Overview of UNCRPD Article 7 in Ireland

Children with Disabilities

October 2020



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# Background to the UNCRPD Article review papers

During 2020 the National Disability Authority (NDA) developed a series of in-depth papers on individual United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) articles. These papers detail the main data available relevant to specific Articles and provides an overview of key policies, programmes, services, supports and data that exist in the Irish context. They are not a critique of what is currently in place but rather a record of what exists. Nevertheless, there are instances where certain gaps or concerns are highlighted, including those advised by the NDA or other stakeholders.

These papers were primarily developed through desk research. However, the papers were also informed by the NDA’s own work, updates and discussions at Departmental Disability Consultative Committees, the National Disability Inclusion Strategy Steering Group, and other relevant committees. They were also informed by interactions with the Disability Stakeholders Group and with persons with disabilities, particularly through participation on a range of working and advisory groups across Government Departments on areas related to NDIS actions. Given their factual nature a more direct consultation process with persons with disabilities was not conducted. However, the NDA envisages continuing to conduct periodic consultations on specific articles of the UNCRPD and related matters which will seek the lived experience of persons with disabilities individually and through their representative bodies.

The purpose of the papers are multiple. They were developed initially to support the development of the State Party report to the UNCRPD Committee. In line with the NDA’s anticipated new statutory function under the UNCRPD, ~~t~~hey are also intended to be useful to support the development by the Irish Human Rights and Equality Commission (IHREC) of the State’s parallel report to the UNCRPD Committee. They will also be used internally as reference papers within the NDA. The NDA has published these documents on our website to make them available to a wider audience to support any work underway to develop shadow reports on implementation of UNCRPD in Ireland.

The NDA sought to ensure that the information is accurate as of October 2020 but recognises that the changing nature of policies, programmes, services, supports and data will require them to be updated periodically to reflect any changes. The papers are not intended to be exhaustive but seek to provide a broad overview of the main issues of relevance to each article.

In the first instance we reviewed nine articles listed below. Five are available at [www.nda.ie](http://www.nda.ie) and the remaining four will be published shortly. These were selected to reflect some of the main topics of concern to the stakeholders noted above and to include some of the cross-cutting issues such as children and women with disabilities. It is intended that the NDA will develop further papers during 2021 focusing on a number of civil and political Articles.

* Article 6, Women with Disabilities
* Article 7, Children with Disabilities
* Article 8, Awareness Raising
* Article 19, Living Independently
* Article 24, Education
* Article 25, Health
* Article 26, Work and employment
* Article 28, Adequate Standard of Living and Social Protection
* Article 31, Statistics and Data Collection

# Introduction

The NDA notes that there have been a number of considerable advances in the legal framework to protect children’s rights over the past number of years. These include a constitutional amendment giving explicit expression to the rights of children as individuals, as well as progressive legislation such as the Child and Family Agency Act 2013, the Children and Family Relationships Act 2015 and the Childcare Support Act 2018. The ratification of the UNCRPD by Ireland in 2018 with a specific article on children and disabilities adds further emphasis to the rights of children.

Following the convention text below this paper then examines the situation of children with disabilities in Ireland looking at key data and research, policies, legislation, and then looking at some specific areas such as early childhood care and education, healthcare, child protection and consultation with children with disabilities.

# Convention text

Article 7 – Children with disabilities

1. States Parties shall take all necessary measures to ensure the full enjoyment by children with disabilities of all human rights and fundamental freedoms on an equal basis with other children.

2. In all actions concerning children with disabilities, the best interests of the child shall be a primary consideration.

3. States Parties shall ensure that children with disabilities have the right to express their views freely on all matters affecting them, their views being given due weight in accordance with their age and maturity, on an equal basis with other children, and to be provided with disability and age-appropriate assistance to realize that right.

# Type of Right

The UNCRPD includes economic, social, cultural and civil and political rights. States which ratify the Convention commit themselves to immediate delivery of civil and political rights to people with disabilities, and to progressive realisation of social and economic rights. Article 7 contains elements of both types of rights.

# Key Data & Research

According to Census 2016, there are 75,963 children and young people with disabilities under the age of 18 in Ireland. Of these, 47,022 are boys and 28,941 are girls. Accordingly, 6.4% of all children aged 0-17 are children with disabilities. In 2011, there were 66,437 children with a disability in Ireland, accounting for 5.8% of the total child population (Table 1).[[1]](#footnote-1)

The most common disability type reported was a difficulty in learning, remembering or concentrating (n=40,157) followed by other illness including chronic illness (n=21,923) and intellectual disability (n= 21,747) (Table 2). Children were reported as having difficulties in many areas of their lives including participating in other activities (n=23,360) and in attending school or college (n=21,042) (Table 3)

Table 1: Number of Children with a Disability and Gender

|  | Boys | Girls | Total |
| --- | --- | --- | --- |
| 2011 | 41,215 | 25,222 | 66,437 |
| 2016 | 47,022 | 28,941 | 75,963 |

Source: 2016 Census

Table 2: Number of children by disability type

| Disability Type | Total |
| --- | --- |
| Blind or a serious visual impairment | 5,081 |
| Deaf or a serious hearing impairment | 4,526 |
| A condition that substantially limits one or more basic physical activities | 10,840 |
| Intellectual disability | 21,747 |
| Difficulty in learning, remembering or concentrating | 40,157 |
| Psychological or emotional condition | 16,772 |
| Other disability, including chronic illness | 21,923 |

Source: 2016 Census

Table 3: Number of children with a disability by difficulty experienced

|  |  |
| --- | --- |
| Disability Type | Total |
| Difficulty in dressing, bathing or getting around inside the home | 16,840 |
| Difficulty going outside home alone2 | 20,344 |
| Difficulty in work or attending school / college | 21,042 |
| Difficulty participating in other activities | 23,360 |

Source: 2016 Census

## National Disability Survey

The NDA commissioned the ESRI to conduct research entitled **Insights into the Lives of Children with Disabilities: Findings from the 2006 National Disability Survey**, which was published in 2015.[[2]](#footnote-2) This research analysed data from the sample of children included in the National Disability Survey (2006). This study showed that boys are 1.7 times more likely than girls to have a disability. In terms of social background characteristics, children and young people with disabilities are more likely to come from disadvantaged and one-parent households compared to the general population. In relation to the type of disability, over three-quarters of respondents reported having intellectual or learning disabilities followed by (i) remembering or concentrating disabilities, (ii) speech disabilities and (iii) Emotional, Psychological and Mental Health (EPMH) disabilities.

The study also found that most children with disabilities were educated in mainstream schools, but this decreased at post-primary level when more children attended special schools. Children with emotional, psychological or mental health issues experienced a lack of social engagement with their peers, and were much more likely to have prolonged absences from school.

## Growing Up in Ireland

Growing Up in Ireland (GUI) is the national longitudinal study of children and youth in Ireland, and is funded and managed by the Department of Children and Youth Affairs[[3]](#footnote-3) in association with the Central Statistics Office.[[4]](#footnote-4) The study is nationally representative with over 20,000 cohort members. The study follows the progress of two cohorts: Cohort ’98 (the ‘Child Cohort’) who were aged 9 years at first interview in 2007 and Cohort ’08 (the Infant Cohort) who were just 9 months in the first wave in 2008. A wide range of topics are covered and fall under the three broad domains of health, education and socio-emotional well-being.

The study has been a rich source of information, with published reports to date highlighting particular issues regarding children with disabilities. For instance, research indicates that those most likely to experience adjustment difficulties when transitioning from an Early Learning and Care setting to primary school are children with disabilities or special educational needs. Additionally, a Key Findings report on the health and physical development of the Cohort ’08 revealed that about 23% of 9-year-old children were reported to have a longstanding illness, condition or disability.[[5]](#footnote-5) Research commissioned by the NDA found that parental expectations for children with disabilities, particularly general learning/intellectual disabilities and specific learning and emotional/behavioural disabilities, are lower than parental expectations for children without disabilities.[[6]](#footnote-6)

# Policies

## Better Outcomes, Brighter Futures

**Better Outcomes**, **Brighter Futures** is the overarching national policy framework for children and young people (aged 0-24 years).[[7]](#footnote-7) The policy framework identifies six areas that have the potential to improve outcomes and transform the effectiveness of existing policies, services and resources in achieving these national outcomes. There are a number of actions related to children with a disability and mental health issues, including:

* Reconfiguring services for children with disabilities under 18 years in line with the HSE’s national programme on ‘Progressing Disability Services for Children and Young People’
* Building on the cross-cutting arrangements in place between the Department of Health, the Department of Education and Skills, and the Department of Children and Youth Affairs to enhance collaboration across the three sectors on children’s disability issues
* Ensuring all young people leaving residential disability settings are adequately prepared and supported to negotiate the system and transition to stable independent living, further education, training or employment through the development and implementation of a quality aftercare plan and the development of protocols in relation to accessing housing, education and training
* In the context of the Early Years Strategy, develop a plan for the inclusion of children with a disability in mainstream pre-school and Early Years settings
* Continuing to provide timely access to educational and therapeutic supports for children who are identified as having special needs

The NDA notes that one of the key messages which emerged from the mid-term review of Better Outcomes, Brighter Futures is that the framework is complicated and there is benefit in focussing on particular priorities.[[8]](#footnote-8) The following key themes were identified as requiring action or further advancement in phase two of implementation covering the period 2018-2020:

1. Child Poverty
2. Child Homelessness
3. Prevention and Early Intervention
4. Mental Health and Wellbeing (personal and communal)
5. Progression of the National Early Years Strategy

## First 5: A Whole-of-Government Strategy for Babies, Young Children and their Families

**First 5** is a whole-of-Government strategy to improve the lives of babies, young children and their families. It is Ireland’s first early years strategy, covering the first five years of a child’s life.[[9]](#footnote-9) Disability-related commitments detailed in the Strategy include:

* Developing a national model of parenting services, from universal to targeted provision, covering key stages of child development, taking account of parents and children in a range of contexts such as parenting children with additional needs
* Reducing children’s waiting lists for primary care and early intervention, including waiting times
* Continuing to develop access to supports for children with a disability/developmental delays through child-serving settings (e.g. AIM, In-School and ELC Therapy Demonstration Project, provision of nursing supports in ELC settings and schools for children with complex needs)
* Improving the Assessment of Need process in order to ensure timely access to appropriate services.
* Providing additional support for parents of babies who receive a diagnosis of disability in the perinatal period and those who experience a traumatic birth or bereavement
* Continuing to roll out AIM to ensure the full inclusion of children with a disability in settings delivering the universal pre-school programme

## National Youth Strategy

The stated aim of the National Youth Strategy 2015-2020 is to enable all young people to realise their maximum potential, by respecting their rights and hearing their voices, while protecting and supporting them as they transition from childhood to adulthood.[[10]](#footnote-10) The Strategy outlines commitments to implement the previous national digital strategy and the New Directions policy on adult day services. Outcome 1 of the Strategy is “Active and healthy, physical and mental well-being”, and some of the key priority actions included the promotion of online youth mental health services among young people, and suicide prevention.

## National Youth Justice Strategy

In February 2019, an Expert Steering Group was established to guide the development of the new Youth Justice Strategy. A draft National Youth Justice Strategy, covering the period 2020-2026, was published for consultation in May 2020.[[11]](#footnote-11)

# Ombudsman for Children

The Ombudsman for Children's Office (OCO) is a national human rights institution and independent statutory body established under primary legislation, the Ombudsman for Children Act 2002. The OCO has an overall statutory mandate to promote and monitor the rights and welfare of children under 18 living in Ireland, without prejudice. The OCO’s functions include providing advice to the Government, encouraging the development of policies, practices and procedures to promote children's rights and welfare, highlighting issues that are of concern to children and monitor and reviewing the operation of legislation insofar as it refers to children. The OCO also has a statutory obligation to hear children’s views and highlight issues that are of concern to them.

The OCO’s Three-Year Strategic Plan 2019–2021 commits to continuing to pursue the progressive realisation of rights of vulnerable groups of children and young people, in particular children with disabilities and children experiencing mental health issues.[[12]](#footnote-12)

Notable disability work undertaken by the OCO to date includes an investigation into children with disabilities in foster care[[13]](#footnote-13), research into young people’s experiences of mental health services[[14]](#footnote-14) and the organisation of Beyond Limits, an event for children and young people with disabilities, which brought together over 1,000 people[[15]](#footnote-15). The NDA is also aware that the OCO has commissioned research on the barriers to realisation of rights of children with disabilities in Ireland.

Furthermore, the OCO has a statutory mandate to receive, examine and investigate complaints made by or on behalf of children and young people in respect of actions on the part of public bodies, schools and all hospitals where children are cared for. In 2019, the OCO received 1,503 new complaints.[[16]](#footnote-16) 14% of all 1,503 complaints related to healthcare, and 11% of the total healthcare complaints related to mental health.[[17]](#footnote-17) In 2018, the OCO received 1,622 new complaints, of which 57 concerned mental health services.[[18]](#footnote-18) The OCO’s 2019 Annual Report notes that it continues to receive complaints about children waiting to obtain an Assessment of Need.[[19]](#footnote-19)

# Best interests of the child

## UN Convention on the Rights of the Child

Ireland ratified the United Nations Convention on the Rights of the Child (UNCRC) in 1992, which gives the child the right to have his or her best interests assessed and taken into account as a primary consideration in all actions or decisions that concern him or her, both in the public and private sphere. However, the UNCRC has not been incorporated into domestic law.

The UN Committee on the Rights of the Child has expressed concern that the right of the child to have his or her best interests taken as a primary consideration has yet to be fully implemented as a positive obligation in all relevant legislation and administrative procedures and decision-making processes in Ireland.[[20]](#footnote-20) The UN Committee has recommended that the State “strengthen its efforts to ensure that this right is appropriately integrated and consistently interpreted and applied in all legislative, administrative and judicial proceedings and decisions as well as in all policies, programmes and projects that are relevant to and have an impact on children.”[[21]](#footnote-21)

## Constitution

Article 42A.4.1° of the Constitution states that provision shall be made by law for the best interests of the child to be ‘the paramount consideration’, in child protection and care proceedings brought by the State, and to judicial proceedings concerning adoption, guardianship or custody of, or access to, any child.

## Legislation

Legislation giving effect to the “best interests” principle exists in certain areas of law. These include:

### Children and Family Relationships Act 2015

The Children and Family Relationships Act 2015 establishes that the best interests of the child are paramount in decisions on custody, guardianship and access[[22]](#footnote-22); and provides guidance to the Courts on what elements to consider when making a determination on the child’s best interests.[[23]](#footnote-23)

### Child and Family Agency Act 2013

The Child and Family Agency Act 2013 requires Tusla (the Child and Family Agency) to have regard to the best interests of the child in making decisions related to certain functions, including supporting and promoting the development, welfare and protection of children.[[24]](#footnote-24) The 2013 Act also provides that Tusla, in performing its functions in respect of an individual child under the Child Care Act 1991 or the Adoption Act 2010, shall regard the best interests of the child as the paramount consideration.[[25]](#footnote-25)

### Child Care (Amendment) Bill 2019

This Bill seeks to amend the Child Care Act to specify that, in any child care proceedings before a court under the Act, including proceedings before the High Court in relation to special care, the court shall regard the best interests of the child as the paramount consideration.

### Education for Persons with Special Educational Needs Act 2004

The Education for Persons with Special Educational Needs Act 2004 contains a more qualified “best interests principle” with regards to the placement of children with special educational needs in inclusive environments:

A child with special educational needs shall be educated in an inclusive environment with children who do not have such needs unless the nature or degree of those needs of the child is such that to do so would be inconsistent with— (a) the best interests of the child as determined in accordance with any assessment carried out under this Act, or (b) the effective provision of education for children with whom the child is to be educated.[[26]](#footnote-26)

The NDA also notes a research study commissioned by the Ombudsman for Children’s Office found that the best interests principle was ‘not used to guide administrative actions or decision-making to any great extent if at all.’[[27]](#footnote-27)

# Early Childhood Care and Childcare

## Early childhood care

Ireland introduced a universal, free pre-school year in 2010 called the Early Childhood Care and Education (ECCE) programme. From September 2018, the ECCE programme was expanded to two universal, free pre-school years for all children between two and five and a half years of age. Launched in 2016, the Access and Inclusion Model (AIM) is a model of support designed to ensure that children with disabilities can participate in the ECCE Programme. Information and data on this scheme is provided in the NDA’s Article 24 paper on education.

The **Universal Design Guidelines for Early Learning and Care settings** were published in June 2019.[[28]](#footnote-28) These guidelines set out the key Universal Design considerations and guidance for Early Learning and Care (ELC) settings in Ireland. The guidelines apply to both new-build and retrofit projects, and provide a flexible Universal Design framework to ensure that settings are accessible, understandable and easy to use for all children, staff, families and visitors.

### Overage exemptions

When the ECCE programme was first introduced, it contained no additional provision or supports for children with disabilities but it did facilitate children with disabilities by allowing them to either commence ECCE later and / or spread their ‘year’ over two years. Where either of these accommodations involved a child participating on ECCE programme above the programme’s upper age limit (5 years and 6 months) an application had to be made to the Department of Children and Youth Affairs. Such applications are known as ‘overage exemptions’. The numbers of children availing of overage exemptions are outlined in Table 4.

In December 2017, a decision to cease the process of overage exemptions prompted stakeholders to raise concerns. The proposed changes were paused to allow for a wider consultation. As part of the consultation process, the NDA was requested to conduct an independent review of the overage exemption process and, thereafter, to provide an additional letter of advice.

The NDA’s review found that a key issue for parents who applied for, and received an overage exemption, was to have an additional year to enhance the child’s level of preparedness for primary school. In light of the ECCE scheme expanding to two years, the NDA did not consider that there was evidence that a third year is in the best interests of a child’s personal and social skills development and transitioning with their peers to primary school.[[29]](#footnote-29) The NDA’s review also noted that the majority of children who received an Overage Exemption had not received any targeted AIM supports (see Table 4 below). However, the NDA noted that there would be rare circumstances where a third year may be required, for instance where a child has a life-limiting condition.

The NDA recommended that an enhanced supportive process should be developed and integrated within the AIM programme, called AIM Plus, and which would include, amongst other things, assessed supports for transitioning for all children with disabilities. Following the publication of the NDA report, an expert group was convened to consider how to support parents in planning for their children’s needs; how to improve the process of transition for children with additional needs from early learning and care settings to primary school and how to ensure that parents are assured that the school will address the children’s need.

The expert group, which includes the NDA, met on a number of occasions in 2019, and a draft report for submission to the Minister was in the process of development at that time. The NDA understands that a final report has yet to be submitted to the Minister, although there have been some recent developments in the area of transitions from ELC settings to primary school, including commitments in the **First 5 Strategy** and the launch of the “**Let’s Get Ready**” initiative.

Table 4 – AIM Supports by disability category

| Disability Type\* | No AIM | Any AIM | Of which AIM Level 7  |
| --- | --- | --- | --- |
| Speech and Language | 167 | 58 | 44 |
| Developmental Delay | 50 | 43 | 34 |
| Down Syndrome | 25 | 20 | 18 |
| ASD | 22 | 24 | 19 |
| Unspecified | 17 | 16 | 14 |
| Intellectual Disability | 3 | 2 | 2 |
| Cerebral Palsy (including Cerebral Palsy + Epilepsy) | 0 | 5 | 4 |
| Other | 20 | 13 | 11 |
| Total | 304 | 181 | 146 |

Source: Department of Children and Youth Affairs and Pobal Administrative Data. n. 485

\* 5 was taken as the as the cut off for “Disability Type” (that is. other disability types / medical conditions with less than 5 children are included in “other”)

## School Age Childcare

In 2017, the former Department of Children and Youth Affairs and the Department of Education and Skills published an Action Plan on School Age Childcare. The aim of the Action Plan is to identify immediate or fundamental requirements in the area of school age childcare, and to have these needs addressed in a relatively short timeframe. In late 2019, a new National Childcare Scheme was launched. Under the auspices of the Childcare Support Act 2018, the National Childcare Scheme provides two types of childcare subsidy for children over 6 months of age - a universal subsidy for children under 3 which is not means tested and an income assessedsubsidy for children up to 15 which is means-tested.[[30]](#footnote-30)

The NDA is aware of concerns amongst some parents that there are no additional supports available to children with a disability to enable them to access the National Childcare Scheme. One of the commitments outlined in the Action Plan is that DCYA will commission research on best practice in the provision of inclusive school age childcare services, to include children with disabilities.[[31]](#footnote-31) DCYA also commits to continue to work closely with the Department of Health and the HSE to further develop linkages between childcare services and disability services so that where needs emerge, they can be responded to in a timely and effective manner. The NDA is currently developing a short issues paper in relation to inclusive School Age Childcare which will examine the limited available literature on this topic and seek to learn from practice in other countries.

## Childminding

Currently, most childminders are exempt from the requirement to register with Tusla, as a result of long-standing exemptions in the Child Care Act 1991. These exemptions include:

* those who care for family members
* those who care for children from just one family
* those who care for fewer than 7 children (provided no more than 3 of those are of pre-school-age) in the childminder's home at any one time.

Registration requirements also do not apply to those who care for children in the children's own home (when they are then regarded as employees of the children's parents). The Child Care Act 1991 (as amended) only requires registration by childminders (working in the childminder's home) who care for 4 or more children of pre-school age or 7 or more children of any age (other than their own children), at the same time. Most childminders do not meet this threshold.

In 2019, the Department of Children and Youth Affairs published a Draft Childminding Action Plan.[[32]](#footnote-32) The Action Plan proposes to extend supports and regulation to all paid, non-relative childminders, with a phased approach to reforms. In light of the home and family setting in which childminders operate, the Draft Childminding Action Plan proposes the development of childminder-specific Regulations. By bringing childminding into the scope of regulation, parents who use childminders will be able to access subsidies under the National Childcare Scheme.

The NDA has welcomed the proposals and general approach outlined by the Department, while also identifying some areas which require additional consideration. For instance, the NDA notes that the parents of a child with a disability who needs to be cared for within their own home may be disadvantaged under the current proposals as they may be unable to avail of subsidies under the National Childcare Scheme. Additionally, the NDA has advised that proposed training for childminders include training on diversity, equality, inclusion and disability awareness. It has also advised that consideration be afforded to expanding vetting requirements to include any adults who work in the childminder’s home, and any other adults who may be regularly present in the home, and that communications are in accessible formats.

# Healthcare

## Entitlement

### Medical & General Practitioner Cards

Eligibility for a Medical or General Practitioner (GP) Visit Card is determined in accordance with the provisions of the Health Act 1970 (as amended). A number of measures have been introduced in recent years to improve access to free GP care and other health services. Since June 2017, all children who qualify for the Domiciliary Care Allowance (DCA) are eligible for a medical card without having to undergo a means-test; they may retain the medical card up to their sixteenth birthday. DCA is a monthly payment for children under 16 with a severe disability who require ongoing care and attention, substantially over and above what is usually needed by a child of the same age. At the end of December 2018, DCA was provided in respect of 39,007 children.[[33]](#footnote-33)

Additionally, since July 2015, all children under 18 years of age with a diagnosis of cancer are awarded a medical card.[[34]](#footnote-34) This card is valid for a period of 5 years. Furthermore, all children under the age of 6 are entitled to a General Practitioner visit card and Budget 2020 committed to expanding the free GP scheme to include children aged six and seven.[[35]](#footnote-35)

## Early Intervention services

There are a number of mainstream DCYA and Tusla-funded early intervention services, including the Area Based Childhood (ABC) programme. Tusla’s Prevention, Partnership and Family Support programme focuses on early intervention and preventative parenting work. Tusla’s Family Resource Centre programme provides core funding to 109 Family Resource Centres, and 11 new centres are planned.[[36]](#footnote-36) Information on HSE-funded early intervention classes for children with autism is outlined in the Article 24 briefing paper.

## Disability Services

### Progressing Disability Services for Children and Young People

In 2010, the HSE established a National Programme entitled ‘Progressing Disability Services for Children and Young People’.[[37]](#footnote-37) The programme is based on the recommendations of the 2009 Report of the Reference Group on Multidisciplinary Services for Children aged 5 to 18 Years, which also includes services and supports for children under five years.[[38]](#footnote-38)

The aim of the programme is to continue the organisational restructuring of children’s disability services in order to deliver equitable family-centred services for children and young people with complex disabilities in every part of Ireland. The new model will provide a clear referral pathway for all children (0–18s), with an integrated care model that will allow children with a disability to be seen close to their home or school. Children’s Disability Network Teams are currently being put into place, with diagnosis-specific services continuing to operate in the interim. As outlined in detail below, the pace at which these Teams were established has been much slower than anticipated, and challenges in the delivery of services and waiting lists remain.

The NDA published a report in 2015 entitled **“Children’s Disability Services in Ireland”** to contribute to the HSE’s programme of work on developing community based early intervention and school age disability teams.[[39]](#footnote-39) An analysis of available data sources on children with disabilities indicates that between 2.7% and 4.1% of children aged 0-18 need access to children’s interdisciplinary disability therapy services. The NDA notes that estimates point to a significant shortfall in therapy provision, which is exacerbated by the non-filling of the significant proportion of regular vacancies (approximately 10%) due to maternity and other leave. With this in mind, the NDA has advised that a policy of filling vacancies due to maternity and parental leave be introduced (with an annual estimated cost of €5.5million) and that 100 additional posts be provided, primarily to cover deficits in speech and language therapy, psychology and occupational therapy.

The NDA’s forecasting work estimated that, at the end of 2017, child therapy services were short between 300 and 400 posts.[[40]](#footnote-40) The cost of additional staffing was estimated to be in the region of €16million to €21million per year. Based on the overall impact of demographic change, it is estimated that an additional 50 child therapy posts would be required by 2021, after which demand should stay steady or drop marginally to 2026.

Budget 2019 provided funding for an additional 100 new therapy posts for children's disability services to be in place by the end of 2019. All of these posts were filled by July 2020.

At the end of December 2019, none of the planned 80 Children’s Disability Network Teams for that year were established.[[41]](#footnote-41) The HSE has attributed the delay in establishing these teams to an industrial relations dispute concerning the reporting arrangements for Children’s Disability Network Managers.[[42]](#footnote-42) The Mid-Term Review of the National Disability Inclusion Strategy states that the HSE will align Children’s Disability Network Teams to 96 Community Healthcare Networks by the end of 2020 (Action 78).[[43]](#footnote-43)

### Outcomes

The Standards and Performance Reporting Working Group of the ‘Progressing Disability Services for Children and Young People’ programme published **Outcomes for Children and their Families - Report on an Outcomes-Focused Performance Management and Accountability Framework for Early Intervention and School Age Disability Network Teams** in 2013.

This report sets out **Outcomes for Children and their Families Framework** (OCFF) which aims to ensure that each Children’s Disability Team’s work and practice are underpinned by a child and family centre philosophy. The OCFF changes the focus of families and services from outputs to outcomes.  It measures what benefit the child and family have experienced as a result of services and supports provided, in other words the added value. Families are, in the main, fully capable of making informed choices and acting on their choices. Parents/carers have the ultimate responsibility for the care of their children and for all decisions made about them;

1. Services exist to support children and families to attain the best possible outcomes;
2. Interventions are appropriate to the needs of the child and family, and emphasise capacity-building, strengthening existing skill sets, promoting the acquisition of new skills, medical care and other supports; and
3. Children, families and service providers all benefit most when services are based on true collaborative partnerships between families and professionals.

### Assessment of Need

Part 2 of the Disability Act 2005 provides for a statutory assessment of need process. People who are of the opinion that they might have a disability (or certain others on their behalf) have the right to:

* apply for an assessment of individual needs, which is carried out without regard to the cost of or the capacity to provide service identified in the assessment
* a related service statement
* access to an independent redress and enforcement process

Part 2 of the Disability Act 2005 and regulations published subsequently establish the following timeframes for which various stages of the statutory assessment of need process must be completed:

* Acknowledgement of an application for an assessment of need under the Act must take place within 14 days of receipt of the application
* The assessment must be commenced without undue delay or within three months of the application being received
* The assessment will be completed and forwarded to the Liaison Officer without undue delay or within three months from the date on which the assessment was commenced

Part 2 of the Disability Act 2005 was commenced for children under the age of 5 on 1 June 2007. It was intended that Part 2 of the Act would be progressively commenced for older age groups. However, as a result of a High Court case, the Health Service Executive have, in effect, been treating all children born after the 1st of June 2002 as eligible to apply for an assessment under Part 2 of the Disability Act.[[44]](#footnote-44)

The NDA also notes that commencement of Part 2 of the Disability Act 2005 for school-aged children was intended to be introduced in parallel with the commencement of relevant sections of the EPSEN Act 2004. This included the provisions relating to assessment of special educational need and statutory Individual Education Plans. However, the relevant provisions relating to the right to an assessment of special education need in the EPSEN Act 2004 have not been commenced. As a result, the only statutory right to an assessment of need process available to parents of a child with a disability is an assessment under the Disability Act 2005, despite the fact that a disability diagnosis is required to access some educational supports, such as SNA support.

There were 6,596 applications for assessment under the Disability Act in 2019, with only 9.8% of assessments completed within the statutory timelines.[[45]](#footnote-45) There was considerable regional variance in terms of meeting the statutory deadlines, with CHO2 completing 51.8% of assessments within the statutory timelines, while CHO9 completed just 3%. The HSE anticipates that it will receive 5,975 requests for assessment of need in 2020.[[46]](#footnote-46) The NDA notes that repeated concerns have been raised about delays in the assessment of need process from a range of disability stakeholder groups.

In 2011, the NDA published a review into the practice of assessment of need under the Disability Act.[[47]](#footnote-47) The findings of this report highlight challenges that have emerged in operating the statutory assessment of need process. These included:

* variations in how long assessors take to conduct statutory assessments of need
* many assessors being unclear as to what is required of them under Part 2 the Disability Act 2005
* use of the assessment of need process to expedite special education assessments in the absence of the commencement of relevant sections of the Education for Persons with Special Education Needs Act 2004

The review also highlighted some good practice and innovations that have been developed to meet the needs of young children and families which are in keeping with the legal requirements of the Disability Act.

The NDA also notes that the Board of the interim HIQA, known as iHIQA, developed standards for the assessment of need process, which were published in May 2007. However, these standards were never formally adopted by HIQA after its establishment. A new standard operating procedure for assessments of need was introduced in January 2020, the stated purpose of which is to ensure that there is a consistent approach to managing requests for a statutory Assessment of Need and processing the resulting referrals. The NDA notes that concerns have been expressed that the new assessment of need process was implemented without addressing issues raised by the Oireachtas Joint Committee on Health[[48]](#footnote-48) and professional bodies[[49]](#footnote-49).

A priority action identified by the HSE for 2020 includes reducing the waiting times for assessment of need under the Disability Act 2005 through the full year provision of 100 additional therapy posts commenced in 2019.[[50]](#footnote-50) In September 2020, the Government announced a €7.8m package of measures to address the backlog for children’s Assessment of Needs, and supporting the roll out of Children’s Disability Network Teams.

## Primary Care

Depending on their needs, children with disabilities may require primary care health services such as physical, occupational, psychological, and/or speech and language therapy. Waiting lists for these services tend to be long with many children of all ages waiting for more than a year for these services. Details of waiting times are listed for occupational therapy, physiotherapy and speech and language therapy in Appendix 1.

## Mental Health

Child and Adolescent Mental Health Services (CAMHS) are a specialist clinical service that provides assessment and treatment to children and young people up to the age of 18 who are experiencing mental health difficulties. CAMHS services consist of specialised and intensive community-based care, as well as inpatient care through specialist mental health inpatient services.

CAMHS inpatient units are situated in three counties nationally, and they generally do not take out-of-hours admissions. The NDA notes the views of the Mental Health Commission that lack of out of-hours services results in children and young people in crisis being left with the unacceptable ‘choice’ between an emergency department, general hospital, children’s hospital, or an adult in-patient unit.[[51]](#footnote-51)

### Key data and statistics

#### Inpatient CAMHS

The total number of admissions of young people to approved centres in 2019 was 443.[[52]](#footnote-52) This compares with 408 in 2018, 439 in 2017 and 509 in 2016. 65% of all child admissions in 2019 were female. The average duration of admission in such units was 50 days (based on discharge information provided for 431 admissions).

In 2019, 54 children were admitted to adult units. This compares to 84 child admissions to adult facilities in 2018 and 82 in 2017. Twenty three of the 54 admissions in 2019 were for less than 48 hours. According to the Mental Health Commission, the reason for the majority of admissions to adult units is due to an immediate risk to the young person or others, or due to the lack of a bed in a specialist CAMHS unit. At the end of 2019, there were 98 CAMHS beds nationally.

The District Court is required to authorise the involuntary admission of a child. In 2019, there were 32 involuntary admissions orders of children to approved centres, pursuant to Section 25 of the Mental Health Act.[[53]](#footnote-53) This included: two orders to adult units and 30 orders to CAMHS units. In addition, there was one High Court Order for the admission of a child into an adult unit.

#### Community CAMHS

Table 5 below shows the level of activity and performance of CAMHS for 2019. The majority of referrals were seen within one year but only 76% of urgent referrals were responded to within 3 days.

Table 5: Community CAMHS Data

|  | Expected Activity / Target for 2019 | Actual activity for 2019 |
| --- | --- | --- |
| CAMHS waiting list | 2,498 | 2,327 |
| Percentage seen within 12 months | 95% | 95.8% |
| Number waiting to be seen for more than 12 months | 0 | 212 |
| Number of new referrals received | 18,128 | 18,831 |
| Number of new referrals seen | 10,833 | 11,139 |
| % of urgent referrals to Child and Adolescent Mental Health Teams responded to within three working days | 100% | 76.3% |

Source: HSE Performance Report, October – December 2019

The HSE has reported that uncertainty about its ability to recruit, and delays in recruitment, are impacting significantly on community CAMHS services, with waiting lists developing in areas where they haven’t existed before.[[54]](#footnote-54)

### Research

In 2018, the Ombudsman for Children’s Office published a report highlighting the experiences, views and ideas of young people under 18 receiving inpatient mental health care and treatment as regards their respective journeys through mental health services.[[55]](#footnote-55) The young people, aged 14-17, spoke about what has helped them on their journey, what they found challenging and what changes they feel are needed to improve mental health supports and services.

The young people highlighted the importance of good relationships with medical professionals and the invaluable support they get from family and peers, among others. However, they raised concerns about insufficient awareness of mental illnesses, including in some schools, and the stigma that attaches to mental illness. They also spoke of problems in the way some medical professionals communicate with them and a belief that they are not heard, including in inpatient units. The young people also spoke of difficulties with accessing local community and inpatient services without delays; inconsistency in services across the country and the impact of staff shortages on their care.

A report from the Department of Children and Youth Affairs, entitled **‘How’s Your Head – Young Voices during COVID-19’**, found that the Covid-19 pandemic has had negative effects on young people’s health and wellbeing, especially amongst marginalised groups. The most common negative effects related to the mental health of respondents, including overthinking, concern, worry, anxiety, depression and a sense of utter hopelessness.

### Policy landscape

#### Sharing the Vision

Published in 2020, **Sharing the Vision: A Mental Health Policy for Everyone** is the national policy for mental health.[[56]](#footnote-56) The policy “adopts a lifecycle approach that places the individual at the centre of service delivery” and “acknowledges that the foundations for mental wellbeing are established before birth and that much can be achieved through interventions and supports to build resilience and improve wellbeing throughout childhood, the teenage years and on into adulthood and later life.” The policy document outlines a number of child-specific commitment, including the development of:

* A comprehensive, specialist mental health out-of-hours service for children and adolescents in all geographical areas
* National criteria for individualised support packages for the specific needs of children and young people who have complex needs
* Early intervention and assessment services in primary care for children with ADHD and autism through collaboration of Primary Care and Mental Health services

#### National Youth Mental Health Taskforce

The National Youth Mental Health Task Force was established to provide national leadership in the field of youth mental health and to enhance how the public, private, voluntary and community sectors work together to improve the mental health and wellbeing of young people.[[57]](#footnote-57) The Taskforce published its report in December 2017. The recommendations are set out under 10 headings, and include amending the Mental Health Act 2001 in relation to consent to mental health treatment for 16 and 17 year olds, improving accessibility and alignment of mental health services through the Pathfinder Project and using digital technologies in the delivery of mental health supports to children and young people.

The NDA notes information from stakeholders that there has been progress in relation to a number of the Taskforce’s recommendations. These include the establishment of a pilot advocacy and information service, the establishment of a 24/7 contact line and the commencement of work on a new strategy for HSE mental health communications.[[58]](#footnote-58) However, it has also been reported that there are a number of recommendations where progress has been slower, and there is no overall implementation plan for the Taskforce recommendations.

#### Connecting for Life

Connecting for Life is Ireland’s national strategy to reduce suicide over the period 2015-2020. Goal 3 of the Strategy is to target approaches to reduce suicidal behaviour and improve mental health among priority groups.[[59]](#footnote-59) Priority groups include young people aged 15 to 24. One of the objectives in this regard is to enhance the supports for young people with mental health problems or vulnerable to suicide, and there are a number of actions detailed in this regard.

The **Connecting for Life** Evaluation Advisory Group undertook an independent Interim Review of Connecting for Life, which was published in 2019. The Group gave an overall assessment of good progress towards the achievement of Goal 3. The review found that good progress had been achieved in relation to the provision by the HSE of:

* early intervention and psychological services for young people and/or specialist services (eating disorders)
* the development and promotion of programmes and guidance resources to support mental health and wellbeing across primary and post-primary settings
* the provision of guidance for the implementation of relevant policies and plans in schools, including support for the development of Student Support Teams and the management of critical incidents by the Department of Education[[60]](#footnote-60)

By contrast, the review found that there had been limited progress made in relation to:

* the delivery of suicide prevention training to key frontline staff, including teaching staff in post-primary schools, psychiatrists and GPs by the HSE’s National Office for Suicide Prevention
* the development of agency and inter-agency operational protocols to assist organisations and agencies to work collaboratively in relation to suicide prevention and the management of critical incidents

The EAG recommended the immediate development of a strategic plan to inform Connecting for Life activity intended to prevent suicidal behaviour among priority groups, including young people.

### Mental Health Act 2001

The Mental Health Act 2001 is the primary legislation governing children with mental health problems and their access to mental health services. Section 25 of the 2001 Act provides for the involuntary admission of children and sets out that the HSE may make an application to the District Court for an order authorising the detention of a child with a “mental disorder” in an approved centre.

The NDA notes concerns raised in the Report of the Steering Group on the Review of the Mental Health Act that the provisions of the 2001 Act relating to children and young people are spread throughout the Act so the extent to which such provisions apply to children is unclear.[[61]](#footnote-61) Similarly, the NDA notes concerns highlighted by the former Special Rapporteur on Child Protection, Geoffrey Shannon, that the Mental Health Act, 2001 operates in a context of uncertainty as regards children and medical consent, and that this can lead to situations whereby parents make decisions in respect of their children that otherwise the children would make for themselves.[[62]](#footnote-62) Although the age of consent for medical treatment is 16 years under the Non‐Fatal Offences Against the Person Act, 1997, under the Mental Health Act, 2001 the age of consent for mental health treatment is 18 years.

According to the Child Care Law Reporting Project, some mental health issues, including a personality order, are not considered a “mental disorder” for the purposes of the Mental Health Act 2001 and therefore children with certain conditions are not eligible for detention and treatment under the 2001 Act.[[63]](#footnote-63)

The Expert Group Report on the Mental Health Act 2001 has recommended that the 2001 Act be amended to safeguard the rights of children and young people, including by recognising that interventions must take into account the views of the child and that those should be given due weight in accordance with their age, evolving capacity and maturity.[[64]](#footnote-64)

## Sexual Health

In 2014, 30.4% of children with a disability and/or chronic illness aged 15–17 reported that they have had sex, compared to 25.8% of children without.[[65]](#footnote-65) The **National Sexual Health Strategy 2015–2020** contains a commitment to support all children and young people in addressing issues that impact on sexual wellbeing such as ability/disability and mental health.[[66]](#footnote-66)

# Children in Care & Child Protection

## Legislation & Regulatory Framework

### Child and Family Agency Act 2013

The 2013 Act provided for the establishment of the Child and Family Agency, named Tusla. The 2013 Act vests statutory responsibility for the provision of specified child and family services in the Child and Family Agency, including, inter alia, to manage and deliver or arrange to have delivered on its behalf, services to support and promote the development, welfare and protection of children; and to support and encourage the effective functioning of families.

### Child Care Act 1991

The Child Care Act 1991 as amended is a wide-ranging piece of legislation which seeks to promote the welfare of children who may not receive adequate care and protection. The legislation covers the following main areas:

* promotion of welfare of children, including the relevant functions of Tusla, the Child and Family Agency
* protection of children in emergencies, including section 12 which governs the powers of An Garda Síochána to take a child to safety
* care proceedings, including the different types of care orders which can be made by a court
* children in need of special care or protection
* private foster care
* jurisdiction and procedure, including provisions for the appointment of a guardian ad litem for a child
* children in the care of the Child and Family Agency
* supervision of preschool services
* children’s residential centres

A review of the Child Care Act 1991 is ongoing.[[67]](#footnote-67)

#### Guardians ad Litem

The Child Care Act 1991 allows a guardian ad litemto be appointed to act on a child’s behalf in childcare proceedings, where the child themselves is not a party. As highlighted by MacMenamin J in *HSE v DK* [2007] IEHC 488, the role of the Guardian ad Litem is twofold:

‘…firstly to place the views of the child before the court, and secondly to give the guardian’s views as to what is in the best interests of the child.’

The NDA underlines that guardians ad litem can be instrumental in ensuring the voices of children with disabilities are heard in childcare proceedings, and in carrying out their functions, they may be required to learn about a child’s disability and its impact on their capacity to form a view.

The Child Care (Amendment) Bill 2019 seeks to reform the system of appointment and the functions of guardians ad litemin child care proceedings in the District Court, and in special care cases in the High Court. The NDA is aware of particular concerns that have been raised in respect of this proposed legislation, including the potential adverse impact on non-verbal children.[[68]](#footnote-68)

### Criminal Justice (Withholding of Information on Offences against Children and Vulnerable Persons) Act 2012

The 2012 Act creates a criminal offence of withholding information relating to the commission of a serious offence, including a sexual offence, against a person under 18 years.

### National Vetting Bureau (Children and Vulnerable Persons) Act 2012

The 2012 Act provides for the establishment of a National Vetting Bureau (of the Garda Síochána) tasked with establishing a database system. The database will contain a register of:

* Relevant organisations that facilitate people coming into contact with children and vulnerable adults through employment, provision of services and training/schooling and undertaking relevant work
* Register of specified information, including information regarding bona fide concerns that a person may harm a child or vulnerable person
* Register of vetted persons

### Children First Act 2015

The Children First Act 2015 introduced statutory obligations for professionals and organisations who provide a service to children and families to report to Tusla where there are reasonable grounds to suspect that a child has been harmed, is being harmed or is at risk of being harmed. The Children First Act 2015 also requires organisations that are providers of ‘relevant services’ to prepare a Child Safeguarding Statement, which is circulated to all staff, displayed publicly and made available to parents, guardians, Tusla and members of the public upon request.

### National Standards for the Protection and Welfare of Children

The National Standards for the Protection and Welfare of Children assess the performance of Tusla in relation to its statutory functions to provide adequate care and protection to children, and under Children First.[[69]](#footnote-69) The Standards also guide Tusla’s response to child protection concerns and how these concerns are managed. The Standards require that “[c]hildren will be listened to and their concerns and complaints are responded to openly and effectively”.

### Joint Protocol for Interagency Collaboration between the Health Service Executive and Tusla

A Joint Protocol sets out the respective roles, duties and legal requirements of the HSE and Child and Family Agency in relation to children and young people with a disability and /or mental health issues.[[70]](#footnote-70) The number of children in residential care (Table 6) represents children receiving residential care from Tusla services. The NDA notes that children with disabilities in residential care may also be in HSE-funded residential care.

Table 6: Total number of children in care, end of January 2020

| Type of care | Number |
| --- | --- |
| Foster care (general) | 3,905 |
| Foster care (relative) | 1,555 |
| Residential care | 400 |
| Other | 111 |
| Total | **5,971** |

Source: Tusla National Performance and Activity Dashboard January 2020

Tusla advised that, at the end of September 2018, 477 children with a diagnosed moderate to severe disability were in foster care placements[[71]](#footnote-71), with February 2019 data indicating that approximately 570 children with disabilities were in state care out of a total of approximately 6,000.[[72]](#footnote-72) The HSE is of the view that the figure of 477 children with a diagnosed moderate to severe disability in foster care placements is not reliable, arguing that the Tusla database uses a broad definition of disability (including children with mild disability and/or a physical or sensory disability) and including children who have yet to be assessed. The Ombudsman for Children has criticised the HSE for failing to reach an agreement with Tusla regarding identification of children in state care with moderate to profound disabilities.[[73]](#footnote-73)

## Investigations & Research

### Molly’s Case

In 2018, the Ombudsman for Children’s Office published **Molly’s Case**, a report detailing a complaint about a child with a disability who is in foster care.[[74]](#footnote-74) Molly was born with Down Syndrome and severe autism. She was abandoned at birth by her biological parents and has grown up with her foster family after being placed there when she was four months old. Molly’s foster carer made a complaint to the OCO about the level of supports and services being provided by Tusla and the HSE to meet Molly’s needs. The OCO found that neither Tusla nor the HSE had an adequate system in place to ensure adequate supports were being provided to children with a severe or moderate disability who are in care, and to their carers. The OCO also found that this was a problem facing 472 other children with a severe or moderate disability who are in care, representing approximately 8% of the foster care population.

The Ombudsman for Children published two follow-up reports on this investigation. In **Molly Two Years On**, the OCO outlined the significant progress made to improve supports and services available to children with moderate to profound disabilities in the care of the state.[[75]](#footnote-75) However, the report also identifies substantial shortcomings, particularly on behalf of the HSE, who two years after the OCO first published Molly’s Case, still cannot agree with Tusla about how to identify the children in state care with moderate to profound disabilities.

### Jack’s Case

A recent investigation by the Ombudsman for Children’s Office examined how the HSE and Tusla provided for and managed the care of a child with profound disabilities. The boy in question, Jack, had suffered brain damage and other significant life changing injuries in a road traffic accident abroad in 2016, resulting in him requiring 24/7 care in all aspects of his life.

The OCO investigation made a number of findings, including:

* The administrative actions of both agencies had a negative impact on the boy’s life. Despite being medically ready for discharge from hospital in August 2017, Jack remained living between hospital settings for two and half years
* Systemic failures by the HSE to provide adequate support and services to children like Jack, with disabilities, who were living in inappropriate settings
* Tusla’s conclusion that Jack’s needs were solely a matter for the HSE was improperly discriminatory on the grounds of disability
* Jack’s eventual placement with a host family by the HSE Disability Services was made without any legal or formal regulatory framework or proper authority

The OCO made a number of recommendations to the HSE and Tusla including:

* HSE Disability Services should immediately and systemically review all cases where a child remains in hospital settings beyond their medical need
* HSE Disability Services should engage with the Department of Health to ensure services and funding are in place to support the right of children with disabilities to grow up at home with their families
* HSE Disability Services should conduct a national review of the current need for alternative care for children with disabilities whose parents or carers are assessed as being either not willing, or not able, to provide for their ongoing care
* Tusla should immediately issue guidance to all social work areas, that child protection and welfare referrals about children with disabilities must be assessed and managed the same as all other referrals and in accordance with national policies and procedures

### Grace Case

The Commission of Investigation (Certain matters relative to a disability service in the South East and related matters) was established on 21 March 2017.[[76]](#footnote-76) It is investigating the care of a woman with intellectual disabilities in a foster home in the Southeast of Ireland, and alleged physical and sexual abuse. ‘Grace' was placed with the foster family in 1989 and remained in the home until 2009, despite a 1995 decision by the South Eastern Health Board to cease using the family for placements and to remove other vulnerable young people.

### Education of Children in Care

In 2013, research commissioned by the Ombudsman for Children’s Office explored the education of children in care.[[77]](#footnote-77) It found that children in care tend to face more challenges to fulfilling their potential due to their personal and familial circumstances. Disruption within the home environment, disruption caused by having to move schools, limited attention from carers towards students’ progress at school, and/or teachers’ limited awareness of children’s personal circumstances and what it means to be ‘in care’ are all factors that can contribute to underachievement.

The situation may be further complicated if these children have special educational needs or behavioural difficulties. A number of measures were proposed to improve the educational experiences of children currently in care and young people who have already left the care system including enhanced data collection and research, better inter-agency coordination and cooperation and strengthened supports through education and care systems.

## Bullying

In 2014, 32% of children with a disability and/or chronic illness aged 10–17 reported that they were bullied at school at least once in the past couple of months.[[78]](#footnote-78) This compares to 24.9% of children without a disability or chronic illness.

## Secure / Special Care

The Child Care Act 1991 as amended by the Child Care (Amendment) Act 2011 provides that Tusla can apply to the High Court for a special care order where it determines that there is reasonable cause to believe that it is necessary to protect the life, health, safety, development or welfare of a child. There must be a therapeutic benefit in order for a child to be placed in secure care; the child must be between the ages of 11 and 18 and the child must not have a “mental disorder” within the terms of the Mental Health Act 2001.

Special care (also known as secure care) is intended to be short-term, stabilising and safe care in a secure therapeutic environment, which aims to enable a child to return to a less secure placement as soon as possible based on need.[[79]](#footnote-79) Special Care Units differ from general residential care in a number of ways: the units are secure, the child is detained, they offer higher staff to young person ratios, education is on-site and there is specialised input such as psychology services.

There are three secure care units in Ireland containing between them 26 places. They are:

* Ballydowd, Dublin – a mixed gender unit
* Crannóg Nua, Dublin – a mixed gender unit
* Coovagh House, Limerick – a mixed gender unit

However, information from the Child Care Law Reporting Project, which examines and reports on child care proceedings, reveals that not all of these 26 spaces are available due to human resource issues within the units.[[80]](#footnote-80) At the end of 2019, 15 children were in special care units.[[81]](#footnote-81)

In addition to placing children in special care units in Ireland, some children with extreme behavioural difficulties are sent abroad for treatment in secure care settings, particularly the United Kingdom.

## Residential Care

A designated residential centre for people with a disability is defined in the Health Act 2007. Designated residential centres may comprise of a number of buildings clustered together as a large campus, a campus made up of a number of individual designated centres, or individual designated centres located in the community. Residential centres for people with disabilities are operated directly by the State through the HSE, by voluntary and non-governmental organisations, or by private entities which are funded by the HSE. HIQA is responsible for regulating these services.

At 31 October 2018, there were 320 residential places in designated centres for children with disabilities, and a further 287 placements for either adults or children.[[82]](#footnote-82) 73 designated centres were for children only, while 43 were mixed centres for adults and children.

# Consultation with children with disabilities

## Legislation

### Constitution

Article 42A.4.2° of the Constitution commits the Oireachtas to legislate to provide that the views of the child are heard and taken into account in the proceedings listed in 4.1 (children in care, child protection, adoption, guardianship, custody and access cases).

The participation of and consultation with children is provided for in a number of pieces of legislation, such as those below. However, a report commissioned by the European Commission noted that the groups and ages of children provided with a legal right to participate vary given the nature and purpose of the statutes from which the right derives.[[83]](#footnote-83)

### Children and Family Relationships Act 2015

The 2015 Act permits the court to give directions to obtain from an expert a report in writing regarding any question affecting the welfare of the child or to appoint an expert to determine and convey the child’s views in proceedings for custody of, access to, or guardianship of a child.[[84]](#footnote-84)

### Domestic Violence Act 2018

The Domestic Violence Act 2018 makes a similar provision to that under the Children and Family Relationships Act 2015, in relation to an application for a domestic violence order (other than an interim/emergency remedy) where the order is sought of behalf of a child.[[85]](#footnote-85)

### Ombudsman for Children’s Act 2002

Section 7(2) of the Ombudsman for Children Act 2002 requires the OCO to establish structures to consult regularly with groups of children that he or she considers to be representative of children in carrying out a range of functions, including:

* advising on the development of policy relating to children
* promoting awareness among members of the public of matters relating to the rights and welfare of children and how those rights can be enforced
* reviewing the operation of legislation concerning matters that relate to the rights and welfare of children

The legislation further stipulates that in such consultations, the views of a child shall be given due weight in accordance with the age and understanding of the child.

### Education Act 1998

Section 27 of the Education Act 1998 states that:

Students of a post-primary school may establish a student council and…a board of a post-primary school shall encourage the establishment by students of a student council…A student council shall promote the interests of the school and the involvement of students in the affairs of the school, in cooperation with the board, parents and teachers.

### Child and Family Agency Act 2013

The Child and Family Agency Act 2013 includes the following two specific provisions on hearing the voice of the child:

* The Agency shall, when planning and reviewing the provision of services in connection with the performance of certain functions, such as supporting and promoting the development, welfare and protection of children, ensure that consideration is given to the views of children[[86]](#footnote-86)
* The Agency shall, in performing its functions in respect of an individual child under certain pieces of legislation, such as the Child Care Act 1991 and the Adoption Act 2010, ensure that the views of that individual child, where that child is capable of forming and expressing his or her own views, be ascertained and given due weight having regard to the age and maturity of the child[[87]](#footnote-87)

### Children Act 2001

Any court, when dealing with a child charged with an offence, is required to have regard to the principle that children have a right to be heard.

### S.I. No. 218/2011 - Office of the Minister for Children and Youth Affairs (Transfer of Departmental Administration and Ministerial Functions) Order 2011

In 2011, the Statutory Instrument transferring functions to the Department of Children and Youth Affairs includes the following as a function of the department:

“overseeing the development, improvement and monitoring of policies and structures to promote and enable participation by children and young people in decision making on matters that affect their lives”.

The Department Children and Youth Affairs’ dedicated Participation Unit has the lead national role in ensuring that children and young people have a voice in the design, delivery and monitoring of services and policies that affect their lives, at national and local level.[[88]](#footnote-88) At the time of writing in October 2020, the Department is undergoing a new restructuring process to form the Department of Children, Disability, Equality, Integration and Youth.

## Policies

### National Strategy on Children and Young People’s Participation in Decision-Making 2015-2020

This strategy seeks to ensure that children and young people will have a voice in their individual and collective everyday lives.[[89]](#footnote-89) The strategy focuses on the everyday lives of children and young people and the places and spaces in which they are entitled to have a voice in decisions that affect their lives and identifies the following priority areas for action:

* children and young people will have a voice in decisions made in their local communities
* children and young people will have a voice in decision-making in early education, schools and the wider formal and non-formal education systems
* children and young people will have a voice in decisions that affect their health and well-being, including on the health and social services delivered to them
* children and young people will have a voice in the Courts and legal system

The Strategy contains one specific commitment on children with disabilities, namely that HSE Disability Services will develop a framework document on how children’s voice will inform the design, implementation and evaluation of disability services. The Strategy also contains a number of actions related to the participation of children and young people with mental health issues.

Additionally, one of the key fundamentals of the National Strategy is the establishment and improvement of mechanisms that ensure the participation of seldom-heard and vulnerable children and young people in decision-making. To this end, in 2015, DCYA and Barnardos published **A practical guide to including seldom-heard children and young people in decision-making**.[[90]](#footnote-90) This guide aims to support organisations to enable the participation of seldom-heard children and young people, aged 8-18, in decision-making. The guide defines “seldom-heard children and young people” as including children with mental health issues and children with physical and intellectual disabilities.

A **Mid-Term Review and Phase Two Action Plan of the National Strategy on Children and Young People’s Participation in Decision-Making, 2015-2020** was published in late 2019.[[91]](#footnote-91) The review does not contain any information with regards to disability or mental health actions. However, the Phase Two Action Plan outlines a number of commitments regarding engagement with children and young people with mental health issues, including:

* Information on the availability and use of the toolkit for young mental health service users will be included in the Annual Report of the Inspector of Mental Health Services
* Key stakeholders will be made aware of and follow best practice in relation to the voice of children and young people in adolescent mental health advocacy services
* The Mental Health Commission will implement recommendations for more autonomy for young adults in making decisions about their mental health care and treatment
* Training for the Mental Health Inspectorate in meeting with child service users will be developed

### Child and Youth Participation Strategy 2019-2023

Tusla, the Child and Family Agency, has developed a **Child and Youth Participation Strategy 2019-2023**.[[92]](#footnote-92) It sets out how Tusla plans to “support, nurture and celebrate a culture of participatory practice in both Tusla and Tusla-funded services.” The Strategy does not contain any disability-specific actions, but one of the principles underpinning it is that the right of children and young people to participate applies without discrimination on any grounds, including disability.

## Key Research

A baseline assessment of children’s participation in decision-making within Tusla found that support for children and young people with disabilities and with communication difficulties (including very young children) was ad hoc. While there was evidence in the data of individual social workers supporting children and young people with communication difficulties to express their views, overall services and support for staff appeared weak in this regard.[[93]](#footnote-93) With just a few exceptions, HIQA consistently reports that Tusla professionals do not have access to Braille, the loop hearing aid system or sign language services to facilitate children and young people with visual or hearing impairments to express their views.[[94]](#footnote-94) A questionnaire amongst Tusla staff rated skills to engage seldom-heard children and young people, and skills to communicate creatively as their top two skills development needs.[[95]](#footnote-95)

A 2011 audit provided insight into children and young people’s participation in decision-making in the statutory and non-statutory sectors. [[96]](#footnote-96) Within a total of 71 Comhairle na nÓg and other organisations that work with those aged 18 years and younger:

* Out of 41 organisations that responded to this question (57.7% of total respondents), 32 (78%) involved children and young people with a learning difficulty in decision-making and 26 (63.4%) involved children and young people with a physical or sensory disability
* Early school-leavers and children and young people with a disability were two groups that were highlighted as being difficult to reach

Within 200 HSE and HSE-funded services:

* Out of the 72 services that responded to this question (36% of total respondents), 65 (90.3%) involved children and young people with learning difficulties in decision-making and 52 (72.2%) involved children and young people with a physical or sensory disability
* Overall, 32.5% of all respondents involved children and young people with learning difficulties in decision-making and 26% involved those with a physical or sensory disability
* Hard-to-reach groups identified by HSE and HSE-funded organisations included children and young people with mental health problems who refuse to engage with services and those with disabilities

## Child Consultation & Participation structures

### Dáil na nÓg and Comhirle na nÓg

Comhairle na nÓg and Dáil na nÓg are the statutory structures for participation by children and young people in the development of policies and services. Comhairle na nÓg are local youth councils, which give children and young people the opportunity to be involved in the development of local services and policies. There is a Comhairle na nÓg in every city and county. Dáil na nÓg is the annual national parliament for young people aged 12-18 years. Delegates are elected to Dáil na nÓg by the Comhairle na nÓg.

### Children and Young People’s Service Committees

Children and Young People’s Services Committees (CYPSC) are responsible for ensuring effective interagency co-ordination and collaboration to achieve the best outcomes for all children and young people in their area. The membership of the CYPSC consists of senior managers from all the major statutory, community and voluntary providers of services to children, young people and families in the CYPSC area.

CYPSCs develop and oversee the implementation of a three-year Children and Young People’s Plan (CYPP) for the county or CYPSC area that is designed to improve outcomes for children and young people. These outcomes are aligned to the five national outcomes under Better Outcomes, Brighter Futures. The CYPP outlines local priorities that the CYPSC has agreed to address and includes a detailed action plan of activities which will be undertaken by the CYPSC and its sub groups to make impact on those priorities.

A national CYPSC Steering Group, under the auspices of the Department of Children and Youth Affairs, supports effective operation and practical implementation of CYPSC at the local level. Consultation with children and young people forms part of the development of CYPSCs and Children and Young People’s Plans. Their age remit spans all children and young people aged from 0 to 24 years.

Published in 2019, **Shared Vision, Next Steps 2019–2024** outlines the further development and vision for CYPSC over a five-year period.[[97]](#footnote-97) It also reflects on what has worked well to date, as well as the learning and challenges involved. One of the commitments detailed therein is that CYPSC will increase the involvement of children and young people with disabilities and children with their local CYPSC.

### Student Councils

Section 27 of Education Act 1998 provides that the board of management of second level schools shall encourage the students to establish a Student Council.

The NDA notes that research has been carried out with children and young people aged between 7 and 17 years, teachers and school principals, and parents, on their attitudes towards and opportunities for participation by students in schools in Ireland.[[98]](#footnote-98) The data reveal that many young people felt that student councils did not offer a real opportunity for expression of their views and that important decisions were not made there. Some young people questioned the representativeness of their student council and many expressed frustration at the lack of communication concerning decisions made by the council and the inadequate power of the council to make any real changes in how their school operates. In contrast with the less-than-positive feedback from the young people, school principals and teachers interviewed for the study consistently referred to the student council as a means of facilitating the participation of children and young people in the school.

While acknowledging the Department of Children and Youth Affairs’ strong record in supporting engagement and consultation with children and young people, the NDA has recommended that the Department build on this track record by:

* maximising the accessibility of consultation and research exercises through the adoption of a universal design approach, for example, by holding such exercises in accessible venues, providing easy-to-use information, by ensuring that research or consultation contractors possess the necessary skills to include the views of those with communication difficulties
* building the capacity of children and young people with disabilities, for example, by supporting peer advocacy that would enable and empower young people with an intellectual disability to engage with the Department’s consultation efforts in a way that is appropriate to them
* publishing information on the nature and level of consultation with children and young people with disabilities

### Ombudsman for Children’s Office

The Office of the Ombudsman for Children (OCO) has a statutory duty to consult children and carries out innovative consultations with children. One such example is how the OCO sought the views of children who were receiving in-patient mental health care in child and adolescent mental health units when developing their 2018 report, **Take My Hand: Young People’s Experiences of Mental Health Services**.[[99]](#footnote-99) The 25 participants were asked how they would like to share their views with the OCO. No method was imposed by the OCO and the choice lay with the children themselves. Some chose to share their views through facilitated focus groups, some through one-to-one interviews, while others chose to share their views through individual or group art.

The Ombudsman for Children’s Office have developed good practice guidance on **Children’s Participation in Decision-making**.[[100]](#footnote-100) The guidance document underlines that all children without exception have the right to have their views heard without discrimination on the disability. The document highlights considerations for including a wide diversity of children in decision-making, including whether the meeting space is accessible to children with disabilities.

### Children’s Rights Alliance

The Children’s Rights Alliance is a coalition of over 100 organisations working to secure the rights of children in Ireland.The Department of Children and Youth Afairs provides some funding to the Children’s Rights Alliance to be a membership voice, which includes youth groups and youth-led groups who are members of the Alliance (although the funding is not to engage with children or young people per se).

# Children with disabilities and societal participation

## Children with disabilities in employment

The Protection of Young Persons (Employment) Act 1996 provides for the participation of children under 18 years in employment. In Census 2016, 1,193 young people with disabilities aged 15-19 years reported that their principal economic status was “persons at work”, equating to 4.18% of all those aged 15-19 years with disabilities (4.18%). This compared to 854 in Census 2011.

## Children with disabilities participating in physical activity and sports

The first all-island **Children's Sport Participation and Physical Activity Study, 2018**, found that significant participation gradients exist for children with disabilities in terms of participation in community sport and membership of a sports club.[[101]](#footnote-101) Key findings included:

* 81% of children without disabilities participated in community sports at primary school level, compared to 72% of children with disabilities
* 61% of children without disabilities participated in community sports at post-primary school level, compared to 43% of children with disabilities
* No differences existed at primary or post primary school level between children with and without disabilities in terms of meeting the National Physical Activity Guidelines of achieve at least 60 minutes of moderate-to-vigorous physical activity daily
* 76% of children without disabilities were members of a sports club at primary school level, compared to 66% of children with disabilities
* 69% of children without disabilities participated in community sports at post-primary school level, compared to 54% of children with disabilities

In 2014, 66.5% of children with a disability and/or chronic illness aged 10–17 reported being physically active for at least 60 minutes per day on more than four days per week.[[102]](#footnote-102) This compared to 68.5% of children without a disability and/or chronic illness.

## Children with disabilities participating in play, recreation and leisure

A 2003 NDA funded study into public play provision for children with disabilities highlighted issues with some play facilities including:

* poor access
* unsuitable loose-fill surfaces which pose problems for those with mobility impairments and the unsuitability of much play equipment for disabled children
* the negative attitudes of other children, parents and some staff
* the lack of supervision of playgrounds and the lack of appropriately trained staff that could support the play of disabled children, even when facilities, such as playgrounds and play schemes, were available[[103]](#footnote-103)

A Disability Access Audit on a random selection of playgrounds was also carried out as part of the research, with 6 considered fully accessible, 12 generally accessible and 3 with limited accessibility. The NDA also funded research by University College Cork on exploring how Universal Design principles relate to outdoor parks and playgrounds.[[104]](#footnote-104)

## Children with disabilities participating in art and culture

Research commissioned by the Arts Council on **Arts and Cultural Participation among Children and Young People: Insights from the Growing Up in Ireland Study** found that children with disabilities tend to watch more television than their peers, but have families more highly engaged in reading and singing with them (at three years) and taking them on educational visits or to the library (at five years).[[105]](#footnote-105)

# Children with disabilities in vulnerable situations

## Children with disabilities who are homeless

The NDA notes research undertaken by the Ombudsman for Children’s Office on children’s views and experiences of living in family hubs, entitled **No Place Like Home**. While most children aged 5-12 consulted as part of the report did not expressly speak about their mental health, they expressed feelings of sadness, confusion and anger throughout the consultation that indicate that their mental health and well-being is being negatively affected by their experience of living in the Hub.[[106]](#footnote-106) The impact of living in the Hub on older children’s (aged 13-17) mental health and well-being was articulated by many participants in terms of feelings of embarrassment and shame, anger and sadness.[[107]](#footnote-107)

The Ombudsman for Children’s Office has noted that children of families who are waiting for social housing or disability adaptations experience adversity by having to stay in inappropriate emergency accommodation for lengthy periods of time or to live in a house that has not been adapted to suit their needs.[[108]](#footnote-108)

Research published by the Royal College of Physicians of Ireland in November 2019 on **The Impact of Homelessness and Inadequate Housing on Children’s Health** found that 38% of homeless children have mental health or behavioural disorders of clinical significance.[[109]](#footnote-109)

Under its 2019 Research Promotion Scheme, the NDA provided funding to Trinity College Dublin and the Daughters of Charity to conduct research on the systems of support required to prevent adults and families with children, with intellectual disability and/or autism becoming at risk of homelessness or homeless.[[110]](#footnote-110) The research found that emergency accommodation, in its present form, is not suitable or appropriate for most families, but is especially challenging for families who have a child with an intellectual disability (ID) and/or Autism Spectrum Disorder (ASD) with a possible attendant physical disability. The placement of a family in one room with limited facilities has led to reports of severe psychological difficulties in carers and behavioural and developmental regression in children. The report recommended that a specific policy be developed that meets the needs of children and their families in gaining and attaining suitable and appropriate housing within the ID and/or ASD cohort.

## Children with disabilities who are in poverty or at risk of poverty

The Department of Children and Youth Affairs have established a child-specific research programme to explore what helps to protect children in poverty or at risk of falling into poverty.[[111]](#footnote-111) The first part of the initiative was commenced in 2019 by establishing a statistical baseline analysis of children’s and families’ financial circumstances, using existing data. The next phase of the child-specific research programme will use child-specific Growing Up in Ireland data and explore what helps to protect children in poverty or at risk of falling into poverty. The NDA has engaged with officials from the Department of Children and Youth Affairs and advised on the importance of ensuring that children with disabilities are specifically included within this research.

Research on the level and nature of unmet service needs of children and adolescents with an Autism Spectrum Disorder (ASD), as well as debt related to meeting the needs of such families in Ireland, found the following:

* The findings from parental-reported responses show over 74% of children and adolescents did not receive one or more services in the previous 12 months
* 33% of families incurred debt in the previous 12 months specifically due to the child’s/children’s condition resulting in an average ASD related family debt of €3,260 per year
* ASD severity and families that had two or more children with an ASD were significantly more likely to experience unmet service needs, while families that had two or more children with an ASD were also significantly more likely to incur debt in the previous 12 months specifically due to the child’s/children’s condition[[112]](#footnote-112)

A Whole of Government Approach to Tackling Child Poverty was published in 2017. It emphasises the need for a combined approach to tackling child poverty levels in Ireland, involving access to income supports, access to affordable, quality services and children’s right to participate.

## Children with disabilities who are in contact with the criminal justice system and in detention

The NDA recently published policy advice on the establishment of a Registered Intermediaries Scheme. The NDA recommended that this Scheme be available to witnesses, victims and accused persons, including children, who may be in need of support, due to their communication difficulties, to give better evidence, at all stages of the criminal justice system, including in Garda stations and in court settings.[[113]](#footnote-113) Following the publication of the O’Malley **Review of Protections for Vulnerable Witnesses in the Investigation and Prosecution of Sexual Offences**, the Department of Justice committed to recruiting a cohort of appropriately qualified intermediaries who have undergone a prescribed course of training on the role of intermediaries.[[114]](#footnote-114)

Data published by Oberstown Children Detention Campus on the characteristics of 75 young people in detention during the first quarter of 2019 revealed that a high number had disabilities and mental health issues. Of the 75 young people on campus, 31 had a mental health need, while 46 were referred to the Assessment Consultation Therapy Services (ACTS) upon admission to Oberstown.[[115]](#footnote-115) In addition, 17 had been prescribed medication at one time for a mental health need, and 23 had been involved with CAMHS at one stage of their lives.

Of the 75 young people in detention, 17 also had some form of diagnosed learning disability.[[116]](#footnote-116) Of the young people with diagnosed disabilities:

* 10 were not engaging in education prior to admission to Oberstown
* 12 exhibited challenging behaviour
* 14 had mental health needs

The over-representation of children with a disability, including those with mental health issues, merits additional consideration, particularly best practice in terms of diversion from and rehabilitation in the child detention system.

# Conclusion

The NDA notes that there have been a number of considerable advances in the legal framework to protect children’s rights over the past number of years. These include a constitutional amendment giving explicit expression to the rights of children as individuals, as well as progressive legislation such as the Child and Family Agency Act 2013, the Children and Family Relationships Act 2015 and the Childcare Support Act 2018. Another welcome initiative, which is providing invaluable information and data on the lives of children with disabilities, is the Growing Up in Ireland study.

However, the NDA notes that particular challenges exist in terms of meeting the needs of some children with disabilities, particularly in the healthcare context. For instance, statutory timelines prescribed by the Disability Act 2005 for the assessment of need process are regularly not met. Legislative reform is required to address shortcomings in the Mental Health Act 2001 as they relate to children and young people with mental issues, and additional action, including funding, is required to improve timely access to disability, therapy and mental health services.

The NDA notes that considerable strides have been made in early learning and care, including through the AIM programme, and that progress is ongoing in relation to other measures, such as school aged childcare and the regulation of childminders. Regarding school aged childcare, the NDA advises that children with a disability are provided with supports to access the National Childcare Scheme.

The NDA further notes that the Ombudsman for Children’s Office investigation into Molly’s Case raises concerns regarding lack of co-ordination between the HSE and Tusla, with negative outcomes for children with disabilities in care. The NDA advises that the structures and processes for cooperation between TUSLA and the HSE for children with disabilities in the care system be enhanced, and particular attention be placed on child protection issues and access to therapeutic assessments and interventions.

Finally, while acknowledging the various, positive mechanisms and structures which are available for children, the NDA notes that additional information and disaggregated data is required to assess the particular situation regarding engagement and consultation with children with disabilities. Although children with disabilities have been involved in consultations in Ireland, these are on an ad hoc basis and there is no ongoing assistance or systematic process to ensure that their voice is heard.

# Appendix 1 – Waiting lists for selected primary care services

## Occupational Therapy

Table 1.1: Total number of occupational therapy service users by age and time waiting to be assessed at the end of September 2019

| Age | Less than 12 weeks | More than 12 weeks but less than 26 weeks | More than 26 weeks but less than 39 weeks | More than 39 weeks but less than 52 weeks | More than 52 weeks | Total |
| --- | --- | --- | --- | --- | --- | --- |
| 0 - 4 years 11 months | 950 | 1,018 | 683 | 561 | 1,330 | 4,542 |
| 5 - 17 years 11 months | 1,818 | 2,374 | 1,848 | 1,472 | 6,779 | 14,291 |
| Total | 2,768 | 3,392 | 2,531 | 2,033 | 8,109 | 18,833 |

Source: HSE Performance Management and Improvement Unit

Table 1.2: Percentage of occupational therapy service users by age on a waiting list for assessment for less than 52 weeks, at the end of September 2019

| Age | % |
| --- | --- |
| 0 - 4 years 11 months | 71% |
| 5 - 17 years 11 months | 53% |

Source: HSE Performance Management and Improvement Unit

Table 1.3: Percentage of occupational therapy service users by age seen for assessment within 12 weeks, at the end of September 2019

| Age | % |
| --- | --- |
| 0 - 4 years 11 months | 21% |
| 5 - 17 years 11 months | 13% |

Source: HSE Performance Management and Improvement Unit

Table 1.4: Number of occupational therapy patients by age seen at the end of September 2019

| Age | Number |
| --- | --- |
| 0 - 4 years 11 months | 2,192 |
| 5 - 17 years 11 months | 7,656 |
| Total | 9,848 |

Source: HSE Performance Management and Improvement Unit

## Physiotherapy

Table 1.5: Total number of physiotherapy service by age waiting to be assessed at the end of September 2019

|  | Less than 12 weeks | More than 12 weeks but less than 26 weeks | More than 26 weeks but less than 39 weeks | More than 39 weeks but less than 52 weeks | More than 52 weeks | Total |
| --- | --- | --- | --- | --- | --- | --- |
| 0 - 4 years 11 months | 1,782 | 678 | 352 | 244 | 365 | 3,421 |
| 5 - 17 years 11 months | 1,696 | 986 | 600 | 397 | 1,483 | 5,162 |
| Total | 3,478 | 1,664 | 952 | 641 | 1,848 | 8,583 |

Source: HSE Performance Management and Improvement Unit

Table: 1.6: Percentage of physiotherapy service users by on waiting list for assessment for less than 52 weeks, at the end of September 2019

| Age | % |
| --- | --- |
| 0 - 4 years 11 months | 89% |
| 5 - 17 years 11 months | 71% |

Source: HSE Performance Management and Improvement Unit

Table 1.7: Percentage of physiotherapy service users by age seen for assessment within 12 weeks, at the end of September 2019

| Age | % |
| --- | --- |
| 0 - 4 years 11 months | 52% |
| 5 - 17 years 11 months | 33% |

Source: HSE Performance Management and Improvement Unit

## Speech and Language Therapy

Table 1.8: Total number of speech and language therapy service users aged less than 18 years who are waiting to be assessed at the end of September 2019

| Age | 0 months – 4 months  | 4 months and 1 day – 8 months | 8 months and 1 day – 12 months | 12 months and 1 day – 18 months | 18 months and 1 day – 24 months | > 24 months | Total |
| --- | --- | --- | --- | --- | --- | --- | --- |
| <18 years | 6,277 | 2,270 | 995 | 442 | 230 | 293 | 10,507 |

Source: HSE Performance Management and Improvement Unit

Table: 1.9: Percentage of speech and language service users aged less than 18 years on waiting list for assessment for less than 52 weeks, at the end of September 2019

| Age | % |
| --- | --- |
| <18 years | 91% |

Source: HSE Performance Management and Improvement Unit

Table 1.10: Total number of speech and language therapy service users aged less than 18 years on the treatment waiting list who are waiting to be seen at the end of September 2019

| Age | 0 months – 4 months  | 4 months and 1 day – 8 months | 8 months and 1 day – 12 months | 12 months and 1 day – 18 months | 18 months and 1 day – 24 months | > 24 months | Total |
| --- | --- | --- | --- | --- | --- | --- | --- |
| <18 years | 3,138 | 2,015 | 1,105 | 809 | 210 | 46 | 7,323 |

Source: HSE Performance Management and Improvement Unit

Table 1.11: Percentage of speech and language service users aged less than 18 years on waiting list for treatment for less than 52 weeks, at the end of September 2019

| Age | % |
| --- | --- |
| <18 years | 85% |

Source: HSE Performance Management and Improvement Unit

Table1.12: Number of speech and language patients aged less than 18 years seen at the end of the end of September 2019

| Age | Number |
| --- | --- |
| <18 years | 17,621 |

Source: HSE Performance Management and Improvement Unit

1. Department of Children and Youth Affairs (2017) **State of the Nation’s Children: Ireland 2016**, Dublin: DCYA, p.33. [↑](#footnote-ref-1)
2. Economic and Social Research Institute (2015) **Insights into the Lives of Children with Disabilities: Findings from the 2006 National Disability Survey,** Dublin: ESRI and NDA. [↑](#footnote-ref-2)
3. The NDA are aware that in October 2020 the Department of Children and Youth Affairs changed its name to the Department of Children, Equality, Disability, Integration and Youth. We have used the Department of Children and Youth Affairs throughout this document as most of the references made pertain to when they used this name. [↑](#footnote-ref-3)
4. More information on the Growing Up in Ireland study is available at the following link: <https://www.growingup.ie/>. [↑](#footnote-ref-4)
5. Growing Up in Ireland (2018) **Key Findings: Cohort ’08 at 9 Years Old**, Dublin: GUI. [↑](#footnote-ref-5)
6. Banks J et al (2016) **Parental Expectations of Children with Disabilities**. ESRI [↑](#footnote-ref-6)
7. Government of Ireland (2014) **Better Outcomes, Brighter Futures: The National Policy Framework for Children and Young People**, Dublin: Stationery Office. [↑](#footnote-ref-7)
8. Department of Children and Youth Affairs (2018) **Mid-term Review of Better Outcomes, Brighter Futures**, Dublin: DCYA. [↑](#footnote-ref-8)
9. Government of Ireland (2019) **First 5: A Whole-of-Government Strategy for Babies, Young Children and their Families 2019-2028**, Dublin: Stationery Office. [↑](#footnote-ref-9)
10. Department of Children and Youth Affairs (2015) **National Youth Strategy 2015-2020**, Dublin: DCYA. [↑](#footnote-ref-10)
11. A copy of the draft strategy is available at the following link: [http://www.justice.ie/en/JELR/Draft\_Youth\_Justice\_Strategy\_2020\_(Public\_Consultation).pdf/Files/Draft\_Youth\_Justice\_Strategy\_2020\_(Public\_Consultation).pdf](http://www.justice.ie/en/JELR/Draft_Youth_Justice_Strategy_2020_%28Public_Consultation%29.pdf/Files/Draft_Youth_Justice_Strategy_2020_%28Public_Consultation%29.pdf). [↑](#footnote-ref-11)
12. Ombudsman for Children’s Office (2019) **Strategic Plan 2019-2021**, Dublin: OCO. [↑](#footnote-ref-12)
13. Ombudsman for Children’s Office (2018) **An Investigation by the Ombudsman for Children’s Office Molly’s case: How Tusla and the HSE provided and coordinated supports for a child with a disability in the care of the State**, Dublin: OCO. [↑](#footnote-ref-13)
14. Ombudsman for Children’s Office (2018) **Take My Hand: Young People’s Experiences of Mental Health Services**, Dublin: OCO. [↑](#footnote-ref-14)
15. More information on this event is available at the **Beyond Limits website** at <https://www.beyondlimits.ie/>. [↑](#footnote-ref-15)
16. Ombudsman for Children’s Office (2020) **Annual Report 2019**, Dublin: OCO, p.13. [↑](#footnote-ref-16)
17. Ombudsman for Children’s Office (2020) **Annual Report 2019**, Dublin: OCO, p.49. [↑](#footnote-ref-17)
18. Ombudsman for Children’s Office (2019) **Annual Report 2018**, Dublin: OCO, p.26. [↑](#footnote-ref-18)
19. Ombudsman for Children’s Office (2020) **Annual Report 2019**, Dublin: OCO, p.49. [↑](#footnote-ref-19)
20. UN Committee on the Rights of the Child (2016) **Concluding observations on the combined third and fourth periodic reports of Ireland**, Geneva: OHCHR, p.6. [↑](#footnote-ref-20)
21. UN Committee on the Rights of the Child (2016) **Concluding observations on the combined third and fourth periodic reports of Ireland**, Geneva: OHCHR, p.6. [↑](#footnote-ref-21)
22. **Children and Family Relationships Act 2015**, section 45. [↑](#footnote-ref-22)
23. **Children and Family Relationships Act 2015**, section 63. [↑](#footnote-ref-23)
24. **Child and Family Agency Act 2013**, section 9(1). [↑](#footnote-ref-24)
25. **Child and Family Agency Act 2013**, section 9(2). [↑](#footnote-ref-25)
26. **Education for Persons with Special Educational Needs Act 2004**, section 2. [↑](#footnote-ref-26)
27. Kilkelly, U. (2011) **A Children’s Rights Analysis of Investigations**, Dublin: Ombudsman for Children, p.5 [↑](#footnote-ref-27)
28. Ring, E., Grey, T., O’Sullivan, L., Corbett, M., Sheerin, J., and Heeney, T. (2019) **Universal Design Guidelines for Early Learning and Care Settings: Literature Review**, Dublin: DCYA & CEUD. [↑](#footnote-ref-28)
29. National Disability Authority (2018) **Review of overage exemptions for the Early Childhood Care and Education (ECCE) Programme**, Dublin: NDA. The NDA’s review, as well as an additional letter of advices, are available at the following link: <https://www.gov.ie/en/press-release/6c15b3-minister-zappone-welcomes-the-report-of-the-national-disability-auth/>. [↑](#footnote-ref-29)
30. More information on the **National Childcare Scheme** is available at the following link: <https://ncs.gov.ie/en/>. [↑](#footnote-ref-30)
31. Department of Children and Youth Affairs and the Department of Education and Skills (2017) **Action Plan on School Age Childcare**, Dublin: DES & DCYA, p.8. [↑](#footnote-ref-31)
32. A copy of the Draft Childminding Action Plan is available at the following link: <https://www.gov.ie/en/consultation/fbfe89-public-consultation-on-the-draft-childminding-action-plan/>. [↑](#footnote-ref-32)
33. Department of Employment Affairs and Social Protection (2019) **Annual Report 2018**, Dublin: DEASP, p.15. [↑](#footnote-ref-33)
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