASD were experiencing exclusion or extended absences from secondary school (AsIAm, 2019). In terms of reaching third level, it is apparent that there is a significant cohort of young people who have disengaged from the education system at a very early stage and that the advantages of a full education are removed entirely.

- During the consultation National Federation members identified that people with disabilities who go to third level sometimes lose all supports, resulting in a breakdown of their educational access and a re-entry into the disability-specific support system. It would instead be better to provide individuals with support in liaison with the university to enable them to navigate the system and succeed in college. It is important to note that individuals sometimes do not identify themselves in college for support and drop out before interventions can be put in place – and this further highlights the need for coordinated transition planning.
- Item 306 of the Draft State Report notes that '*Education is compulsory from the ages of six to sixteen, or until students have completed three years of second-level education'.* Irish "Special Schools" are funded under "Primary Curriculum" and are therefore treated as primary schools having several unintended impacts – e.g.:
    - Funding during COVID-19 for devices for students to attend remotely was mainly targeted at Post-Primary schools, leaving Special Schools to compete for a much smaller allocation.
    - Appropriate Post-Primary programmes such as "Transition Year" or "Career Guidance" are not available in Special Schools to students of "secondary" age because these programmes do not fit with "primary curriculum".
    - Work Experience programmes for students to explore the world of work while in school are not widely available because Primary Schools do not routinely support work experience and therefore there is a need for capacity building around this area.
- Article 24 (5) sets down that States Parties

  > "*shall ensure that persons with disabilities are able to access general tertiary education, vocational training, adult education and lifelong learning without discrimination and on an equal basis with others".*

  It is unfortunate that the Draft State Report does not indicate that Specialist Training Provision (STP) in the further education sector, which caters for large numbers of people with disabilities and other disadvantages, operates to a different funding model than mainstream further education. Under the current funding model, the provider is only paid based on student attendance rather than on the cost of providing the service: in effect, the most prohibitive funding model is used to fund the further education of people with disabilities.
- The inadequacies of the STP funding model directly affect the extent to which training and education services can be provided, and undermines progression opportunities for people with disabilities, their continuation in education and their access to employment. The inadequacies of this system have been particularly highlighted during the Covid-19 pandemic, since a specialist-training provider's ability to maintain revenue to deliver programmes is dependent on a continuous intake of students and generation of a referral stream, both of which have been disrupted by Covid-19. Specialist training providers working with people with disabilities have been curtailed in starting new students or generating referrals due to the ongoing Covid-19 restrictions. The funding model was already flawed but relying on the model in the context of the pandemic has put services in a precarious position, and ultimately it is jeopardising the education of students. Evidently, STP further education is not on an equal footing with mainstream further education. There is a need to provide security of funding to specialist training providers so that people with disabilities who require individualised, person-centred supports are treated on the same basis as everyone else.

3.6 Article 27 - Work & Employment

The National Federation has consulted with people with intellectual disabilities and autism (ASD) supported by our members, about the meaning of work in their lives. They have told us that in addition to the financial benefits associated with working, having a job holds great meaning in the person's life. Employment offers opportunities to make friends, expand social connectedness, enhance self-esteem and confidence, and build capacity in a wide range of skills. In this way implementing Article 27 is strongly linked with facilitating the choices and community connections envisaged through Article 19. The Commission on the Status of People with Disabilities (1996) highlighted the importance of having a job as a means to achieve economic and social independence.

It is clear that for people with intellectual disabilities and/or ASD, the model of employment can include a flexible range of options such as independently held full-time employment; supported employment; customised employment; capacity building towards employment; shorter hours - and within each maintain the significant value in the person's life.

Positive progress

Article 27 of the CPRD sets out that:

> *"States Parties recognize the right of persons with disabilities to work, on an equal basis with others; this includes the right to the opportunity to gain a living by work freely chosen or accepted in a labour market and work environment that is open, inclusive and accessible to persons with disabilities."*

The Draft State Report sets out a wide range of areas in which the employment of people with disabilities is the focus of Government policy, including at the broadest level, the *Comprehensive Employment Strategy;* a 10 year cross governmental approach that brings together actions by various departments and state agencies in a concerted effort to address the barriers and challenges that impact on the employment of people with disabilities. Aspects of this Strategy that have been implemented – such as the *Make Work Pay* policy, are of significant benefit to people with disabilities. The *Ability Programme* projects have been particularly useful in supporting young people with intellectual disabilities (aged 15-29) to develop their employability skills, and to gain and sustain employment in the open labour market and there is a need for continued support to programmes such as these.

Issues of concern

However, in spite of the positive developments outlined in the Draft State Report, people with intellectual disabilities and ASD continue to experience particular challenges in accessing the necessary supports to enable them to find employment and there is strong evidence of a lack of a joined-up approach which leaves these citizens outside of the reach of many of the positive approaches outlined in the Draft State Report.

- Employment levels of people with disabilities in Ireland remains stubbornly low; and in particular the employment rate of people with intellectual disabilities and ASD needs to be addressed.

- Many of the challenges faced by people with intellectual disability and autism begin with the issues outlined in this submission in response to Article 24 (Education) above; such as the lack of transition planning; absence of career guidance supports in special schools; and the lack of targeted 3rd level educational supports that include people with ID.
- The lack of clarity of Departmental responsibilities (outlined as a general issue in the introduction to this submission) is significantly adversely affecting the supports available to people with intellectual disabilities and ASD. Strategic Priority 5 of the *Comprehensive Employment Strategy* is the provision of 'coordinated and seamless support'. However, the implementation of the Strategy to date has not resulted in more coordinated services; rather the HSE has stated that no new supported employment resources will be deployed via health-funded services, whilst the required resources are not present in mainstream employment services at this time to adequately cater for the employment supports needed by people with intellectual disabilities. Requirements to be 'job ready' and the ability to work more than 8 hours rules out many people with intellectual disabilities who require more specific accommodations. A report by the Citizens Information Board (2017) states that supports are not integrated and that there continues to be a distinct lack of joint thinking between the very entities tasked with coordinating seamless supports.
- In Article 27, the CPRD includes detail on the State's responsibilities, to:

  > *"(d) Enable persons with disabilities to have effective access to general technical and vocational guidance programmes, placement services and vocational and continuing training;"*

  There is an urgent need for cross-Departmental working to address the provision of supported employment to people with ID and to ensure local and national structures are in place and fit-for-purpose, including maintaining the expertise built up over many decades of supported employment through disability service providers. Over many decades the member organisations of the National Federation have built up expertise and experience in delivering the supports necessary for individuals to access employment suited to their abilities and supporting their growth and capacity. The collective experience and expertise of the voluntary sector in this area should be harnessed and measures put in place to ensure that citizens can avail of this expertise without barriers.
- Although the Employability service's mission is very positive, members reported that it is unintentionally discriminatory toward people with ASD as the assessment model does not make accommodations for people who struggle in the areas of social interaction, social imagination, communication, high levels of anxiety, environmental sensitivities, executive functioning, sensory issues, etc.
- A recent review of supports available to people with disabilities and ASD transitioning from education or training into employment, conducted by the Oireachtas (2019)[xxx] highlighted the complex issues that people with disabilities encounter in their endeavours to engage with education and employment. To remove existing barriers and ensure that coordinated and seamless supports are available, there needs to be a focus on supported transitions and ongoing career support which takes a holistic and understanding view[xxxi]. Data should be gathered to track 'post-school progression' for students with disabilities and special educational need, in terms of their access to the workforce. This data should inform the ongoing implementation of measurable targets to improve seamless support to these citizens.

In summary, unfortunately, the current reality for people with intellectual disability and/or ASD in Ireland is in stark contrast to the vision for change and equality as set out in the aforementioned publications and others. There should be full implementation of the *Comprehensive Employment Strategy* with a focus on ensuring that people with intellectual disabilities and ASD are included in all aspects of the progressive realisation of Article 27 of the CRPD.

3.7 Article 25 – Health

The CRPD sets out the State's obligations in relation to the health of persons with disabilities, and as the cornerstone of this Article:

> *"States Parties recognize that persons with disabilities have the right to the enjoyment of the highest attainable standard of health without discrimination on the basis of disability."*

It is worrying that, as described in Item 328 of the Draft State Report, just 38% of persons with disabilities described their health as 'very good' or 'good' compared with 89% of non-disabled people (Irish Health Survey, 2015). Whilst it is true that a proportion of the gap between the health outcomes of people with disabilities and those without a disability are based on impairment associated with the disability and increased age, it is essential that this gap is interrogated and that responses to the health-related needs of people with disabilities are based on a targeted, evidence-based approach. Existing evidence, as this submission will set out below, indicates that may be additional factors apart from the specific impairment and age of the individual that are also influencing the health status of people with intellectual disabilities in the State.

We are fortunate in Ireland that very comprehensive research on the health outcomes of older adults with intellectual disabilities is available through the Intellectual Disability Supplement[1] to the TILDA[2] study. The National Federation has consulted with Prof Mary McCarron, Director of the Trinity Centre for Ageing and Intellectual Disability, which leads this research; and with the Irish Society for Disability and Oral Health, in highlighting key findings relevant to the Draft State Report and in turn to the State's response to the health needs of people with disabilities.

A summary of the key findings of the relevant research is provided below, and a detailed presentation of the evidence is provided in Appendix I of this submission.

- There are aspects of the health of individuals with an intellectual disability that are showing more positive indicators than the general population as compared between IDS-Tilda and the mainstream Tilda study. For instance, *self-reported health* for more than 85% of adults with intellectual disability was 'good' or better.
- The levels of high cholesterol in people with intellectual disability was less than in the general population: 36.5% (n=220) reported high cholesterol which was lower than that reported by the TILDA of the general population of older adults at 41% (Nolan et al 2016).
- However, the IDS Tilda study has identified worrying levels of overweight and obesity in people with intellectual disability: levels of measured overweight and obesity increased from 61 % in Wave 2 to 79.7 % in Wave 3, and now equals rates reported by TILDA for the general population at 79% (Leahy, Nolan, O'Connell, & Kenny, 2014). Higher levels of overweight and obesity were identified in those aged 50-64 years at 80.6% compared to 77.6% in those 65 years and over. Those with a mild/moderate level of intellectual disability presented with greater levels of obesity at 87.5% versus 64.3% for those in the severe/profound disability. Females had higher prevalence of overweight and obesity compared to males at 83.1% versus 75.9% respectively.

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[1] https://www.tcd.ie/tcaid/research/researchome.php

[2] TIlDA – The Irish Longitudinal Study on Ageing; https://tilda.tcd.ie/

- In relation to Mental Health, the findings from IDS Tilda have indicated that outcomes for people with intellectual disability were significantly less favourable than for those without: 52% reported a diagnosis of an emotional, nervous or psychiatric condition; there was a 15.1% prevalence of anxiety; and a 10% prevalence of depression – compared with 5% prevalence of depression in TILDA general population.
- O'Dwyer et al. (2017) found that 59.1% (436) of IDS-TILDA participants were exposed to any psychotropic drugs. Of these, 66.2% reported psychotropic polypharmacy. Antipsychotics were the most frequently used psychotropic class, reported by 43% of participants. The study found that living in a residential institution and having a history of reporting a mental health condition or sleep problems were associated with psychotropic polypharmacy.
- Good oral health is an important factor in people's general health and quality of life. Evidence shows that people with disabilities have poorer oral health and more problems in accessing dental services than the remainder of the general population. In Wave 3 of IDS-TILDA, 28.3% (n=171/603) of participants reported that they had no teeth at all. This finding represented an increase of 3% since Wave 1, when the corresponding figure was 25.4% (n=191/751). In contrast, in the general population of older adults just 16.9% (n=1,115) of Wave 3 TILDA participants reported total tooth loss, down from 17.7% in Wave 1(n=1,502), despite the TILDA sample being older. The National Federation is particularly concerned that when total tooth loss occurred, a large proportion of people with intellectual disability (67.8% of IDS-TILDA Wave 3 sample without any teeth, n=116) **did not receive prosthetic dentures to restore function.** Conversely, this did not occur among the general population sample where only 5.3% of those without teeth were without dentures (n=58). This represents a twelve-fold negative impact of oral disability in people with an intellectual disability when compared with the general population.
- The Irish Society for Disability and Oral Health reports that while Government developed an oral health policy in 2019[xxxii] where the needs of people with disabilities were prioritised in the state's oral health care delivery; implementation has been inconsistent, often relying on local champions and in which scarce resources have only succeeded in partially establishing a basic infrastructure in Special Care Dentistry (SCD) in some parts of the country. The current provision therefore results in inequitable access to essential dental services for people with disabilities across the country. These challenges have been further exacerbated through the Covid-19 crisis. (See further information Appendix I)
- Lower levels of physical activity than the general population of older people were reported in the IDS Tilda findings among people with intellectual disability, and the findings suggest that levels of moderate and vigorous activity among people with Intellectual disability remain too low to accrue health benefits.
- There are particular concerns for people with disabilities in relation to the prevalence of dementia. In the general population, it is estimated that incidence of dementia is 2% for those 60 years and older [xxxiii]. However, the rates of diagnosis are significantly higher in people with intellectual disabilities, and in particular for people with Down syndrome, for whom there is a genetic predisposition to the disease. In the IDS Tilda findings, there was an overall incident rate of 9.1% in participants between Wave 3, and within Waves 2 and 3 an incidence rate of 22.5% (n=20) was found for participants with Down syndrome. The average age of diagnosis of dementia for those with Down syndrome was 52.3 years compared to 65.5 years for those with intellectual disability from other aetiologies.
- In the context of the significant incident rates of dementia in people with disabilities, the National Federation particularly welcome the development of the National Intellectual Disability Memory Service (NIDMS). This service is committed to improving the early detection of dementia in people

with an intellectual disability and offering post-diagnostic supports. Over time, this will provide clinical data on dementia diagnosis, blood biomarkers and longitudinal trajectories of cognitive assessments and blood biomarkers. This data will help to advise service planning. This work is also vital to the development of an understanding of dementia among people with intellectual disability, the contributory factors specific to this population and how the development of the condition can be slowed down or prevented for greater numbers of people with intellectual disability.
- Rates of uptake of breast and bowel screening amongst adults with intellectual disabilities has been improving across the waves of data collection and analysis of the IDS Tilda study. There has been very positive work carried out collaboratively between the National Federation and the HSE that supports accessible information for people with an intellectual disability to support this trend.
- It is important that in the implementation of national health related strategies such as Slaintecare and the Healthy Ireland Framework, the needs of people with intellectual disabilties are fully considered and included.

The findings of recent Irish research as outlined above in relation to the health outcomes of adults with intellectual disabilities have significant implications for both the health-related responses of the State and the social supports provided to respond to the changing needs of older adults with disabilities to support them to age in place and live well into older age. The National Federation calls on Government to ensure that appropriate clinical and social supports form significant elements of the CRPD implementation plan set out in Item 12 of the Draft State Report, and that these responses should be informed by the evidence of the available research.

3.8 Articles 1-4 - General obligations

In relation to the general obligations set out under Articles 1 – 4 of the CRPD, the National Federation welcomes the establishment of the new Disability Participation and Consultation Network in 2020, described in Item 6 of the Draft State Report. This is a positive initiative to support the involvement of people with disabilities in the reporting process. It is also very welcome that all draft legislation is now examined by the Office of the Attorney General with a view to ensuring that it is compliant with the CRPD. There is a need for a review of existing legislation to ensure that there is consistency – for instance there are differences between Acts in the understanding of 'Next of Kin' that should be reviewed in the context of the implementation of the ADM.

Most important, however, in relation to the section, is the intention set out in Item 12 of the Draft State Report, that '*following a mid-term review of the NDIS it was agreed that Ireland will develop a CRPD implementation plan'.* It will be essential that this implementation plan is based on a progressive realisation approach that sets out specific, actionable, measurable, cross-Departmental targets.

In view of the difficulties experienced by citizens as highlighted throughout this report, it will be important for the implementation plan to have regard to the actions that result in tangible improvements in the lives of people with disabilities. The National Federation calls on Government to publish the Capacity Review of Disability Services without delay, to support the identification of key priorities in which citizens are experiencing unmet needs.

4.0 Feedback on Draft State Response to CRPD Articles in numerical order

4.1 Article 5 - Equality & non-discrimination

Article 5 of the CRPD recognises that all persons are equal before and under the law, and are entitled without any discrimination to the equal protection and equal benefit of the law.

The National Federation acknowledges the range of equality legislation in place in Ireland which is inclusive of persons with a disability including the Employment Equality Acts 1998 and 2004; the Equal Status Acts 2000 to 2004; the National Disability Authority Act 1999.

- The National Federation welcomes the proposed legislation to extend the 'not exceeding a disproportionate burden' standard to all public services.
- The Disability Act (2005), provides a statutory basis to advance the participation of persons with a disability in everyday life. Areas of this Act remain to be fully implemented e.g.
    - full access to mainstream public services and actions to support access to public buildings, services, and information;
    - provision of real choice and opportunities for persons with a disability and their involvement in the decisions which affect them from the outset
    - independent assessment of individual health needs and educational services for persons with disabilities over 18 years:
- However, the Disability Act in itself has proved problematic in its focus on providing for an Assessment and Statement of Need, without providing the requisite supports and services outlined in the Statement as a matter of right. The process of assessment for children's services, for instance, has proved a significant draw on scarce multi-disciplinary supports, without delivering sufficiently on the required services directly to children and families that are needed.

It is the view of the National Federation that there is a need for review of key pieces of legislation in light of CRPD State responsibilities, including the Disability Act, to bring about a legislative shift to an enhanced rights-based focus.

4.2 Article 6 – Women

Article 6 of the CRPD recognises that women and girls with a disability are subject to multiple discriminations and that as a result, there should be focused measures to ensure the full and equal enjoyment by women of all human rights and fundamental freedoms. While there have been positive steps taken to address the intersectionality of women with disabilities, more needs to be achieved. It has been submitted that policies and supports for people with disabilities are gender-neutral, however, research suggests that the reality is more challenging and requires recognition[xxxiv]. The following feedback relates to the Draft State Report on progress in implementing Article 6.

- The State Report highlights the *National Strategy for Women and Girls* (2017-2020)[xxxv] as a policy framework to advance the rights of women with disabilities. Due to the specific challenges faced by women with disabilities, however, there should be greater focus on disabled women to achieve the vision as outlined of "..*an Ireland where all women enjoy equality with men and can achieve their full potential, while enjoying a safe and fulfilling life*" with greater resourcing of such strategies to realise their implementation.
- In relation to the *Istanbul Convention Combating Violence Against Women*, the Irish Human Rights and Equality Commission (IHREC) has noted the lack of data collection and reporting mechanisms in place and a need to focus on combatting violence against women with disabilities and on intersectionality (2019)[xxxvi].
- IHREC also highlights that Ireland has less than one-third of the required domestic violence refuges, with nine counties having none, and draws attention to the deficiencies in the accessibility of supports for women with disabilities (2019).
- In March 2021, to mark international women's day, presentations were made by the National Women's Council of Ireland and Disabled Women Ireland to members of the Dail Joint Committee on Disability Matters. Key points made included research findings of higher levels of violence against women with disabilities compared with the general population and an inability to access supports; a lack of public facilities and assistive equipment; a lack of personal assistance services; and the requirement for parental capacity assessments, which no other group in society are is asked to complete. [xxxvii]
- Women's health is a key issue and ensuring that national health measures are targeted at women with a disability is vital. Examples to note in this regard include:
  - National Cancer Screening Programmes should be inclusive and customised to the needs of women with a disability, including those with an intellectual disability (this should build upon the the positive development of accessible breast cancer screening resource materials for women with an intellectual disability referenced earlier).
  - Full implementation of the Women's Health Taskforce, established in 2019, which focuses on improving women's health outcomes and their experiences of healthcare, is essential.
- Regarding the capacity assessment for women with intellectual disabilities who become parents - to assess their fitness as a parent; when the principles of the ADM Act are implemented and followed in all polices and legislation, this process will need to be fundamentally reviewed. There is a need to ensure appropriate supports for people with ID or ASD who are parents themselves.

4.1 Article 8 – Awareness raising

The Draft State Report sets out the broad range of positive actions and initiatives that are underway to support Article 8. Nonethless, National Federation members highlighted that the need for awareness raising remains an area requiring continuing investment, with a particular need to focus on the following:

- Addressing the culture that exists whereby consent is often sought from families/carers rather than directly from the person with a disability.
- Promoting the online / eLearning disability awareness training module, developed by the National Disability Authority (NDA) for employer's, along with the general disability awareness module for the public service.
- Involving people with a disability in national campaigns and public life and providing them with opportunities to share their lived experience.

4.2 Article 10: Right to life

The Draft State Report notes the protection of the right to life in the Irish Constitution and under the European Convention on Human Rights Act 2003, both of which equally apply to people with disabilities. The private members *Dying with Dignity* Bill 2020 currently being considered by the Oireachtas has particular relevance for disabled people. As highlighted by the report of the UN Special Rapporteur on the rights of persons with disabilities, 2019;

> *'from a disability rights perspective, there is grave concern that legalizing euthanasia and assisted suicide could put at risk the lives of persons with disabilities.'*
>
> (UN Human Rights Council A/HRC/43/41 p9 Para37)

- It is imperative that the voice of people with disability, including intellectual disability, is heard as this Bill is considered by the Oireachtas and that legislators be fully cognisant of their views.
- All legislative changes need to ensure the promotion of and respect for the inherent rights and dignity of people with a disability. Consequently the *'Dying with Dignity Bill, 2020'* must not proceed further without significant consultation and engagement with key stakeholders and those who provide them with essential support.
- An appropriate timeframe must be allowed, particularly in light of the challenges faced by people with disabilities and those who provide them with support in the context of responding to the Covid-19 pandemic. For further detail see full submission of the Federation of Voluntary Service Providers.

4.3 Article 11 - Situations of risk and humanitarian emergencies

When Ireland ratified the CRPD in 2018, it could scarcely have been imagined that the provisions of Article 11 would become as relevant as has recently been the case as a consequence of the Covid-19 pandemic.

Positive progress

In that short time there has been evidence that significant measures have been undertaken to safeguard the life and health of people with disabilities within the pandemic response:

- In particular, whilst the risk profile of those with a disability living in residential settings was identified as very high from the outset of the crisis, it has been the case that the number of people living in these settings who have contracted Covid -9, and the mortality rate, have been notably low. This is in sharp contrast to reports from other jurisdictions including the UK and US where there have been adverse outcomes in significant numbers reported for individuals with intellectual disabilities in particular.[xxxviii]
- The National Federation has pointed to a range of factors supporting lower levels of infection and mortality in disability residential settings including:
    - Rigorous implementation of infection prevention and control measures;
    - Highly skilled and trained staff cohort;
    - Establishment of isolation centres to support individuals who contracted or were close contacts for Covid-19;
    - Extensive partnership working between HSE, voluntary disability service providers locally and nationally, and the Department of Health; to ensure clear communication and guidance about all aspects of the operational response to Covid-19;

  - The closure of day services and respite (as outlined in Item 132 of the Draft State Report) during the early stages of the pandemic – which was very challenging for individuals who missed their service and for family carers - was nonetheless a success factor in halting the spread of infection, which in turn influenced the mortality rates observed.
- In the absence of, or reduced capacity of in-location supports there has been progress in the development of digital or virtual supports. These are not suitable for all people supported, some of whom do not wish to or cannot engage with online support, however for those who express a preference to be involved in online supports they have been a vital source of connection in the face of reduced services and reduction in opportunities in the community.
- The extension of the July provision to all school age children with complex needs and the continued emergency provision to those most in need, were positive initiatives to support individuals and their families.
- The Department of Health's publication of an *Ethical Framework for decision-making*[xxxix] in the context of Covid-19 was of assistance to policymakers and healthcare planners and providers in acute and community settings; and the Department's publication of *Ethical Considerations Relating to Long-Term Residential Care Facilities in the context of COVID-19*[xl] as described in Item 135 of the Draft State Report was designed to give ethical guidance for the provision of person-centred, rights-based care to people living in long-term residential care settings during the pandemic. These publications are a very welcome expression of a rights-based approach within a crisis, that is in line with the expectations of Article 11.
- The implementation of vaccination for staff and service users since January/February is very welcome. People with intellectual disability may be more vulnerable to Covid-19 because of limited mobility and /or reliance on direct support for personal care and activities of daily living difficulty in understanding information or practicing preventive measures and difficulties in communicating symptoms.

Issues of concern

It is unsurprising that a crisis of the magnitude of Covid-19 has also brought with it issues that require further consideration. Amongst these include the following:

- **Community Call - Framework for Community Support:** Community Call Fora were established in all Local Authorities in response to the crisis and were generally seen as welcome initiatives in supporting older and vulnerable people. However, there is little evidence of the inclusion of disabled people in these services/initiatives.[xli] This may reflect an overall societal issue with the inclusion of people with disabilities in communities; the capacity of communities to include disabled people; or the perception that people with disabilities were already being supported by disability agencies. Equally it may reflect a belief that people with disabilities in receipt of support from specialist services do not need access to generic community supports. The CRPD mandates that disabled people should have access on an equal basis with others to all community services and facilities. Throughout the public health emergency, supports for many disabled people (especially respite and day supports) were greatly reduced and many families were therefore providing 24-hour care and support. It is unfortunate that Community Call, the most important community-based initiative supported by local and national government, was slow to understand the need to tailor its responses to people with disabilities living in the community.
- **Vaccination:** There remain gaps in the vaccination programme for family carers and for individuals living in the community who do not access residential or day services.

- **Addressing underlying resource and digital divide issues:** as outlined above, day supports for people with ID living at home were severely impacted by the public health restrictions, specifically with the closure of day services in the initial phase of the pandemic and the later reduction in capacity. The 2017 report of the National Intellectual Disability Database indicated that almost 19,600 people with ID were living at home with their families and a further 1223 were living independently[xlii]. The risk of isolation, loss of contact with friends, loss of work and/or day service activities together with the increased dependence of family support has had a significant impact on the lives of people with disabilities (see for example the Inclusion Ireland report; *The Experiences of Adults with Intellectual Disabilities in Ireland During the Covid-19 Crisis,* September 2020).
- Disability service providers have introduced virtual supports, and maintained in person support in situations of very high need; and most services have now re-opened on albeit with reduced capacity. However, the impact of the crisis for people with disabilities has been very significant, and serves to highlight the importance of Government working to address underlying unmet need for supports to be provided to individuals and families, many of whom are providing substantial care into older age as outlined in detail in response to Article 19 and in the introduction to this submission, above. It also highlights the need, during crisis situations, for focus on the needs of individuals who access day services; and the requirement for measures to reduce the digital divide experienced by people with disabilities and their families.
- **Maintaining rights-based approach**: there is a need for vigilance to ensure that during crises such as the pandemic, the use of permission-based language and dialogue is not allowed to seep into the approach to supporting people with disabilities. It is important that the principles of the Assisted Decision-Making Act 2015 are maintained as the focus in the development of all communications.
- **School Closures:** A report by Inclusion Ireland, AsIAm and Down Syndrome Ireland[xliii] noted that home education during the March-July 2020 school closures did not work for most children with special educational needs for a variety of reasons; these barriers included ability to access remote education, the child's ability to learn at home, parents working from home and more than one child learning from home. A sizable cohort of pupils had no access to any form of technology for learning (11%) with only 56% having access to high-speed broadband.

It is important that in the context of any future humanitarian crisis, people with disabilities are given full consideration on an equal basis and that their needs are taken fully into account in planning the national and local responses.

4.4 Article 13 - Access to Justice

Positive Progress

There have been positive developments in recent years that support people with disabilities in accessing justice. The Legal Aid Board (LAB) in Ireland provides Civil and Criminal Legal Aid to eligible persons in Ireland and has appointed an Access Officer in accordance with the Disability Act. It is also very welcome that the Courts Service has taken measures to improve the accessibility of the courts system for persons with disabilities through the introduction of induction loops, signage and contact details for court offices in Braille. There are wheelchair ramps in some courts, and it is important that progress continues on physical accessibility.

It is welcome that ahead of the commencement of the Assisted Decision Making (Capacity) Act, draft rules of court to facilitate the operation of the new capacity regime have been prepared by the Courts Service. Also of note is the Review of Protections for Vulnerable Witnesses in the Investigation and Prosecution of Sexual Offences, published in 2020 and the launch of the *Garda Diversity and Integration Strategy* 2019-2021.

Issues of concern

Work is needed in many areas to achieve equal access to justice. As noted in the Report – *Access to Justice of Persons with Disabilities* [xliv], access to justice is '*an issue of critical importance for the enjoyment and fulfilment of all human rights*' (Flynn et al., 2019, p70).

- The lack of progress on the ADM Act 2015 is a barrier to people with disabilities regarding access to justice.
- In addition, the current Wards of Court system poses further barriers for anyone under this system.
- An acknowledgement is required that vulnerabilities of people can be increased when there is a disability present, and comprehensive training for all staff who are in roles supporting victims of crime who have a disability is required.
- In 2019, the Centre for Disability law and Policy reviewed Article 13 of the CRPD and noted the following areas where attention is required:
    - accessibility to buildings and services;
    - communication facilities and supports;
    - training for staff in various agencies regarding supporting people with disabilities;
    - access to information on the rights of persons with disabilities;
    - access to legal aid;
    - access to all criminal and civil complaints mechanism;
    - equal participation in adjudicative processes [xlv]

4.5 Article 14 - Liberty and security of person

It is noted and of importance that the Draft State Report acknowledges that need for work to take place in the area of ensuring the liberty and security of the person. The Government has committed to progressing legislation in this area.

- There should be a review of the legal position regarding the deprivation of liberty and this process should include full consultation any future legislation;
- Any new legislation should be based on the full implementation of the ADM Act 2015;

  A) to ensure the availability of the decision-supports that may be required by the person in order to exercise their legal capacity in deciding about their residential care arrangements.

  B) the incorporation of the principles of the ADM (Capacity) Act into any legislation and procedures developed to ensure compliance with Article 14
- There should be inclusion of multi-disciplinary personnel in the assessment of capacity when admission to residential care is being considered
- Independent Advocacy for people with disabilities should be provided when residential care services are being considered
- Independent monitoring and review of cases of deprivation of liberty should be provided for.

4.6 Article 16 – Freedom from exploitation, violence and abuse

Positive progress

There have been many important developments in recent years in Ireland in supporting Article 16 of the CRPD which requires state parties to take;

> *'..all appropriate legislative, administrative, social, educational and other measures to protect persons with disabilities, both within and outside the home, from all forms of exploitation, violence and abuse, including their gender-based aspects'.*

Significant in this regard include the following:

- Commencement of HIQA inspections based on the Health Care Act, 2007 / regulations in disability residential services (2013) which includes inspections on safeguarding adherence in relevant settings.
- Introduction of the HSE *Adult Safeguarding Policy* within the Social Care sector (2014) which places an obligation on funded agencies to adopt a 'zero tolerance' approach to safeguarding and promote a culture to support this. The development of a national safeguarding training programme has been key in supporting implementation of the policy and the work of appointed Designated Officers.
- Commencement of the provisions of the Children First Act, 2015 and publication of supporting documentation including *Children First: National Guidance for the Protection and Welfare of Children* (2017) and the HSE *Children First Child Protection and Welfare Policy* (2019).
- Publication of the HIQA / MHC *National Standards for Adult Safeguarding* (2019) which seek to support organisations in preventing and responding to harm by reducing the risk of harm, promoting people's rights, health and wellbeing and empowering people to protect themselves.
- Publication of Law Reform Commission issues paper on '*A Regulatory Framework for Adult Safeguarding'* (2020).
- Commencement of work on a comprehensive *National Safeguarding Policy* for the health and social care sector which will apply to all service settings – public, voluntary, and private settings (on-going).

In realising the provisions of Article 16 in full, the National Federation makes the following recommendations:

- There is a need for full resourcing of the revised HSE *Adult Safeguarding Policy*, due to be implemented in 2021, with appropriate funding being provided to organisations to meet their obligations in relation to adult safeguarding.
- Appropriate training should be provided to support staff in recognising and dealing with concerns of abuse which arise and continuing to build a culture of 'zero tolerance' within services.
- People with a disability should be supported in how to avoid, recognise, and report instances of exploitation and abuse through the provision of appropriate training / easy read resource materials. It is vital that people with a disability are supported appropriately when they are involved in any safeguarding related incident.
- The issue of the multiplicity of agencies involved in adult safeguarding which in many instances have differing definitions of abuse and thresholds for reporting needs to be addressed / streamlined e.g. a single incident that occurs may have to be reported via the HSE Adult Safeguarding Policy, HSE National Incident Management Framework, HIQA, Health & Safety Authority, etc.

- In relation to the introduction of safeguarding legislation there is a need to define the categories of adults that would come within such a statutory regulatory framework for adult safeguarding – this is complex area requiring detailed debate and research to guide legislation. Definitions reached and agreed should be applied across all sectors i.e., legislation, social policy and education; to reach a shared understanding and consistent approach. Currently there are various definitions across health, social services, welfare, justice and across legislation, policy and regulations that can give rise to confusion.
- Defining abuse and safeguarding should also include research and debate on thresholds. Within child protection, professionals and policy can use thresholds to help determine seriousness and the most proportionate response. Such guidance or professional knowledge is currently not in use within national adult safeguarding policy but needs to be considered.
- There is a need for an extended / independent advocacy service to support adults at risk or who have experienced abuse. Related to this is the need for good research evidence to promote practice, principals, and policies across services to promote advocacy and the voice of adults at risk in all of what we do. Advocacy principles should be proactively promoted throughout services such as informing people of their rights; consultation; and ensuring peoples' views and wishes are heard; and as needed access to an independent advocate.
- Managing issues of individuals compatibility to live together continues to be a challenge for services where there are repeated safeguarding notifications arising from the need for alternative living accommodation. The resourcing of such alternative accommodation options presents a significant challenge for many Service providers.
- In relation to children's services, a key challenge faced by voluntary providers is when a parent advises they are no longer able to provide for the care of their child with a disability. Despite meeting the threshold for abandonment / neglect under the Child and Family Agency Act (2013) this may not always be identified as a child protection issue by Tusla. This places the child in a situation whereby they have no available primary carer and have been left in the care of a voluntary organisation that has no remit to act in loco parentis. When children need care and protection, the challenges they face in respect of diagnosis or disability should be a secondary consideration to the fact that they are first and foremost a child. Unfortunately, the presence of a disability appears to further disenfranchise children when they are at their most vulnerable. This is a wholly unsatisfactory position for the child and there is a need for Tusla to work in collaboration with voluntary agencies to ensure the wellbeing of the child remains *the* paramount consideration.

4.7 Article 21 – Freedom of expression and opinion, and access to information

Article 21 of the CRPD highlights the need for state parties to take

> *'…all appropriate measures to ensure that persons with disabilities can exercise the right to freedom of expression and opinion, including the freedom to seek, receive and impart information and ideas on an equal basis with others and through all forms of communication of their choice.'*

The need for appropriate action to support persons with a disability to fully achieve active citizenship and engagement under this article is key.

- All processes of consultation relevant to people with disabilities should proactively seek to include the voice of people with lived experience of disability. Relevant bodies / parties should commit to meaningful consultation with people with disabilities on all key areas of health legislation, policy, and practice.
- As outlined in the introduction to this submission, for the lived experience of people with intellectual disabilities to be fully included, this will require consultation processes to allow sufficient time to allow for people with ID to be supported to understand documentation, deliberate on the information they would like to put forward, and formulate and submit their responses. Materials seeking submissions should be provided in accessible formats.
- There is also a particular need to ensure that self-advocacy on the part of people with intellectual disabilities is supported and funded. It is likely that innovative approaches will be required to achieve this goal, to ensure that the independent voice of people with intellectual disabilities is present in decision-making processes. Consultation processes must be structured in such a matter as to actively engage people with a disability, for example, providing easily understandable information / focus group sessions which aim to secure verbal rather than written feedback / meeting people at a local level, etc. Genuine consultation is essential – consultation which not only seeks the views of people with a disability, but which takes this feedback on board, and actively reflects same in the resulting processes, policy, legislation, etc.
- In the case of children with disabilities and for adults where family members are providing significant support, it is important that the voice of families is also included in key consultations (whilst respecting the primacy of the voice of the individual).
- Individuals with disabilities have indicated that video summaries of key content with Irish Sign Language (ISL), as well as Easy-to-Read and Plain English formats are helpful.
- There is a need for the ongoing promotion and support for Lamh, a manual sign language system to support communication used by many children and adults with intellectual disabilities and communication needs.
- We welcome the approach adopted by HIQA in seeking the views of residents in residential disability services in relation to their experiences and their quality-of-life outcomes. By seeking direct feedback from those being supported the learning / recommendations arising from this research will be very informative both for HIQA as the statutory regulator and organisations in terms of service provision.
- The report '*Mind the Gap: Barriers to the realisation of the rights of children with disabilities in Ireland'* (2021), commissioned by the Ombudsman for Children's Office (OCO) highlights that there are no specific measures in place to capture the voices of children with disabilities in monitoring either the National Disability Inclusion Strategy or Better Outcomes Brighter Futures.
- There is a need for training, capacity building and the allocation of resources to support children's voices to be heard – in the design, implementation and evaluation of disability services and decision making.

4.8 Article 22 – Respect for privacy

Article 22 focuses on the protection of personal, health and rehabilitation information of persons with disabilities on an equal basis with others.

- The National Federation welcomes the assertion that the State will defend and vindicate the personal rights of all citizens, including persons with a disability and that the provisions of the Data Protection Act 2018 and the EU General Data Protection Regulation (GDPR) apply equally to all persons in Ireland. In this regard all information gathered/retained by organisations / state bodies relating to persons with an intellectual disability must meet relevant legal requirements.
- HIQA's *National Standards for Residential Services for Children and Adults with Disabilities* include standards for the protection and respect for the privacy of people with a disability. HIQA monitors adherence to privacy standards in residential disability services as part of its role in the monitoring, inspection, and registration of designated centres for adults and children with a disability.
- There is a need for full clarity in relation to the sharing of information/data relating to people with a disability between agencies. While it is recognised there is a clear need for inter-agency co-operation in many instances, there must be clear legal grounds supporting such sharing of data to protect individuals' rights (e.g. sharing of information between Tusla, the HSE, HIQA, Gardai, etc).

4.9 Article 23 – Respect for home and the family

Relationships:

- The commencement of ADM 7.(1) has ensured that the Marriage of Lunatics Act 1811 has been repealed, and this has been a most welcome development.
- The Criminal Law (Sexual Offences) Act, 2017 focuses on a person's capacity to make the decision to have sexual contact and less on the person's status as having a disability and has removed legal barriers that exist to a person enjoying their full rights in respect of sexual relationships, the right to marry and have a family. There is a need however for far greater supports and capacity building for people with an intellectual disability in this area – including in the areas of sexual health, relationships, and parenting.

Family Planning:

- The information outlined in the Draft State Report does not detail the supports available or barriers experienced by a person with a disability with regards to family planning. Evidence is required to illustrate the commitment to accessible and affordable information and the educational supports required relating to family planning.
- Regarding the assessment of a person's suitability to adopt or foster a child, including people with a disability, there is a need for data to demonstrate show how this is working in practice. Data gathered should include the number of people with a disability apply to adopt or foster a child and the success rate of applications. These statistics should provide comparison data to the outcomes for the non-disabled population.

Supports for family and home life:

- There is a need for a statutory entitlement to homecare with the aim of supporting people to live in dignity and independence in their own homes/communities for as long as possible; without this the will and preference of the person will not be enabled. As outlined above in relation to Article 25, there is a particular need for comprehensive planning in relation to the changing needs of older adults with disabilities.
- The aim of the *National Carers Strategy* in supporting people to live with dignity and in independence in their own homes and communities for as long as possible is vitally important. However, there is a need for much greater support for carers, including increased access to financial supports (Carers Allowance and Carers Benefit) and access to respite services. The provisions outlined in *HSE Service Plan 2021* to '*provide nine additional centre-based services, providing some 10,400 additional respite nights along with a range of alternative respite projects including Saturday Clubs, breakaway schemes and summer scheme, and the provision of 214 intensive respite support packages to children and young adults'* is very welcome. There should be continued development of such options to support people with a disability and their families.
- As outlined earlier in this submission, while it is highlighted in the Draft State Report that there are a *'range of early intervention services offering support from multidisciplinary teams for children with disabilities'*; the reality is that the full range of early intervention services is currently not available to access for many children with disabilities and there are long waiting lists leading to many children waiting excessive periods to access services. Sustained multi-annual investment and a statutory entitlement is required to enable and influence the support required.
- The National Federation supports the commitment to family centred practice including empowerment of families and team interventions as set out in the *Progressing Disability Services for Children and Young People* programme.

Protections for children:

- When there are concerns in relation to a child's welfare, care, or protection; Tusla – the Child and Family Agency, should be required and resourced to take a much more active role with the family in the best interests of the child with a disability. Currently, in many instances the support requirements are deemed a function of disability services rather than recognising that the child/children are firstly a child and only then consider the additional needs. This has resulted in a number of children with a disability living in long term residential services without the backup of a legal framework of care orders. This issue needs to be addressed as a matter of urgency.
- The recommendations of key reports published by the Ombudsman for Children should be implemented by the key parties involved, namely the HSE and Tusla.
- In considering the wishes of children, particularly in family court, appropriate/suitably qualified and experienced personnel should be made available to support children with a disability who have specific communication needs.

4.10 Article 26 - Habilitation and Rehabilitation

Article 26 focuses on States' responsibilities in taking:

> *'effective and appropriate measures to enable persons with disabilities to attain and maintain maximum independence, full physical, mental, social and vocational ability, and full inclusion and participation in all aspects of life'.*

- The National Federation welcomes the establishment of the National Clinical Programme for Disability in 2020 as a very welcome development, with its emphasis on a rights-based ethos and direct involvement of key stakeholders and people with a disability in its Disability Advisory Group.
- There should be equalisation of funding throughout all sectors providing disability services to ensure equality of opportunity and quality of support for people accessing services.
- Article 26 details that '*state parties shall promote the development of initial and continuing training for professionals and staff working in habilitation and rehabilitation services*'. There is a need to focus on the continual development of staff skills, competencies and abilities through the provision of appropriate Continuous Professional Development (CPD) opportunities and the registration of health and social professionals through the work of CORU.
- Article 26 also focuses on the need for state parties to promote the availability, knowledge and use of assistive devices, designed for person with disabilities, as they relate to habilitation and rehabilitation'. There a need for significant investment in this area with Services / individuals with a disability being funded to avail of aids, appliances, and assistive technologies to support everyday living. The work as outlined in the state's initial report under the NDIS, and the Working Group established needs to be adequately resourced and supported.
- A significant shortage of capital funding undermines the ability of service providers to respond to the needs of people with disabilities. Over recent years there has been very limited capital funding for the purchase / development of facilities from which Day Services or Children Disability Services can be provided, leaving the State reliant on private providers to fund capital investment. There is a need for a comprehensive, multi-annual programme of investment to respond to the needs of individuals with disabilities.

4.11 Article 28 – Adequate standard of living

Positive progress

The Draft State Report outlines the array of income support measures in place for people with disability and their families. The research currently underway on the Cost of Disability is welcome and requires action, as is the commitment to reduce the percentage of those *At Risk of Poverty* from 36.9% to 28.7% by 2025 and to 22.7% by 2030. The National Federation welcomes the commitment to develop and consult on a proposal to restructure long-term disability payments to simplify the system.

Issues to be addressed

- **Disability and Poverty:** There is a strong correlation between disability and poverty; the 2019 CSO *Survey on Income and Living Conditions* found that those most at risk of poverty were people who were not at work due to illness or disability. Poverty rates for people with disabilities in Ireland are

10% higher than the EU average[xlvi]. The data indicates a need to address levels of income for people with disabilities through the social welfare system and access to employment.

- **Cost of Disability:** The 2004 *Indecon Report on the Cost of Disability* commissioned by the NDA showed that people face extra costs of living related to disability, over and above those currently met by state services or supports. As far back as 1996 the *Commission on the Status of People with Disabilities* recommended that a Cost of Disability payment be introduced. The research on the Cost of Disability payment is to be welcomed. However, this should be accelerated and firm proposals developed.
- **Housing:** Article 28 of the CRPD asserts the right of people with disability to an adequate standard of living, including adequate housing. The issue of housing is addressed in the Draft State Report under Article 19. The most recent statistics in relation to social housing point to the fact that over 5000 people were assessed as being in need of social housing supports because of a disability of some form i.e., 8.2% of all those assessed as being in need of social housing overall[xlvii]. In addition, as outlined above at the end of 2019, 2,914 people with intellectual disabilities were still living in congregated settings. Some of those may already be represented on social housing waiting lists.
- In light of the figures quoted above, the following recommendations from the Oireachtas Disability Group Pre-Budget Submission 2021 were co-signed by the National Federation of the Voluntary Service Providers recommending that:
  A) Government commit 7.5% of social housing for people on social housing waiting lists because of disability
  B) Increase funding for Housing Adaptation Grants by €25.9m and expand eligibility criteria.
  C) Provide a minimum of €100m funding for the Capital Assistance Scheme.
  D) Increase funding for the de-institutionalisation and complete full transition to community living within 5 years.
  E) Target funding for community support and housing adaptation packages to move people under-65 out of nursing homes

4.12 Article 29 – Participation

Positive progress

The National Federation welcomes the *National Disability Inclusion Strategy* 2017-2021 commitment to progressing the accessibility of voting and voter information, building on learning from National Disability Authority research and from experience and best practice.

Issues of concern

Issues highlighted by the NDA Accessible Voting Discussion Paper (2012) regarding voting and people with ID include:
A) Lack of accessible information on candidates and on voting system
B) Lack of legal capacity legislation
C) Lack of training for polling station staff with regard to disability
D) Access to voting procedures – including transport to polling stations, access to the polling station, availability of assisted voting and alternative methods of voting.

The following recommendations are made by the National Federation:

- The needs of people with intellectual disability/autism should be included in electoral reform when considering accessibility of voting and of voter information – taking account of the findings in the NDA 2012 Accessible Voting Discussion Paper;
- There should be acknowledgement that some people with Intellectual Disability or ASD may need to have a support person accompany them when voting;
- The ADM Act should be fully commenced so that people who require decision making support can appoint a decision making assistant or co-decision maker when deciding how to vote;
- All polling stations should be made fully accessible for people with disabilities;
- The provision of accessible information on voting procedures should be mandated and measures introduced to encourage all candidates to provide information in accessible formats.

Article 31 – Statistics and Data Collection:

Article 31 of the CRPD outlines the obligation on state parties to collect appropriate information, including statistical and research data, to enable them to formulate and implement policies to give full effect to the requirements of the Convention. This also includes a provision to;

> *'..assume responsibility for the dissemination of these statistics and ensure their accessibility to persons with disabilities and others'.*

There is also an onus on states to;

> *'..identify and address the barriers faced by persons with disabilities in exercising their rights'.*

Key comments in relation to the Draft State Report include:

- We welcome that following public consultation and pilot testing, the 2021 Census will include enhanced questions on disability and plans to conduct a post-Census National Disability Study (NDS) post the Census scheduled for 2026.
- The disability database for those receiving specialist disability services, the National Ability Supports System, is a key tool in gathering robust accurate data relating to those receiving services and those requiring services into the future. There is a need to ensure that the necessary IT and administrative supports are in place to ensure the data available through the NASS is as comprehensive / accurate as possible.
- The IDS-TILDA study, which is focused on researching aging in Ireland among people with an intellectual disability aged 40 and over and comparing the ageing of people with intellectual disability with the general aging population, is yielding very valuable data which needs to inform future policy and health practices.
- As highlighted in a recent report commissioned by the Ombudsman for Children (2021)

  > *'…there is (also) limited data available on children with disabilities' experiences of discrimination in Ireland…children with disabilities are often only included within research on discrimination in education or healthcare contexts, rather than in access to goods and services more broadly'*

The introduction of a legislative requirement to collect and publish data disaggregated by disability, including complaints regarding discrimination across all sectors could support monitoring of progress in the field of equality and non-discrimination (OCO Report, 2021).

- The work of groups run directly by people with a disability or that represent people with a disability e.g. the recently established Disability & Participation Network are vitally important in hearing directly from people with a disability about their lived experiences. The research undertaken by groups such as the Inclusive Research Network is a valuable source of evidence and information that should be consulted.
- Data protection in relation to how data is gathered / stored / retained is vitally important for all stakeholders and it is necesssary to ensure appropriate safeguards are in place in relation to the collection of data and adherence to the requirements of the GDPR / Data Protection Acts 1988-2018.
- The HIQA *National Standards for Residential Services for Children and Adults with Disabilities* highlight the importance of quality information and effective information systems which are seen as being central to improving the quality of residential services for people with disabilities. Quality information, which is accurate, complete, legible, relevant, reliable, timely and valid, is an important resource for service providers in planning, managing, delivering, and monitoring residential services. Organisations need to be resourced to build such IT systems that will enable this information to be captured.
- Statutory notifications of adverse events from residential care facilities for older persons and people with disabilities are collected by HIQA and used to inform the monitoring approach for these services. In 2019, HIQA was awarded a research grant from the Health Research Board to develop an open access database of these notifications and undertake secondary analyses. This database was launched in early 2021 and HIQA encourages researchers and others to use the database to answer their own research questions. The use of such existing data for further research / learning is vitally important and will allow us to develop better understandings in key areas.

5.0 Conclusion

The National Federation appreciates the opportunity to comment on this important first *Draft Initial State Report under the United Nations Convention on the Rights of Persons with Disabilities* and the increased focus on the implementation of the CRPD that national consideration of this process is promoting.

We welcome the progress to date as outlined in many of the items within the report, and note the need for a comprehensive plan to guide the State and all stakeholders in making progress to move forward with progressive realisation of the Convention.

Appendix I – Supporting information regarding Article 25

Research findings provided by Trinity Centre for Ageing and Intellectual Disability to support National Federation response to Article 25

Item 328 in Draft State Report:

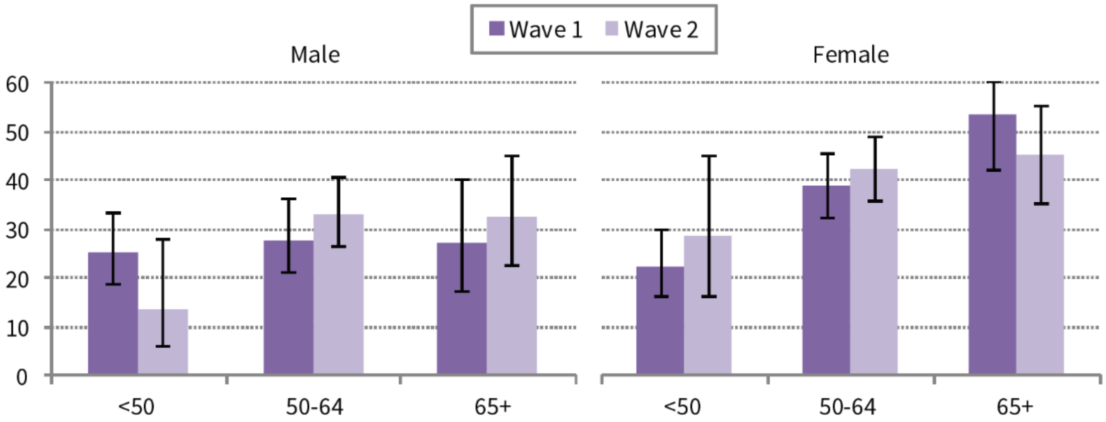
> “Some persons with disabilities have impairments that are associated with a health condition. In addition, persons with disabilities are older on average than the rest of the population, as prevalence of impairment rises with age. These two factors are associated with increased vulnerability to ill-health. The Irish Health Survey 2015 indicated that 38% of persons with disabilities described their health as ‘very good’ or ‘good’, compared to 89% of non-disabled people in these two categories.”

- Excellent = 9.8% (59)
- Very good = 35.6% (215)
- Good = 40.2% (243)
- Fair = 11.3% (68)
- Poor = 3.1% (19)

85.6% described rated their health as ‘good’ or better. Chronic Health Conditions (IDS-TILDA Wave 3) (McCarron, Haigh, & McCallion, 2017)

Cholesterol:
Unlike the TILDA study, which drew blood samples and measured cholesterol levels, IDS-TILDA asked participants to report from their medical files their doctor’s diagnosis of high cholesterol. Overall, 36.5% (n=220) reported high cholesterol which was lower than that reported by TILDA for the general population at 41% (Nolan et al 2016). In Wave 3, 93% (n=506) reported having had a blood test for cholesterol within the previous two years. Women presented with higher levels than men; 41.5% versus 30.2% respectively (figure 3.4). Of those who had high cholesterol, 68.7% (n=189) were taking medication to control their cholesterol, and 57.8% (n=159) reported that they had made lifestyle changes to address their high levels.

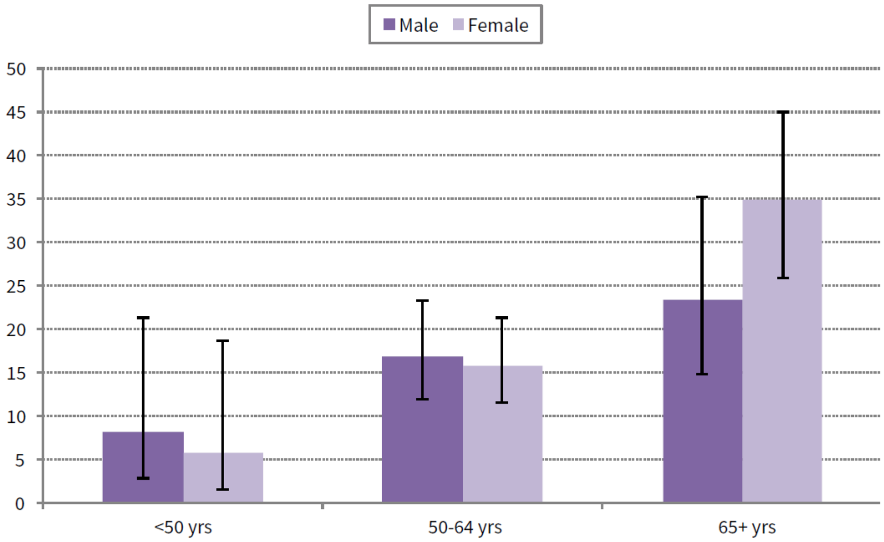
Figure 3.4 High cholesterol between Wave 1 and Wave 3 by age and gender



Hypertension:

In Wave 3 of the IDS Tilda findings, the prevalence of hypertension was 18.7% with an incidence rate of 3.3% since the second wave. The prevalence of hypertension continued to be lower than objectively measured hypertension reported by TILDA at Wave 3, 18.7% versus 40% respectively (Murphy et al, 2015). In Wave 2 of IDS-TILDA there was very little difference between doctor's diagnosis and objectively measured hypertension at 17.5% versus 18.1% (McCarron et al., 2014). In total, 19.9% of females and 17.2% of males reported hypertension. Of note is that prevalence increased with age, with 6.9% (n=5) reporting hypertension under the age of 50 years, 16.2% (n=61) between 50 and 64 years, and 30.1% (n=47) with hypertension over the age of 65. What is notable is that females in the younger and middle age groups presented with slightly lower prevalence of hypertension than males. However, as can be seen in Figure. 3.5 below, by the age of 65 years and over the prevalence of hypertension among females far exceeds that of older men, 34.8% versus 23.4% respectively.

Figure 3.5 Doctor's diagnosis of hypertension stratified by gender and age



A paper by O’Brien et al. (2021) used self/proxy reports in addition to objective blood pressure (BP) measurement to identify hypertension prevalence of 35.2%. Of those with hypertension, 44.3% were aware of their hypertensive status, and 64.2% were taking antihypertensive medication. Among those on treatment, 70.8% had their BP controlled to below 140/90 mmHg. Significant predictors of awareness were age (p=0.036) and level of intellectual disability (p=0.004). Predictors of treatment were age (p=0.002), level of intellectual disability (p=0.019), and diabetes (p=0.001). Both diabetes (p=0.013) and female gender (p=0.037) were predictors of control of hypertension.

The paper concluded that: The prevalence of hypertension in older adults with ID was lower than reports for the general Irish population, with overall levels of treatment and control, when identified, higher in the ID population. There was under-treatment and lower levels of awareness among those with more severe ID, which requires addressing. The finding, that when diagnosed, people with ID respond well to treatment should encourage addressing the under-treatment.

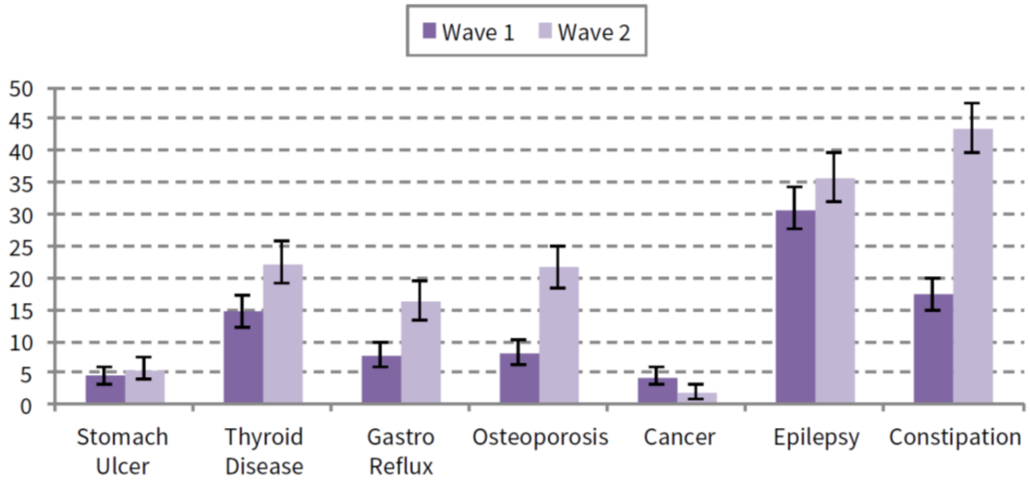
Diabetes:

Overall, the prevalence of diabetes was 9.3%, a slight increase from the 8.2% reported at Wave 1 of IDS-TILDA. An overall incidence of 1.8% was found between Wave 2 and Wave 3. The prevalence of diabetes was higher in females at 11.3% compared to males at 6.7% which was a similar trend to that observed at Wave 1 of the study. This contrasts to general population findings where the prevalence of diabetes was higher in males than females at 12% versus 7% respectively (Leahy et al., 2015). Similar to the general population, there was a strong relationship with increasing age, with a prevalence of 12.2% in those aged 65 years and over versus 1.4% in those under 50 years. Considering levels of intellectual disability, for those with a mild level of intellectual disability, 12.5% were diagnosed with diabetes compared to 10.9% of those with a moderate level and 4.9% of those with a severe/profound level of intellectual disability.

Other Chronic Conditions (stomach ulcer, thyroid disease, gastro reflux, osteoporosis, cancer, epilepsy, constipation)

Prevalence of epilepsy rose from 30.5% in Wave 1 to 35.7% in Wave 3. Of particular concern was the high prevalence of gastric reflux which doubled between Wave 1 and Wave 3 from 7.8% to 16.3%, and osteoporosis increasing three-fold from 8.1% to 21.6%. Nevertheless, doctor’s diagnosis of osteoporosis appears low given that in Wave 2, on objective measurement of bone health, 41% met criteria for osteoporosis (Burke, McCallion, Walsh & McCarron, 2016a). Of particular concern is the increase observed in doctor’s reported diagnosis of chronic constipation. This increased from Wave 1 to Wave 3 substantially, 17.3% to 43.5% respectively.

Figure 3.6 Changes in chronic health conditions between Wave 1 and Wave 3



											ilepsy	
												95% CI
Male	6.3	4-9.9	17.9	13.8-22.9	15.7	11.8-20.5	14.6	10.8-19.3	1.9	0.8-4.3	34.7	29.3-40.6
Female	4.8	3.0-7.6	25.7	21.3-30.6	16.7	13.1-21.1	27.2	22.7-32.2	1.8	0.8-3.9	36.4	31.4-41.7
Age												
<50	5.6	2.2-13.6	19.7	12.1-30.4	9.9	4.9-19.0	8.5	3.9-17.2	2.8	0.8-9.7	31	21.4-42.5
50-64	3.7	2.2-62	23.4	19.4-27.9	15.4	12.1-19.4	19.1	15.5-23.4	1.3	0.6-3.1	37.5	32.8-42.5
65+	9.6	5.9-15.3	20.5	14.9-27.5	21.2	15.5-28.2	33.3	26.4-41.1	2.6	1.0-6.4	33.3	26.4-41.1
Level of ID												
Mild	3	1.2-7.4	15.6	10.4-22.6	11.9	7.4-18.4	15.6	10.4-22.6	1.5	0.4-5.2	27.4	20.6-35.5
Moderate	6.2	3.9-9.9	26.8	21.8-32.6	14	10.3-18.8	24.9	20.0-30.5	1.9	0.8-4.5	34.2	28.7-40.2
Severe/Profound	5.5	2.9-10.2	22.7	16.9-29.7	25.8	19.7-33.0	21.5	15.9-28.4	1.8	0.6-5.3	49.7	42.1-57.3

See also:

- Monaghan, R., O'Dwyer, M., Luus, R., Mulryan, N., McCallion, P., McCarron, M., & Henman, M. C. (2021). Antiepileptic drugs, occurrence of seizures and effect of co-administration of potential seizure threshold-lowering psychotropic drugs in adults with intellectual disability who have epilepsy. *Journal of Applied Research in Intellectual Disabilities*. https://doi-org.elib.tcd.ie/10.1111/jar.12857

Improving health outcomes

Item 329 in Draft State Report:

The HSE funds the public system of primary, specialist and hospital care provided to the general public, including persons with disabilities. It also provides a range of specialist services for persons with disabilities, including assessment, habilitation, rehabilitation and specialist multi-disciplinary therapies, community support services, respite, and residential care. These are delivered by the HSE and by non-profit and private sector bodies, funded through service arrangements.

Item 331 in Draft State Report:

Sláintecare is the ten-year programme to transform health and social care services. It is the roadmap for building a world-class health and social care service in Ireland. Its focus is on delivery of healthcare in the community, as close to the source of demand as possible. Work has begun to scope a Social Care Strategy that will address the challenges involved in supporting a growing population of persons with disabilities to live with independence

Research findings from IDS Tilda:

Wave 3 IDS-TILDA (McCarron, Haigh, et al., 2017) highlighted:

- 93.9% of IDS-TILDA participants had medical/GP card use in Wave 3 (compared with 38% for the TILDA general population)
- 0.5% of IDS-TILDA participants had private medical insurance (compared with 35% for the TILDA general population)
- 95.8% reported use of GP (compared with 91% for the TILDA general population)
- 29.1% visited the emergency department (compared with 18% for the TILDA general population)
- Hospital admissions rose from 11.1% in Wave 1 to 14.9% at Wave 3

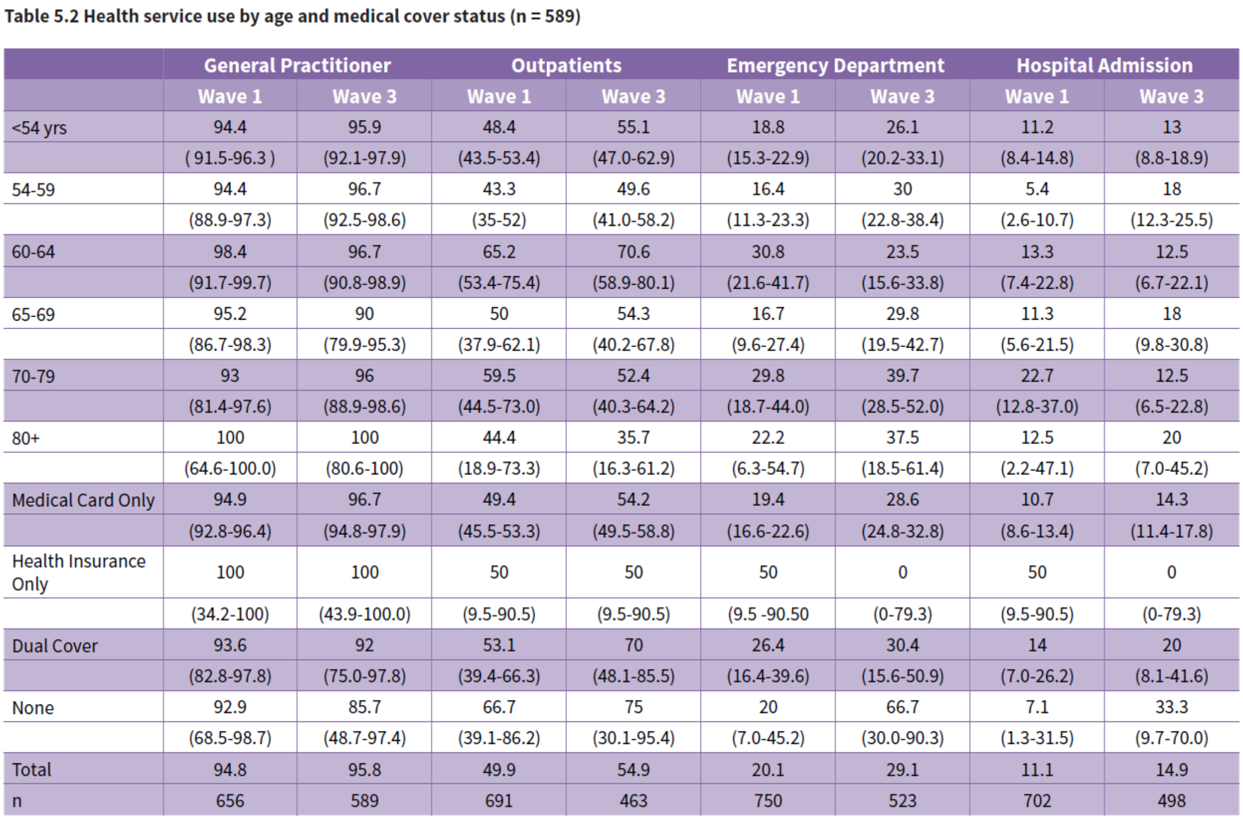


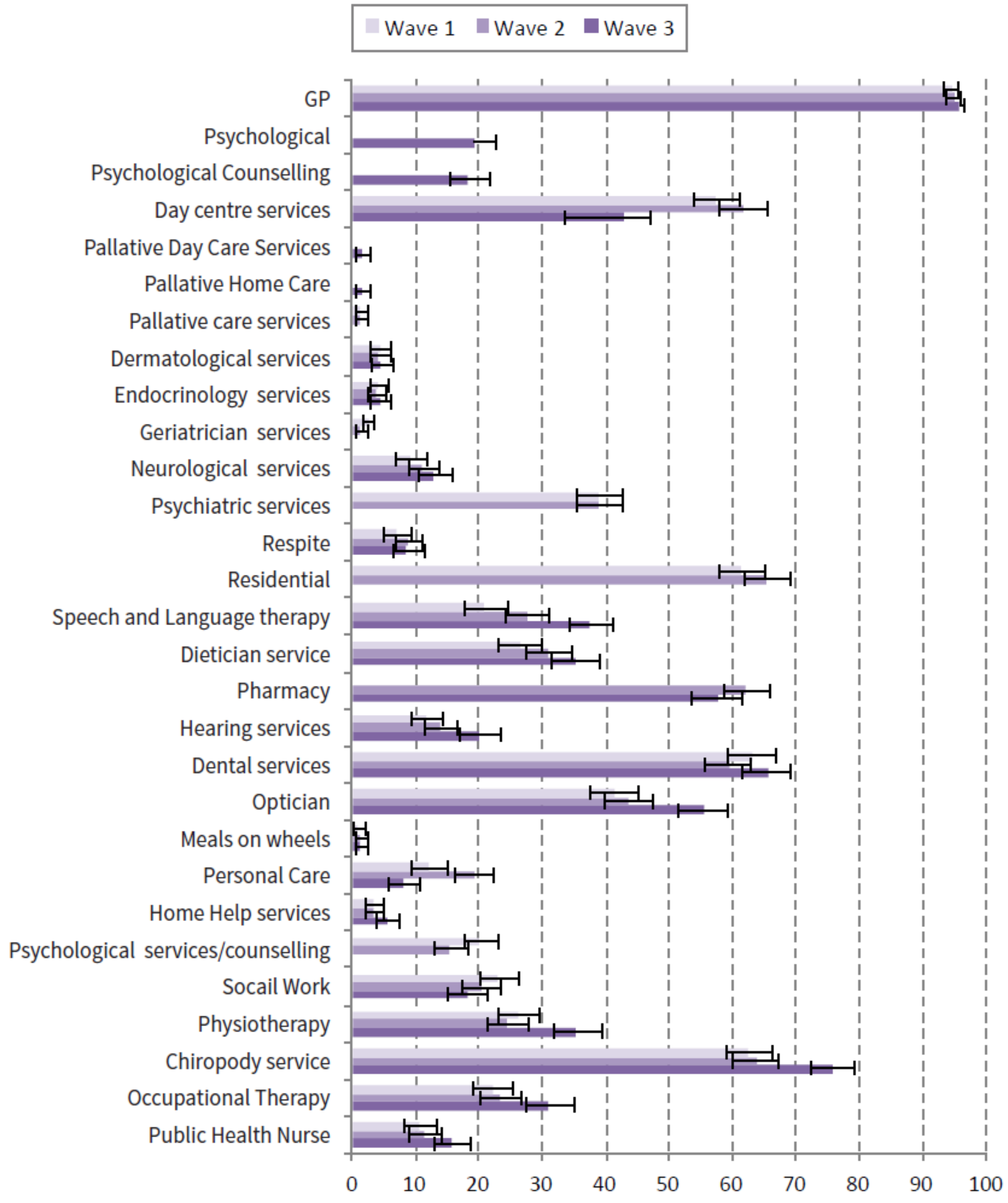
Table 5.2 Health service use by age and medical cover status (n = 589)

	General Practitioner		Outpatients		Emergency Department		Hospital Admission	
	Wave 1	Wave 3	Wave 1	Wave 3	Wave 1	Wave 3	Wave 1	Wave 3
<54 yrs	94.4	95.9	48.4	55.1	18.8	26.1	11.2	13
	(91.5-96.3)	(92.1-97.9)	(43.5-53.4)	(47.0-62.9)	(15.3-22.9)	(20.2-33.1)	(8.4-14.8)	(8.8-18.9)
54-59	94.4	96.7	43.3	49.6	16.4	30	5.4	18
	(88.9-97.3)	(92.5-98.6)	(35-52)	(41.0-58.2)	(11.3-23.3)	(22.8-38.4)	(2.6-10.7)	(12.3-25.5)
60-64	98.4	96.7	65.2	70.6	30.8	23.5	13.3	12.5
	(91.7-99.7)	(90.8-98.9)	(53.4-75.4)	(58.9-80.1)	(21.6-41.7)	(15.6-33.8)	(7.4-22.8)	(6.7-22.1)
65-69	95.2	90	50	54.3	16.7	29.8	11.3	18
	(86.7-98.3)	(79.9-95.3)	(37.9-62.1)	(40.2-67.8)	(9.6-27.4)	(19.5-42.7)	(5.6-21.5)	(9.8-30.8)
70-79	93	96	59.5	52.4	29.8	39.7	22.7	12.5
	(81.4-97.6)	(88.9-98.6)	(44.5-73.0)	(40.3-64.2)	(18.7-44.0)	(28.5-52.0)	(12.8-37.0)	(6.5-22.8)
80+	100	100	44.4	35.7	22.2	37.5	12.5	20
	(64.6-100.0)	(80.6-100)	(18.9-73.3)	(16.3-61.2)	(6.3-54.7)	(18.5-61.4)	(2.2-47.1)	(7.0-45.2)
Medical Card Only	94.9	96.7	49.4	54.2	19.4	28.6	10.7	14.3
	(92.8-96.4)	(94.8-97.9)	(45.5-53.3)	(49.5-58.8)	(16.6-22.6)	(24.8-32.8)	(8.6-13.4)	(11.4-17.8)
Health Insurance Only	100	100	50	50	50	0	50	0
	(34.2-100)	(43.9-100.0)	(9.5-90.5)	(9.5-90.5)	(9.5 -90.50	(0-79.3)	(9.5-90.5)	(0-79.3)
Dual Cover	93.6	92	53.1	70	26.4	30.4	14	20
	(82.8-97.8)	(75.0-97.8)	(39.4-66.3)	(48.1-85.5)	(16.4-39.6)	(15.6-50.9)	(7.0-26.2)	(8.1-41.6)
None	92.9	85.7	66.7	75	20	66.7	7.1	33.3
	(68.5-98.7)	(48.7-97.4)	(39.1-86.2)	(30.1-95.4)	(7.0-45.2)	(30.0-90.3)	(1.3-31.5)	(9.7-70.0)
Total	94.8	95.8	49.9	54.9	20.1	29.1	11.1	14.9
n	656	589	691	463	750	523	702	498

GP services were used by 95.8% of Wave 3 participants. The next most frequently used health and social care services were dental (65.6%), pharmacy (57.6%), optician (55.4%) and day services (42.9%). As may be seen in figure 5.4, the rates were consistent across all three waves.

Also to be seen in figure 5.4, are increases in the use between Wave 1 and Wave 3 for optician services (55.4% up from 41.4% in Wave 1), public health nurse (15.7% up from 10.7%), occupational therapy services (31.0% up from 22.1%), chiropody services (76.0% up from 62.5%) and physiotherapy (35.4% up from 26.2%). Use of dental services at Wave 3 was 65.6%, up from 59.4% at Wave 2 which had been a drop from 63.2% at Wave 1.

Figure 5.4 Use of specialist health and social care services across three waves



Item 333 in Draft State Report

Sharing the Vision – a Mental Health Policy for Everyone 2020-2030 envisages a mental health system that addresses the needs of population through a focus on the requirements of the individual. It is action-oriented and outcome-focussed, placing the individual at the centre of service delivery.

Sharing the Vision makes recommendations across the lifespan, particularly the development of Mental Health and Intellectual Disability (MHID) teams across the country. It recommends acute beds and day hospital services for mental health and ID treatment.

- Recommendation 48: A cross-disability and mental health group should be convened to develop national competence in the commissioning, design and provision of intensive supports for people with complex mental health difficulties and intellectual disabilities and to develop a set of criteria to govern the provision of this service.
- Recommendation 50: The development of a national network of MHID teams and acute treatment beds for people of all ages with an intellectual disability should be prioritised.
- Recommendation 57: A tiered model of integrated service provision for individuals with a dual diagnosis (e.g. substance misuse with mental illness) should be developed to ensure that pathways to care are clear. Similarly, tiered models of support should be available to people with a dual diagnosis of intellectual disability and/or autism and a mental health difficulty.

The HSE National Model of Service and framework for MHID was launched in 2021. Ramsay, Mulryan, McCallion, and McCarron (2016) used IDS-TILDA data to examine differences in access to psychiatry services for people with an intellectual disability according to geography. Treatment by a psychiatrist was associated with both health region ($p = 0.029$) and degree of urbanicity ($p = 0.015$) before controlling for group differences; but only health region was significantly associated after controlling for age, gender and level of intellectual disability. Antipsychotic use without a psychiatrist was associated with degree of urbanicity ($p = 0.036$) but not with health service region ($p = 0.989$).

Geographic factors were found to be associated with access to mental health services among those with intellectual disability in the Republic of Ireland. This may be partly due to movement of people with intellectual disability away from their area of origin, highlighting the need for locally tailored specialist intellectual disability mental health teams and for further research into barriers to treatment.

IDS-TILDA Wave 3 findings for Mental Health:

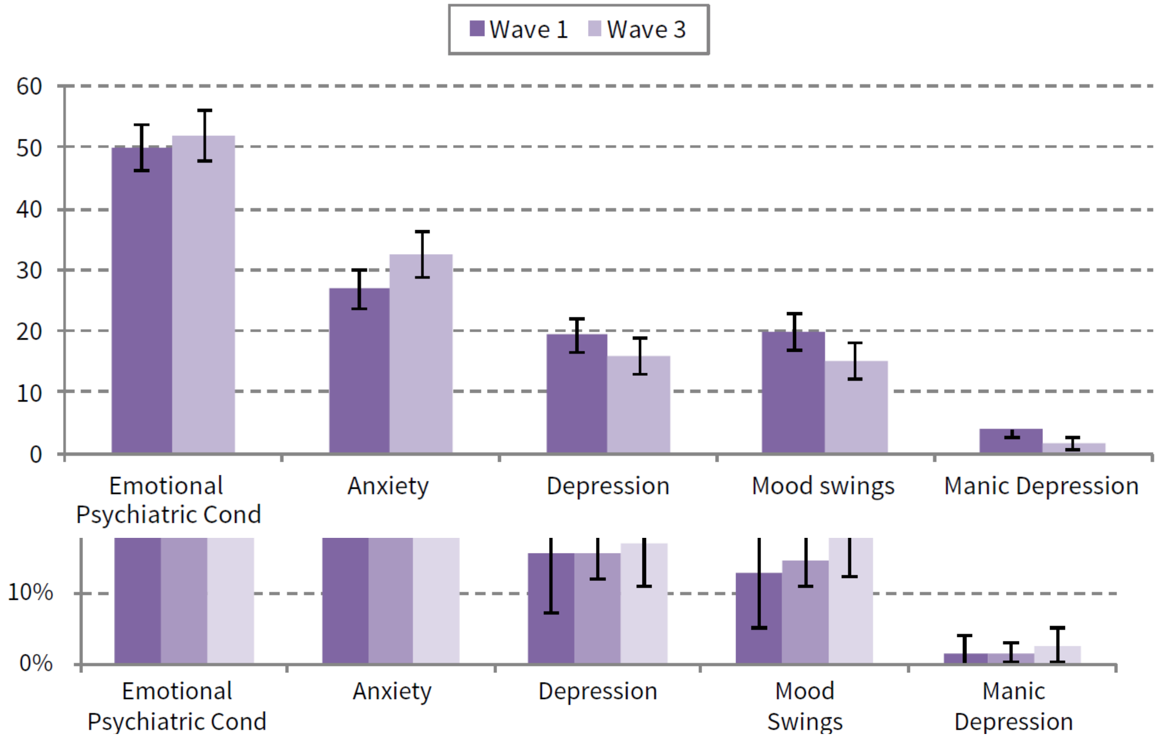
(Sheerin, Carroll, Mulryan, McCallion, & McCarron, 2017)

- 52% reported a diagnosis of an emotional, nervous or psychiatric condition.
- 15.1% prevalence of anxiety (GAS-LD)
- 10% prevalence of depression (GDS-LD) – compared with 5% prevalence of depression in TILDA general population (CES-D8)

Reported diagnosis:
The overall prevalence of mental health diagnoses in IDS-TILDA Wave 3 (51.9%) indicates little overall change from Wave 1 (49.9%). Anxiety remained the most prevalent condition and rates increased from Wave 1 to Wave 3 (Wave 1: 26.8%; Wave 3: 32.4%), followed by depression (Wave 1: 19.3%; Wave 3: 15.8%) and mood swings (Wave 1: 19.9%; Wave 3: 15.1%). This compares with the TILDA finding that 13% of people experienced ‘case-level’ symptoms for anxiety (O’Regan et al., 2011). Manic depression was the next most prevalent (Wave 1: 3.9%; Wave 3: 1.8%) (Figure 4.1).

All of these diagnoses, with the exception of anxiety, were found to have a higher prevalence in women and, whereas the findings in Wave 2 showed increasing prevalence with advancing age, Wave 3 findings showed greater variance (Figure 4.2). Those in the 65+ years category reported a greater overall prevalence for mental health diagnoses (58.4%) but participants aged 50-64 years showed a slightly lower prevalence (49.2%) than those in the <50 years category (52.1%). Overall, prevalence remained highest among those with severe or profound intellectual disability (65.6%).

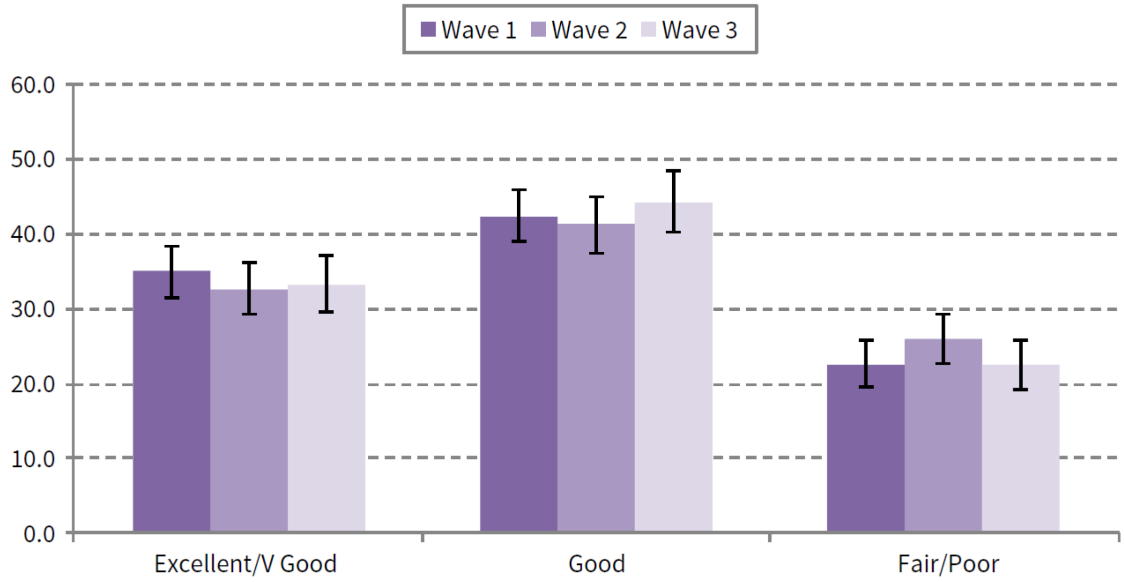
Figure 4.1 Prevalence of emotional and psychiatric conditions Wave 1 & Wave 3



Self/proxy rated emotional and mental health:

Respondents and/or their proxies were asked to rate their perception of the participant's mental and emotional health on a five-point Likert scale with options ranging from poor to excellent. A total of 592 valid responses were obtained, of which 113 were self-reports. Although participants reported high prevalence of mental health conditions, more than three-quarters rated their overall emotional and mental health as either excellent/very good (33.3%), or good (44.3%). Rates have remained the same across all three waves with some increase in fair/poor ratings in Wave 2 (Figure 4.3). However, the combined positive Wave 3 rating of 77.5% was lower than the rate for the general population (90%) reported by TILDA (O'Regan et al., 2011).

Figure 4.3 Self-rated mental health Waves 1, 2 and 3



Psychotropic Medication

O'Dwyer et al. (2017) found that 59.1% (436) of IDS-TILDA participants were exposed to any psychotropic drugs. Of these, 66.2% reported psychotropic polypharmacy. Antipsychotics were the most frequently used psychotropic class, reported by 43% of participants. Living in a residential institution and having a history of reporting a mental health condition or sleep problems were associated with psychotropic polypharmacy.[3]

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[3] See also: Wormald, A. D., McCallion, P., & McCarron, M. (2019). The antecedents of loneliness in older people with an intellectual disability. *Research in Developmental Disabilities*, 85, 116-130. https://doi-org.elib.tcd.ie/10.1016/j.ridd.2018.11.009
Bond, L., Carroll, R., Mulryan, N., O'Dwyer, M., O'Connell, J., Monaghan, R., . . . McCarron, M. (2019). The association of life events and mental ill health in older adults with intellectual disability: results of the wave 3 intellectual disability supplement to the Irish longitudinal study on ageing. *Journal of Intellectual Disability Research*, 63(5), 454-465. https://doi-org.elib.tcd.ie/10.1111/jir.12595

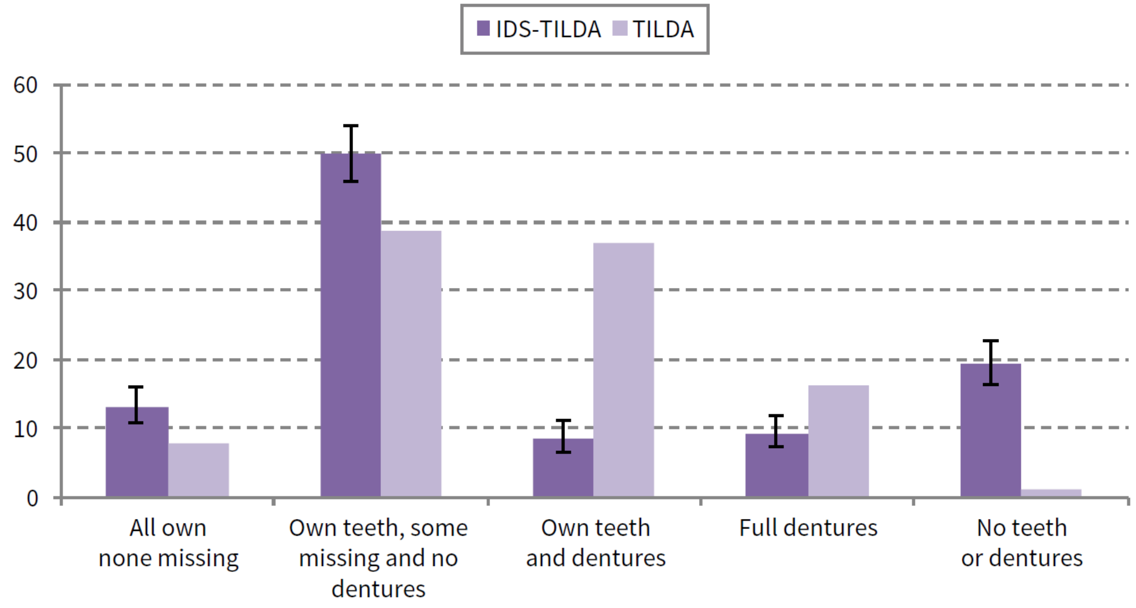
Item 335 in Draft State Report

> In 2019 the Government published Smile agus Sláinte – the National Oral Health Policy. It recognises that the current system has left gaps in oral health care, in particular for persons with disabilities. The policy takes account of the mainstreaming agenda for persons with disabilities but also their extra needs, specifically referring to people who have profound disabilities, or are non-ambulatory.

In Wave 3 of IDS-TILDA, 28.3% (n=171/603) of participants reported that they had no teeth at all (Figure 3.17). This represented an increase of 3% since Wave 1, when the corresponding figure was 25.4% (n=191/751). In contrast, only 16.9% (n=1,115) of Wave 3 TILDA participants reported total tooth loss, down from 17.7% in Wave 1(n=1,502), despite the TILDA sample being older.

When total tooth loss occurred, a large proportion of people with intellectual disability (67.8% of IDS-TILDA Wave 3 sample without any teeth, n=116) did not receive prosthetic dentures to restore function. Conversely, this did not occur among the TILDA Wave 3 sample where only 5.3% of those without teeth were without dentures (n=58). (McCarron, Haigh, et al., 2017)[4]

Figure 3.17 Comparing the proportion reporting oral status in IDS-TILDA and TILDA



Note: n = 603; Missing Obvs = 6; Error bars correspond to 95% confidence intervals

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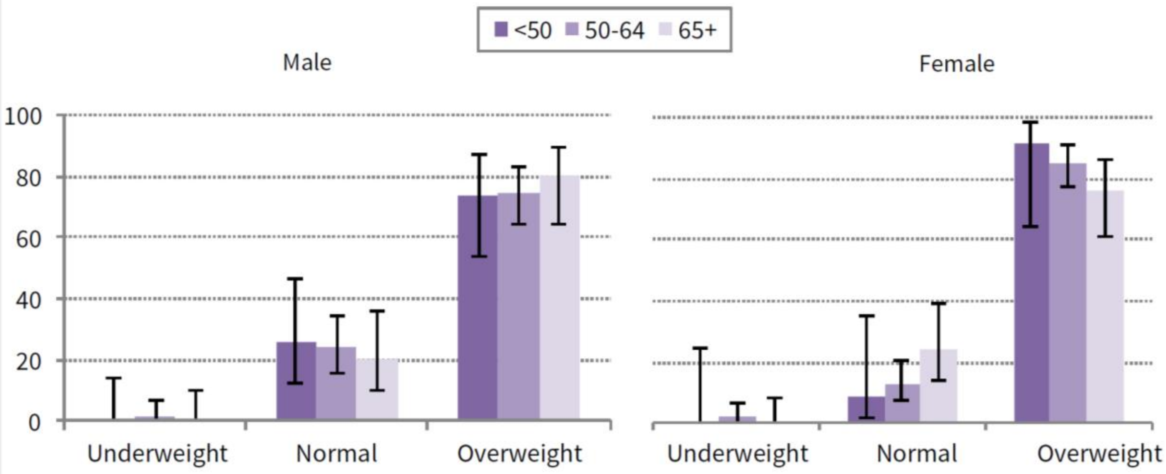
[4] See also: Mac Giolla Phadraig, C., Griffiths, C., McCallion, P., McCarron, M., & Nunn, J. (2019). Communication-based behaviour support for adults with intellectual disabilities receiving dental care: A focus group study exploring dentists' decision-making and communication. *Journal of Intellectual Disabilities*, 23(4), 526-540. https://doi-org.elib.tcd.ie/10.1177%2F1744629517738404

Item 336

A Healthy Weight for Ireland is Ireland's Obesity Policy and Action Plan for the period 2016-2025. The Strategy notes that persons with disabilities are one of the groups most at risk of obesity. It also notes that obesity can impact on mental health.

Levels of measured overweight and obesity increased from 61 % in Wave 2 to 79.7 % in Wave 3, and now equals rates reported by TILDA for the general population at 79% (Leahy, Nolan, O'Connell, & Kenny, 2014). Higher levels of overweight and obesity were identified in those aged 50-64 years at 80.6% compared to 77.6% in those 65 years and over. Those with a mild/ moderate level of intellectual disability presented with greater levels of obesity at 87.5% versus 64.3% for those in the severe/profound disability. Females had higher prevalence of overweight and obesity compared to males at 83.1% versus 75.9% respectively. And consistent with Wave 1, females with a mild level of intellectual disability showed the highest levels of overweight and obesity at 89.1% (n=49). Figure 3.1 for weight status stratified by gender and age.

Figure 3.1 BMI stratified by gender and age



Among participants who self-reported their perception of their own weight, approximately a third who were overweight or obese perceived themselves as being in this category with the majority, while most (63.7%) perceived themselves as just about the right weight. (McCarron, Haigh, et al., 2017)

Mac Giolla Phadraig, C., Nunn, J., McCallion, P., Donnelly-Swift, E., van Harten, M., & McCarron, M. (2019). Total tooth loss without denture wear is a risk indicator for difficulty eating among older adults with intellectual disabilities. Journal of Oral Rehabilitation, 46(2), 170-178. https://doi-org.elib.tcd.ie/10.1111/joor.12738

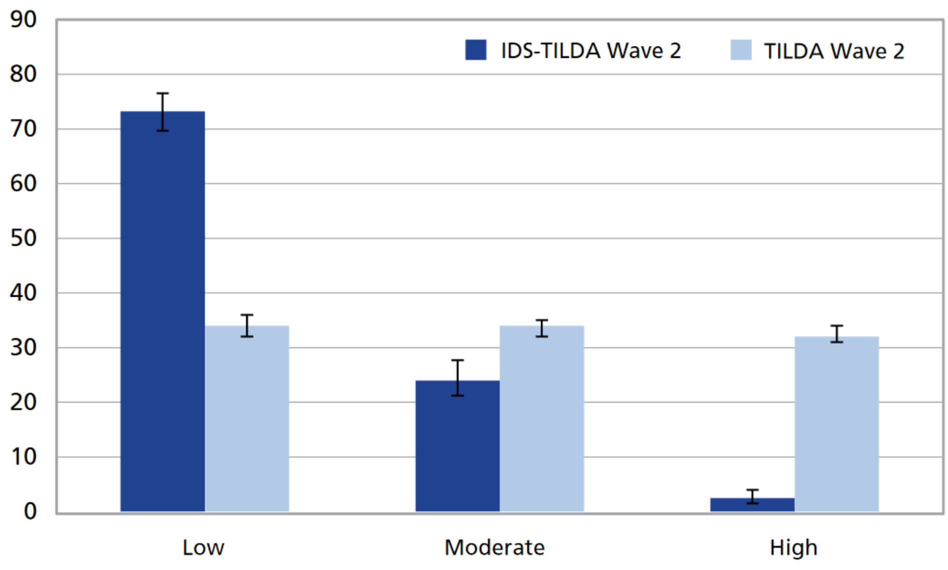
Item 339 A Healthy Weight for Ireland is Ireland's Obesity Policy and Action Plan.

> 'Ireland has a National Physical Activity Plan aimed at increasing physical activity levels across the whole population, including persons with a disability. The plan identifies specific actions in the area of disability, including the development of guidelines, support materials and referral pathways to promote physical activity for organisations providing mental health services and disability services.'

In IDS-TILDA Wave 2, data for physical activity in the 7 days prior to participants' interviews using the International Physical Activity Questionnaire (IPAQ) (Craig et al., 2003) allowed comparison between IDS-TILDA and TILDA findings.

The majority of IDS-TILDA Wave 2 participants engaged in low levels of physical activity (73.2%, n=506), with 24.3% (n=168) engaging in moderate activity and just 2.5% (n=17) reporting engagement in high levels of physical activity. These findings contrast with TILDA findings of 34% of people engaging in low levels of physical activity, 34% in moderate physical activity and 33% in high levels of physical activity (see figure 3.17). Levels of activity for IDS-TILDA participants at Wave 2 were similar to findings at Wave 1 and it is concerning that low levels of reported activity continue among people with ID. Levels of moderate and vigorous activity among people with ID remain too low to accrue health benefits.

Figure 3.17: Comparing levels of physical activity between Wave 2 IDS-TILDA and Wave 2 TILDA.



(E. Burke, McCallion, & McCarron, 2014)

Early detection and intervention programmes

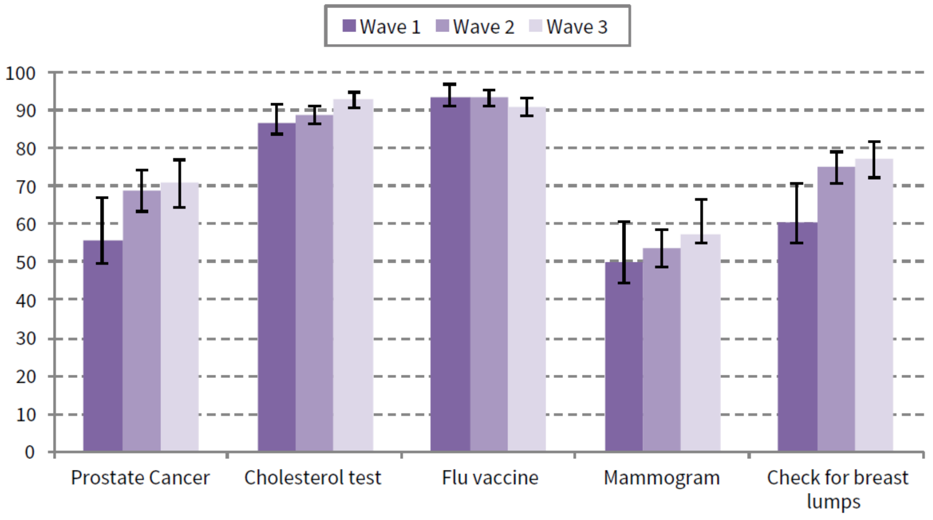
Item 343.

Ireland has a National Screening Service (NSS) that encompasses the national breast, cervical, bowel and diabetic retina screening programmes. The Service has a Screening Promotion Team that aims to enable the entire eligible population, including persons with a disability, to participate in these programmes. This is achieved by developing and implementing effective screening promotion strategies in collaboration with community partners and health professionals. In partnership with women with intellectual disabilities,

- Flu vaccination: relatively stable across the three waves, with a slight decrease in Wave 3 (90.9% down from 93.4% at Wave 2) and were substantially greater than for the general older population as reported in Wave 3 TILDA (47.5%).
- Prostate cancer checks: (77.1% at Wave 3, up from 55.7% at Wave 1)
- Breast checks: (77.3% up from 60.2% at Wave 1).
- Smaller increases in screening were found for cholesterol and mammogram checks, corresponding with general older population trends of screening uptake increasing with age.
- Levels of breast checks found among women with ID also were comparable with the general older population. In Wave 3 of TILDA, 64.6% of older adult women in the general population reported that they check their breasts for lumps regularly and 54.7% of older adult women in Ireland reported that they had a mammogram since their last interview, comparable to 57.2% of IDSTILDA participants. Rates for cholesterol checks were found to be higher among IDS-TILDA participants than for the older general population.

(McCarron, Haigh, et al., 2017)

Figure 5.3 Health screening across three waves



Note: Wave 1 n = 736; Wave 2 n= 685; Wave 3 n = 571; Error bars correspond to 95% confidence intervals

Preventing further harm or disability

Item 344.

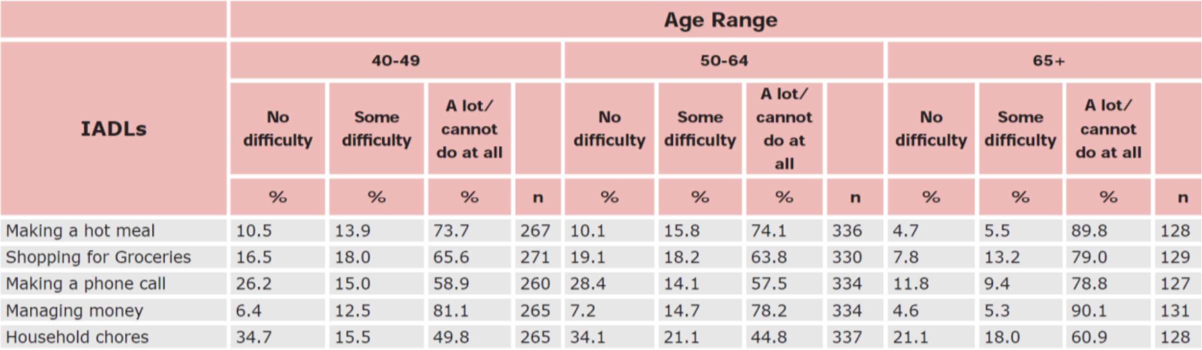
The National Positive Ageing Strategy (NPAS), first published in 2013, is a catalyst for action and innovation to promote the health, wellbeing and quality of life of people as they age by focusing attention on issues relevant to older people across the policy development and service delivery process. One of the national goals of the strategy commits to supporting people as they age to maintain, improve or manage their physical and mental health and wellbeing, with one of the objectives to prevent and reduce disability, chronic disease and premature mortality as people age.

See data on chronic health conditions as people age at section 328 above.

Activities of Daily Living (ADLs)

	Age Range											
ADLs	**40-49**				**50-64**				**65+**			
	No difficulty	**Some difficulty**	**A lot/ cannot do at all**		**No difficulty**	**Some difficulty**	**A lot/ cannot do at all**		**No difficulty**	**Some difficulty**	**A lot/ cannot do at all**	
	%	%	%	n	%	%	%	n	%	%	%	n
Dressing including shoes and socks	57.6	21.2	21.2	229	58.8	20.3	20.8	340	48.1	28.6	23.3	133
Walking across a room	85.3	5.1	9.5	272	83	5.6	11.4	342	73.7	9.8	16.5	133
Bathing or showering	36.1	29.4	34.5	269	35.7	28.9	35.4	339	17.3	37.6	45.1	133
Cleaning your teeth/ dentures	55.9	13.7	30.3	270	57.9	13.5	28.5	340	48.5	16.7	34.8	132
Eating/cutting up your food	57.2	15.6	15.6	238	60.4	23.2	16.4	341	50.8	27.3	22.0	132
Getting in and out of bed	87.4	3.3	9.3	269	80.4	7	12.6	341	74.6	9.0	16.4	134
Using the toilet including getting up and down	82.1	6.7	11.2	248	80.5	7.1	12.5	338	72.9	6.8	20.3	133

Instrumental Activities of Daily Living (IADLs)



	Age Range											
IADLs	**40-49**				**50-64**				**65+**			
	No difficulty	**Some difficulty**	**A lot/ cannot do at all**		**No difficulty**	**Some difficulty**	**A lot/ cannot do at all**		**No difficulty**	**Some difficulty**	**A lot/ cannot do at all**	
	%	%	%	n	%	%	%	n	%	%	%	n
Making a hot meal	10.5	13.9	73.7	267	10.1	15.8	74.1	336	4.7	5.5	89.8	128
Shopping for Groceries	16.5	18.0	65.6	271	19.1	18.2	63.8	330	7.8	13.2	79.0	129
Making a phone call	26.2	15.0	58.9	260	28.4	14.1	57.5	334	11.8	9.4	78.8	127
Managing money	6.4	12.5	81.1	265	7.2	14.7	78.2	334	4.6	5.3	90.1	131
Household chores	34.7	15.5	49.8	265	34.1	21.1	44.8	337	21.1	18.0	60.9	128

(McCarron et al., 2011)

The *Positive Ageing Indicators for People with an Intellectual Disability 2018* report also provides a baseline to track positive ageing for this population across a wide range of nationally agreed measures of health, well-being and quality of life that are comparable with the general population. These indicators address Goal 4 of the National Positive Ageing Strategy, and provide data on issues across pillars related to participation, healthy ageing, security and cross cutting objectives (McGlinchey et al., 2019). (https://assets.gov.ie/9674/abcdfeef1474423b983e531d2bde645d.pdf)

See also:

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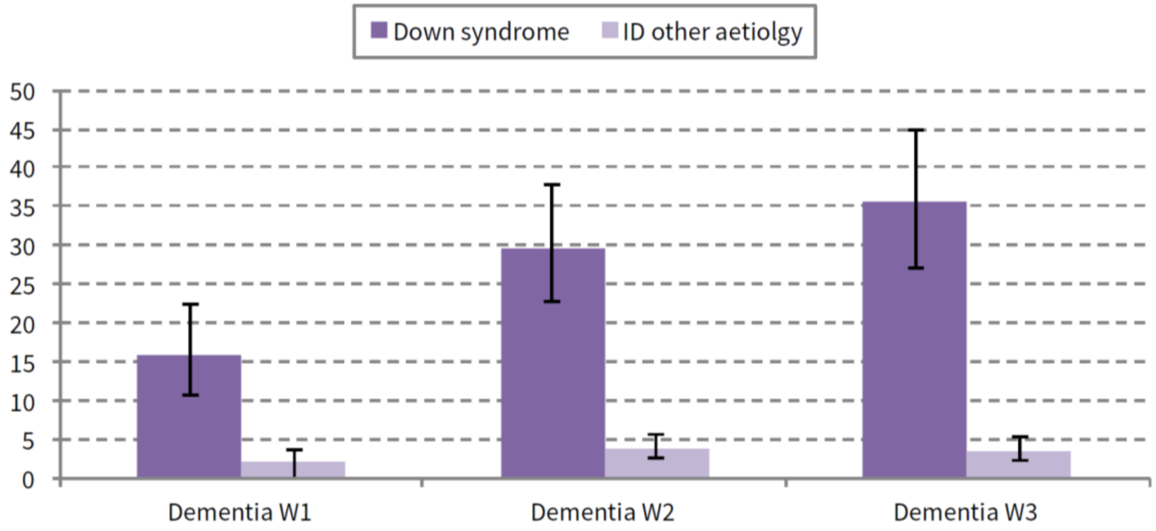
Item 346.

The Irish National Dementia Strategy was launched in 2014. 74 Underpinned by the principles of personhood and citizenship, it aims to improve service and supports so that people with dementia can live well for as long as possible in their own communities. A National Dementia Office drives the Strategy's implementation.

- Prevalence of a doctor's diagnosis for dementia increased from 5.8% in Wave 1 to 9.1% in Wave 3.
- Overall, there was an incidence of 4.7% (n=27) between Waves 2 and 3, of whom 20 individuals (74%) had Down syndrome.
- Of the 147 people with Down syndrome who began the study in Wave 1, 44.2% (n=65) received a diagnosis of dementia.
- In Wave 3, 35.5% (n=38) of people with Down syndrome had a doctor's diagnosis of dementia, which rose from 15.6% in Wave 1. (Figure 3.22 below).
- This compared to 3.4% (n=17) of those with intellectual disability from other aetiologies.
- The average age of diagnosis of dementia for those with Down syndrome was 52.3 years compared to 65.5 years for those with intellectual disability from other aetiologies.

- An incidence rate of 22.5% (n=20) was found for participants with Down syndrome between Waves 2 and 3, an incidence rate of 7.5% per year. In the general population, it is estimated that incidence of dementia is 2% for those 60 years and older (Satizabal, 2016).

Figure 3.22 Dementia prevalence across three waves



(McCarron, Haigh, et al., 2017)
Based on assessments for dementia, McCarron, McCallion, et al. (2017) additionally reported that risk for dementia among people with Down syndrome increased from 23% in those aged 50 years to 45% at age 55 and lifetime risk was 88% in those aged 65 years and above, with an average age of onset of 55 years.

National Intellectual Disability Memory Service
The National Intellectual Disability Memory Service (NIDMS) is committed to improving the early detection of dementia in people with an intellectual disability and offering post-diagnostic supports. Over time, this will provide clinical data on dementia diagnosis, blood biomarkers and longitudinal trajectories of cognitive assessments and blood biomarkers. This data will help to advise service planning. This work is also vital to the development of an understanding of dementia among people with intellectual disability, what are the contributory factors specific to this population and how the development of the condition can be slowed down or prevented for greater numbers of people with intellectual disability.
https://www.tcd.ie/tcaid/research/NIDMS.php

Accessible and equal health care

Item 348.

The National Guidelines on Accessible Health and Social Care Services were created to give effect to obligations under the Disability Act. 75 The guidelines detail statutory obligations in relation to the provision of accessible services and give practical guidance to staff on providing accessible services to patients and clients with disabilities. Over 200 health care workers have been trained across the HSE to support access to services.

IDS-TILDA data had formed the basis for translational activities that support accessible health services for people with an intellectual disability. For example:

- Dr Eilish Burke, Ussher Assistant Professor, School of Nursing & Midwifery, designed an accessible health assessment for people with an intellectual disability in 2013 and led its rollout in IDS-TILDA Wave 2 and Wave 4 (https://idstilda.tcd.ie/accessible/videos/health-assessment.php)

  This approach formed the basis for a Massive Open Online Course (MOOC) entitled 'Improving Health Assessments for People with an Intellectual Disability'. The course is accredited by the Nursing and Midwifery Board of Ireland and has been completed by over 6,000 health professionals worldwide (https://www.futurelearn.com/courses/health-assessment/3)
  See also: Burke, É. A., Walsh, J. B., McCallion, P., & McCarron, M. (2020). Making reasonable adjustment to enable and support people with intellectual disability engage in objective health measures in a research study—the health fair in the intellectual disability supplement to the Irish longitudinal study on ageing. *Inclusion*, 8(2), 124-137.
- Prof Mary McCarron has used IDS-TILDA data to support the development of the National Intellectual Disability Memory Service (NIDMS), a centre of excellence in proactive dementia assessment and diagnosis for people with an intellectual disability. The NIDMS is particularly supporting people with Down syndrome given their increased genetic risk for dementia.

  Education and Training for health care workers and family carers is an important component of the NIDMS to equip them with the necessary knowledge and skills. Unfamiliarity in working with people with intellectual disability by a clinical professional or memory clinic may lead to problems with eliciting information from the person (particularly if that person is non-verbal). That unfamiliarity may lead to misinterpretation on both sides about what is being asked and what answers might mean. Dementia symptoms may be confused with other symptoms caused by separate issues such as depression or constipation, leading to dementia being incorrectly diagnosed or, conversely, to dementia symptoms being masked by the presence of other issues. Family, staff or care-workers who are engaged with the person with intellectual disability may not be alert to the early symptoms of dementia which, thereby, may lead to a delay in diagnosis.

- Dr Caoimhin Mac Giolla Phadraig, Assistant Prof in Public Dental Health, has used IDS-TILDA data to develop an accessible website to show people with an intellectual disability how to manage their oral health (www.brushmyteeth.ie)

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