NDA Submission on the Policy Framework for Children and Young People in Ireland

March 2022

# Introduction

The National Disability Authority (NDA) is the independent statutory body with a duty to provide information and advice to the Government on policy and practice relevant to the lives of persons with disabilities, and to promote Universal Design. The NDA welcomes the opportunity to make a submission on the next National Policy Framework for Children and Young People.

# Survey questions

## 1. What’s going well for children and young people in Ireland?

Ireland ratified the UN Convention on the Rights of Persons with Disabilities (UNCRPD) in March 2018. Article 7 of UNCRPD ‘Children with Disabilities’ further reaffirms Ireland’s commitment to upholding the rights of children and young people with disabilities[[1]](#footnote-1).

The NDA notes that the Department of Children, Equality, Disability Integration and Youth launched the National Framework on Children and Young People’s Participation in Decision Making in April 2021 which is underpinned by UNCRPD. We are pleased to note that children with disabilities have been identified by the Department as a priority cohort for this year and that it is intended that inclusive methodologies will be developed and piloted to strengthen the delivery of the Framework for this group.

The NDA also highlights in particular the success of the Access and Inclusion Model (AIM). The NDA understands that the 3-year AIM evaluation, which has yet to be published, will state that the model has made positive impact on children and families’ outcomes and on the capacity of Early Learning and Care settings.

While many young people with disabilities are not well prepared for post-school education, training and employment, it must be noted that rates of progress to further and higher education among students with disabilities, particularly for some groups, have increased (from less than 1000 in 1993/4 or 0.7% of all students to just under 16,000 or 6.3% of all students in 2019/20[[2]](#footnote-2)).

The trend of lower numbers of children being admitted to adult inpatient mental health services has continued to fall. 27 children were admitted in 2020 compared to 68 in 2016[[3]](#footnote-3). The number of CAMHS beds has increased from a low base of 14 beds in 2008 to approximately 100.

## 2. What’s not going well for children and young people in Ireland?

As will be addressed in more detail in the our answers to the questions below children with disabilities

* Have worse outcomes on a range of health and wellbeing related measures (children with disabilities / chronic illnesses are less likely to be “happy with their lives” and “happy with the way they are” or to be physically active and more likely to have taken drugs, alcohol and had sex[[4]](#footnote-4)) then children without any disabilities / chronic illnesses
* Can have less positive experiences of education (are less positive about school, are expected to do less well in school, find education transitions more difficult and are increasingly likely to educated **outside** a mainstream classroom and are more likely to be bullied[[5]](#footnote-5)).
* Are more likely to live in families who have difficulties in “making ends meet” and to experience deprivation[[6]](#footnote-6), their primary carers are less likely to be employed (when compared to a primary carer of a child without a disability) and the presence of a child with a disability in a household was strongly correlated with poorer socioeconomic outcomes[[7]](#footnote-7) [[8]](#footnote-8)
* May have to wait for considerable periods of time to access an assessment and some of the interventions that they require. Also, parents of children with disabilities tend to report that they find the systems of supports available to them hard to access and difficult to navigate.

## 3. What can be done to ensure children and young people are active and healthy, with positive physical and mental wellbeing?

Providing eligibility to GP cards for children aged 0 to 6 in 2015 ensured that all children in the age cohort have access to certain primary health care services. Current plans - as set out in the Health (General Practitioner Service and Alteration of Criteria for Eligibility) Act 2020 - for the phased expansion of the GP cards to all children aged 12 years and under are welcome.

However, many children including children with disabilities face considerable waiting times to access assessments and interventions for health procedures, therapies and mental health services. Waiting lists for assessments and interventions / treatments have been significantly impacted by Covid-19 but for many of these areas there were significant waiting lists prior to: 10,500 waiting for a Speech and Language a primary care Speech and Language Therapy assessment in 2019; 19,000 waiting for a primary care Occupational Therapy assessment in 2019).

The number of referrals to child and adolescent mental health services (CAMHS) increased from 12,800 in 2011 to 18,100 in 2019[[9]](#footnote-9). There were 2,500 children and young people on the CAMHS waiting list in 2019[[10]](#footnote-10). The number of children and young people on the Primary Care waiting list for Psychology in 2021 was over 8,500[[11]](#footnote-11).

The NDA is concerned that a small number of children and young people with disabilities, mental health difficulties and behavioral challenges are placed in out of state care each year. The NDA has had preliminary discussions with the Mental Health Commission about potential research examining out of state child placements arrangements and what measures could be taken to reduce the need for such placements.

Therefore, for children with disabilities and chronic health conditions the capacity of the health system to deliver services is a barrier to better physical and mental health.

The NDA acknowledges that progress has been made in relation to Better Outcomes Brighter Futures (BOBF) G.31 - reconfigure services for children with disabilities. Reconfigured teams are now established across the country. The NDA advises that in developing the new policy framework it would be important to consider and address the capacity of the teams to meet demand (the NDA, Department of Health, HSE have examined the capacity issue[[12]](#footnote-12)) and to look at how the model is meeting children and family outcomes. NDA also advises that a formal evaluation of Progressing Disability Services that could build on the ongoing work to implement the Children’s and Families Outcomes Framework is conducted in the near future.

A study using Growing up in Ireland data showed that parents of children with disabilities were at significantly more risk of having poor mental health than parents of children without a disability[[13]](#footnote-13). While the risk to parental mental health is an issue in and of itself, it is also a significant concern because the available evidence shows that poor mental health in parents of children with disabilities is associated with a range of negative health and social family outcomes[[14]](#footnote-14). Another Growing Up in Ireland study showed the risk factors for social and emotional difficulties in young children (which commonly manifests as behavior difficulties in school) are having a developmental disability, being male, parental educational level, family income, primary care giver wellbeing and being a lone parent[[15]](#footnote-15). NDA secondary analysis of the Growing up in Ireland data has shown how having a sibling with a disability can have negative outcomes for children in certain circumstances (including where parents have poor mental health)[[16]](#footnote-16). Therefore, supporting children and young people with disabilities and their families is complex and requires inputs from many public sector and publicly funded organisations.

From our direct engagement with parents of families of children with disabilities (through research but also through unsolicited contact from the public) the NDA advises that many parents of children with disabilities experience the range of supports available to them as uncoordinated and difficult to navigate and often difficult to access in a timely way. It is imperative therefore that families of children with disabilities are considered in a holistic way. The NDA acknowledges that there has been efforts under BOBF Action 2.18 to increase coordination across the health, education and children’s sectors. However, the NDA advises that it remains the case that there is a need to consider how the supports available to children with disabilities and their families could be delivered in a way that is more joined up and easier to access and more focused on the outcomes for the whole family.

The Better Outcomes Brighter Futures Indictor Set show that some key mental health indictors have worsened in recent years. For example, the percentage of those 15 to 24 years displaying optimal levels of mental health has decreased from 21% in 2015 to 12% in 2021, and the percentage with probable mental health problems has increased from 10% to 20% in the same time period[[17]](#footnote-17). While some of this decline may be related to Covid-19 and Covid-19 related restrictions it nonetheless points to the importance of sufficiently resourced Primary Care Psychology services, CAMHS services, school based mental health programmes and positive mental health and wellbeing programmes across the child and youth population and among priority groups.

The 2022 State of the Nations Children report showed that children with disabilities and/ or a chronic health condition were less likely to participate in physical activity. BOBF Action 1.6 addresses the issue of making children and youth sport more accessible and affordable. There has been progress in this area. Over 1,400 organisations have signed the Sport Disability Inclusion Charter[[18]](#footnote-18) in recent years. The NDA advises therefore that there is an opportunity for the new policy framework to build on this development and address the participation of children and young people with disabilities in physical activity.

The State of the Nation’s Children report also shows that children (10 to 17) with a disability or chronic illness are more likely to have used alcohol and cannabis and more likely to have had sex then children without a disability or chronic illness. This group of children may therefore require more targeted or more appropriately designed support to reduce risky behaviour.

## 4. What can be done to ensure children and young people are achieving their full potential in school and all areas of learning and development?

The 3 Year Evaluation of AIM is being finalised but the NDA understands that evaluation will show that AIM has made positive impact on children and families’ outcomes and on the capacity of Early Learning and Care settings. The NDA has previously advised the Department that AIM (with appropriate modifications) should be expanded to children with disabilities availing of School Aged Childcare[[19]](#footnote-19). The NDA acknowledges that the Department also needs to consider whether AIM could / should be expanded to include other groups of children who require support to participate in State-funded Early Learning and Care programmes. Given the importance of Early Learning and Care in the lives and children and families the NDA advises that the expansion(s) of AIM should be a key priority of the new policy framework. We also advise that the importance of creating a more inclusive educational environment though applying the principles of Universal Design and Universal Design for Learning that enables all students to prosper and grow and in particular for children with disabilities.[[20]](#footnote-20) That communication, whether verbal, written, signed or digital, is designed so that they are accessible, understandable and usable by all children is also important. This links to a new statutory requirement that public websites and mobile apps are accessible from June 2021.[[21]](#footnote-21) [[22]](#footnote-22)

Action 2.20 of BOBF committed to working towards more timely access to special education and therapeutic supports for children with special educational needs. It is certainly the case that there has been considerable investment in special education in recent years. Between 2011 and 2020 the budget for special education increased by more than 50%. In 2022 the special education budget of 2 billion Euros is 25% of the Department of Education’s budget. Budget 2022 provided funding for an additional 1,165 Special Needs Assistants and 116 new special classes, bringing the total number of special classes to 2115 (there were 550 special classes in 2011). The reconfiguration of the various support services into regional support teams under the NCSE and the piloting of the In-School Therapy Demonstration Project (now rolled into the new School Inclusion Model) are positive developments which have supported schools to build capacity to support the inclusion of children with disabilities.

For the majority of children who require special education supports in schools a formal diagnosis of a disability is no longer required due to the Special Education Teacher Allocation Model and the more recent rollover of SNA allocations process. However, a diagnosis of a disability and recommendation from an appropriate professional is still required for example for placement in a special school or special class placement. The vast majority of these placement recommendations come from professionals who do not work in the education system. Placement recommendations (typically made when children are very young) are “rarely if ever reviewed”[[23]](#footnote-23).

While the rates of progress to further and higher education among students with disabilities, particularly for some groups, have increased (from less than 1000 in 1993/4 or 0.7% of all students to just under 16,000 or 6.3% of all students in 2019/20[[24]](#footnote-24)) many young people with disabilities are not well prepared for post-school education, training and employment.

Many children with disabilities don’t have access to work experience or career guidance because special schools don’t have Transition Year or access to Career Guidance as they are not designated as post-primary schools. The Indecon Report on Career Guidance stated that the international literature shows that career guidance is one of the most effective career supports that can be provided. The Indecon Report notes that while parents and others shape young people’s career choices that young people from poorer families were less likely to receive career advice from their parents[[25]](#footnote-25). Therefore children in special schools, particularly if they are not from better off families are at a significant disadvantage in terms of the supports available to them to select post-school options which may be open to them.

NDA advises that providing career guidance for all young people with disabilities or special educational needs be addressed in the new policy framework. In keeping with the national policy of mainstreaming, it is important that the whole of education provision from school to further education, training services and lifelong learning reflect the diversity of the population served. Career guidance, therefore, should equally serve people with disabilities, across the spectrum of disability and learning style and include special education settings.

We know from studies using Growing Up In Ireland data that children and young people have a poorer self concept than children without disabilities[[26]](#footnote-26) (though this various by disability and aspects of self concept, e.g. academic, social, etc); that they are less engaged with and feel less positive about school[[27]](#footnote-27); that parents of children with disabilities have lower expectations of them (compared to expectations of children without disabilities) and that those lower parental expectations have an impact both on the academic and social and emotional outcomes for children with special educational needs[[28]](#footnote-28); and that children with disabilities to tend to find transitions from one level of education to another more challenging[[29]](#footnote-29). As noted below we know from the State of the Nation’s Children report that children with disabilities are more likely to be bullied.

The Comprehensive Employment Strategy for People with Disabilities 2015 to 2024 recognised the importance of high expectations around work, education and training for children and young people with disabilities and included a commitment to raise expectations[[30]](#footnote-30). The HSE funded programme Informing Families[[31]](#footnote-31) has sought to ensure that professionals communicate key messages around positive expectations from point of diagnosis of disability. However, the NDA advises that there is still a need for a programme across health, education and children’s sectors to ensure that professionals are communicating high expectations around work, training and education to children and young people with a disability and their families.

The forthcoming Report on the Operation of the Irish Sign Language Act 2017 will show that there is considerable progress required to implement the provisions of Section 5 of the Act (Education Supports for Deaf Children). The consultation report appended to the report highlights the severe difficulties that the small number of children who require Irish Sign Language supports in schools can face. The NDA advises that once the Report is published that Departments addresses the issues raised in the Report[[32]](#footnote-32) as relevant and appropriate.

The NDA supported the Department of Children and Youth Affairs to develop Universal Design Guidelines for Early Learning and Care Settings[[33]](#footnote-33) and Department of Children, Equality, Disability Integration and Youth to raise awareness and develop the capacity of relevant built environment and ELC professionals. The NDA advises that universal design guidelines for schools to ensure that they are designed to meet the needs of all students, staff and visitors would be worthwhile initiative.

Therefore, while acknowledging that there has been very substantial investment and some substantial policy innovations in the education of children and young people with disabilities, significant challenges remain. The NDA advises that with the ratification of the UN Convention on the Rights of Persons with Disabilities in 2018, the NCSE’s Policy Advice on the Future Role of Special Schools and Special Classes (interim advice published in 2019 and final advice due in mid 2022), with the forthcoming 3 Year Evaluation of AIM and the recently announced review of the EPSEN Act, 2004 there is an opportunity (during the lifetime of the new policy framework) for the vision of inclusive education provision for children with disabilities or additional / specific learning support needs to be re-considered to ensure that the ongoing substantial investment is producing the best possible outcomes. People with disabilities, including children and young people, should be at the center of considering the new vision of inclusion education in Ireland.

## 5. What can be done to ensure children and young people are safe and protected?

The NDA advises that the Department build upon the commitment in the previous strategy to listen to and involve children and young people, giving particular attention to children and young people with disabilities. For example, facilitating children and young people with disabilities in care to have meaningful participation in their care planning and ensuring mechanisms which provide children with the opportunity to be heard in judicial proceedings affecting them are fully inclusive.

The NDA advises that the Department build upon its commitment to adopt an effective interagency approach in relation to cases of child protection and welfare. In the first instance, it is advised that a mapping of relevant intersecting policies and strategies across Departments and agencies take place. For example, actions within the Child Protection and Welfare Strategy 2017 – 2022 (TUSLA), the Youth Justice Strategy 2021 – 2027 (Department of Justice) and Progressing Disability Services for Children and Young People (HSE) will have implications for interdepartmental and interagency cooperation,

The NDA advises that a key area of focus be the development and enhancement of robust structures and processes for cooperation between TUSLA and the HSE for children with disabilities in the care system and in the youth detention system. While progress has been made in this area (such as the agreement to the 2017 Inter-agency Protocol and related training) the Ombudsman for Children’s “Molly” follow up report found that there was still much to be done to improve coordination between the two agencies[[34]](#footnote-34). The NDA advises that improved service delivery to children and families who require the support of both TUSLA and the HSE, particularly mental health and disability supports, should be a priority objective within the new policy framework.

The NDA wishes to highlight the balance between ensuring children and young people are safe and protected while also upholding their right to be supported to make their own decisions. The NDA suggests that the Department ensure the next policy framework should give consideration to the Assisted Decision Making (Capacity) Act which is due to be commenced this year and which applies to those aged 18 and over. The NDA advises that capacity-building support be provided to young people aged 16-17 who may need to engage with supported decision making so that they are empowered to do so once they reach the age of 18. The NDA advises that the Department liaise with the Decision Support Service regarding supported decision making arrangements that may be relevant to young people and how best to ensure these, as well as capacity-building initiatives, are in place.

It is important that sectors providing state funded services to children have robust quality assurance and oversight arrangements in place. Schools, Early Learning and Care, services for children in care, residential disability services, in-patient mental health services all have external oversight in place. However, other areas such as CAMHs and children’s disability therapy services, home support hours (often used to provide in home respite hours to families of children with disabilities) do not have any external oversight in place. All external oversight comes with compliance costs and administrative burden and the risk of unintended impacts. Therefore, the NDA advises that areas that currently have no external oversight should be examined to see how children’s safety and outcomes could be best overseen in a way which minimises the risk of resources being diverted to regulatory compliance.

## 6. What can be done to ensure children and young people have opportunity in life and economic security?

Putting employment on the agenda for young people with disabilities during their school years has a positive impact on longer-term employment prospects. Evidence shows that a focus on employment and career planning needs to start as early as age 13, or the first year of post-primary school.[[35]](#footnote-35) Children attending a special school do not have access to career guidance counsellors for the duration of their education. The NDA has underlined that career guidance should be available to all students, including those in special education provision.

In addition, research shows that young people with disabilities who take part in work experience during their school years, and in particular, paid work, have a significantly higher employment rate.[[36]](#footnote-36) This has implications for provision of Transition Year and other work-placement initiatives within the education system.

The NDA advises that the Department align the new policy framework with the actions of the Comprehensive Employment Strategy (CES) related to transitions which aims to support the transition of school-leavers with disabilities into employment or further education.[[37]](#footnote-37)

## 7. What can be done to ensure that children and young people in Ireland are free from poverty, disadvantage and social exclusion?

The NDA highlights that children and young people with disabilities experience poverty, disadvantage and social exclusion to a disproportionate extent compared to children without disabilities. According to a 2021 Indecon report commissioned by the Department of Social Protection, on average, households with a member with a disability have nearly €8,000 less annual equivalised income than a household without a member with a disability. Households with a member with a disability also display higher rates of arrears and a higher rate of poverty.[[38]](#footnote-38)

According to the State of the Nation’s Children report (2020)[[39]](#footnote-39), children with a disability and/or chronic illness were more likely to report having been bullied at school in the past couple of months.[[40]](#footnote-40) The previous strategy also highlights the high risk of social exclusion for children leaving care. The NDA advises that the new policy framework include transitions from care, particularly for children and young people with disabilities as a priority area. Children and young people with disabilities face disadvantage in educational and employment related outcomes as outlined in previous sections of this submissions. The NDA advises that targeting these areas would be a significant step towards reducing inequalities for disabled children and youth.

## 8. What can be done to ensure children and young people are respected and able to contribute to their world?

The NDA advises that the new policy framework commit to the creation of a new National Strategy on Children and Young People’s Participation in Decision-Making, and that such a strategy place a greater focus on the participation of children and young people with disabilities in decision-making.

We particularly wish to highlight that UNCRPD Article 4(3)[[41]](#footnote-41) requires that State Parties “closely consult with and actively involve persons with disabilities, including children with disabilities, through their representative organizations”. Therefore, it is advised that the Department, through this strategy, set out how it will support the development of children and youth-led/partnered Disabled Person’s Organisations as part of its effort to promote child and youth participation in decision making. Through its General Comment 7, the UNCRPD Committee states that “States parties should create an enabling environment for the establishment and functioning of representative organizations of children with disabilities…”. It further states that children and young people themselves are best placed to express their own requirements and experiences and that the role of parents, relatives and caregivers in such organisations should be to “assist and empower” children and youth with disabilities to have a voice.[[42]](#footnote-42) The NDA advises that the Department set out how it will support the development of these organisations and initiatives, including how it will ensure their long-term sustainability through the provision of funding and other supports as required.

Children and young people with disabilities, and their organisations, experience additional barriers to engagement. The NDA advises delivering consultation processes through a universal design approach, for example, by holding them in accessible venues, providing easy-to-use information, ensuring that the consulting body has the necessary skills to include the views of those with communication difficulties.

It is also necessary to consider how to facilitate capacity building for children and young people with disabilities and their organisations. Without such capacity building some children and young people with disabilities may not be able to engage with participation initiatives on an equal basis with others. Additionally, some children with disabilities (for example children with disabilities in the care system) will require access to advocacy services to support them to have their voice heard. It is also recommended that capacity-building of Departments and agencies take place regarding how to effectively support the participation of disabled children and young people and their representative organisations in consultation processes and mechanisms. The National Disability Authority is currently revising and updating our Ask Me Guidelines for Effective Consultation with People with Disabilities[[43]](#footnote-43). As part of this revision process we hope to work collaboratively with the Department of Children, Equality, Disability, Integration and Youth to develop guidelines for consulting with children and young people with disabilities.

## 9. Have the lives of children and young people in Ireland improved over the last decade, and if so, how? *And* 10. How has Better Outcomes, Brighter Futures helped achieve these improvements?

For some key indictaors such as being at risk of poverty (with a slight reversal in 2020), being on a waiting list for social housing[[44]](#footnote-44), child homelessness[[45]](#footnote-45), and progression to further and higher education for students with disabilities[[46]](#footnote-46), admissions to adult in patient mental health services[[47]](#footnote-47) there has been progress.

In relation to poverty and housing it is worth looking at some of these positive findings with reference to the Cost of Disability in Ireland report[[48]](#footnote-48). Overall the Cost of Disability Report found that households with a member with a disability were more likely to live in poverty than households with a member with a disability.

Proportion of those in consistent poverty and at risk of poverty by type of disability

|  | Nature of condition/illness | | | |
| --- | --- | --- | --- | --- |
|  | Physical Condition | Psychological Condition | A difficulty with pain, breathing or any other chronic illness or condition | No Illness or Condition |
| Poverty indicator |  |  |  |  |
| In consistent poverty | 13% | 19% | 10% | 5% |
| At risk of poverty | 23% | 27% | 19% | 14% |

Source: Indecon (2021) Cost of Disability in Ireland

The ombudsman for children commissioned report Mind the Gap cited evidence from a study based on Growing Up in Ireland data that primary carers of a child with a disability is considerably less likely to be employed (when compared to a primary carer of a child without a disability) and that across a range of socioeconomic measures, presence of a child with a disability in a household was strongly correlated with worse outcomes[[49]](#footnote-49).

The NDA therefore advises that any key policy ambitions of the new policy framework should be based on an analysis that looks at global targets and global outcomes but should also be based on an analysis of how those policy goals will impact on particular groups of children and young people and their families, including children with disability and their families.

Similarly the focus on early years in Better Outcomes Brighter Futures has produced positive outcomes with significantly more children attending early learning and care and attending higher quality ELCs (ELCs in receipt of higher capitation)[[50]](#footnote-50) and children’s transition from pre-school to school have been supported through the **Let’s Get Ready**. In addition to these universal interventions the targeted measures such as provision of AIM (within the ELC sector) and the Area Based Childhood (ABC) Programme and the work by the Tusla the Department of Children and Youth Affairs (now Department of Children, Equality, Disability, Integration and Youth) to embed evidenced based approaches to prevention and early intervention services has meant that much stronger support infrastructure for young children and their families has been established over the life time of Better Outcomes Brighter Future. However, as noted above families of children and young people with disabilities still experience support provision as fragmented and difficult to navigate.

With the move of the Disability Unit from the Department of Health to the Department of Children, Equality, Disability, Integration and Youth there is an opportunity to see if the evidenced based approach and coordination infrastructure that has been developed in relation to mainstream early intervention and prevention and family supports can be leveraged to assist in the coordination supports to children with disabilities and their families.

The EPSEN Act, 2004 and Part 2 of the Disability were supposed to provide a legislative basis for cooperation across the health and education sectors. Given that EPSEN is now being reviewed the NDA advises that part of the work on improving the coordination of sectors important to the lives of children and young people with disabilities and their families could be a joint review of EPSEN and Part 2 of the Disability.

## 11. What could be done to respond to the impact of Covid-19 on children and young people?

NDA Lockdowns Unlock Innovations Report published in 2021 outlined a number of areas where the move to online reduced barriers for some people with disabilities to participate in employment, education, health disability / mental health services while lack of technology and / or broadband and inaccessible platforms created barriers for others[[51]](#footnote-51). Therefore ongoing hybrid service provision particularly where a Universal Design approach has been adopted to service provision and platform design will make public services more accessible for some people (including children and young people) with disabilities.

Similarly the HSE published a report on conducting remote assessments for people with disabilities. While the report noted a number of challenges to therapists working remotely with people with disabilities it also noted that;

Clinicians also reported examples of where remote services offer significant benefits; such as flexibility and convenience for families and the ability to assess a person in their real-world home environment. Remote methods were also reported to promote greater reach for services; facilitating ‘attendance’ by those who lived far from service centres, or were usually less frequent attenders for other reasons[[52]](#footnote-52)

Therefore, the NDA advises that there should be consideration to services such as therapy services offering hybrid assessment / interventions in circumstances where this works for children and young people and their families.

Many teachers and parents commented that Covid- related school closures had a greater impact on children with disabilities / special education need. However, at present there is an absence of hard evidence for the differential impact of Covid- related school closures. The impacts are likely to be different within and between groups of children with disabilities / special education need (depending on age, family circumstances, extent / quality of remote teaching etc.). NCSE has commissioned a team from UCD to examine the impact of the Covid- related school closures on students with Special Education Needs (partly based on secondary analysis of the Our School Lives data). This report should be published in quarter 3 2022 and should provide a solid evidence base for impacts of the Covid-related school closures for children with disabilities / special education need and should facilitate policy response considerations.

While the expanded Summer Education Programme was a welcome development in summer 2020 and summer 2021 there were issues with capacity of school and tutor supply. Given these issues and given that impact of Covid-19 related school closures is likely to have been social as well as educational, the NDA advises that the capacity of other sectors (summer camps, after school clubs, School Aged Childcare providers) to deliver “catch up programmes” for targeted groups should be considered (in addition to school-based programmes).

As noted above waiting lists for therapy assessment and intervention have been impacted by Covid-19. However, this was an exacerbation of existing issues rather than something completely caused by the pandemic. Given the issues experienced with therapist recruitment as part of the In-School Therapy Project and now with the new School Inclusion Model and in the disability and mental health sectors there is a need (which the impact of Covid-19 amplified) to plan for increased supply, recruitment and retention of therapists and other professionals across a range of service areas crucial to children’s outcomes. The NDA advises that the new policy framework should as a priority address the issue of supply of professional on a cross-Departmental basis as delayed intervention for children and families (either directly or indirectly through building school / ELC capacity) impacts on children’s and families’ outcomes and is likely to ultimately cost the State more in the medium and longer term.

## 12. What top five priorities should the new policy framework focus on, to improve the lives of children and young people by 2028?

Based on the points set out above the National Disability Authority advises that the top five priorities that the new policy framework should address are –

* Developing awareness of the need to include the **voice of children and young people** with disabilities in the decision making processes that will have an impact on their lives. This will require awareness raising and training for policy makers and service managers, support for capacity building for children and young people with disabilities, strengthening of advocacy services and cooperation with the Decision Support Service to ensure that frontline services supporting children and young people with disabilities have appropriate processes in place to ensure that young people over 18 are supported to make decisions and that capacity-building support is provided to young people aged 16-17 who may need to engage with supported decision making so that they are empowered to do so once they reach the age of 18.
* Developing a **renewed vision** for the **education provision** for children and young people who require extra learning supports in school. The ratification of the UN Convention on the Rights of Persons with Disabilities in 2018, the forthcoming NCSE’s Policy Advice on the Future Role of Special Schools and Special Classes, the forthcoming 3 Year Evaluation of AIM and the recently announced review of the EPSEN Act, 2004 there is an opportunity to set out a vision for the inclusive education of children and young people with disabilities and those require extra learning supports in school that could be progressively realised over an appropriate timeframe.
* Ensuring that children with disabilities are **no more likely to be at risk of living in poverty than other children**. The publication of the Cost of Disability in Ireland report in 2021 has provided an impetus and evidence base for the cost of disability to be addressed through a cross-Departmental approach. Progress on addressing child poverty was an important achievement in the later years of Better Outcomes Brighter Futures. Therefore work on the cost of disability under the National Disability Inclusion Strategy could benefit from a focus on anti-poverty initiatives for children and young people with disability under the new (children and young people’s) policy framework.
* Ensure that **the systems of supports** for children and young people with disabilities have the **capacity to deliver the required supports**. This is likely to require cross-Departmental approach to increasing the supply of certain key professionals. Ensuring that primary care, Disability Network Teams, in-school Therapy (new School Inclusion Model), National Education Psychological Service, CAMHS can deliver timely intervention is critical as delayed intervention for children and families (either directly or indirectly through building school / ELC capacity) impacts on children’s and families’ outcomes.
* Supporting children and young people with disabilities and their families will also require better **coordination** (across sectors and across specialist and mainstream) in the provision on ongoing support but in particular to supporting children and young people **transitioning** from one setting / phase to another. Given the work under the Better Outcomes Brighter Futures on improving the coordination of mainstream early intervention and prevention services (including by improving the evidence base) the new policy framework could provide a mechanism for improving the coordination of supports for children and young people with disabilities and their families.

## Further engagement

The National Disability Authority would welcome being involved in any further consultation on the new policy framework and would ask to kept informed about any consultation events. We are also available to discuss any of the points raised above in more detail if that would be of assistance to the Department’s work.

1. The NDA has produced a briefing paper on UNCRPD Article 7 which highlights key data and measures in place relevant to Article 7. We will periodically update this briefing paper. National Disability Authority, 2020, Article 7 Briefing Paper https://nda.ie/publications/others/uncrpd/series-of-papers-on-individual-united-nations-convention-on-the-rights-of-persons-with-disabilities-uncrpd-articles.html [↑](#footnote-ref-1)
2. Ahead (2021) Students with Disabilities Engaged with Support Services in Higher Education in Ireland 2019/20. <https://www.ahead.ie/userfiles/files/AHEAD_Research_Report_21_digital.pdf> [↑](#footnote-ref-2)
3. Mental Health Commission (2021) Mental Health Commission Annual Repot 2020. https://www.mhcirl.ie/sites/default/files/2021-07/Mental-Health-Commission-Annual-Report-2020-screen.pdf [↑](#footnote-ref-3)
4. State of the Nation’s Children (2020) https://www.gov.ie/en/campaigns/1f703-state-of-the-nations-children/ [↑](#footnote-ref-4)
5. Cosgrove, J. (2018) Educational Experiences and Outcomes of Children with Special Educational Needs: Phase 2 – from age 9 to 13 A Secondary Analysis of Data from the Growing Up in Ireland Study. <https://ncse.ie/wp-content/uploads/2018/03/03263-NCSE-EdExps-Children-SEN-FINAL-UPLOAD.pdf>; Banks, J. et al (2016) Parental Educational Expectations of Children with Disabilities. ESRI. Dublin (Commissioned by the National Disability Authority); Mihut, G. (2020) Academic and Socio-Emotional Outcomes of Young People with Special Educational Needs and the Role of Parental Educational Expectations. <https://www.esri.ie/system/files/publications/WP692.pdf> (Commissioned by the National Disability Authority); Smyth, E. (2018) The Transition to Primary Education: Insights from GUI Study. ESRI. Dublin (Commissioned by the NCCA) and State of the Nation’s Children (2020) https://www.gov.ie/en/campaigns/1f703-state-of-the-nations-children/ [↑](#footnote-ref-5)
6. Roddy, A (2012) A Socioeconomic Profile of Childhood Disability in Ireland: Evidence from the Growing Up in Ireland Survey. Growing Up in Ireland Research Conference 2012 presentation [↑](#footnote-ref-6)
7. John Cullinan and Aine Roddy ‘A socioeconomic profile of childhood disability’ in John Cullinan, Seán Lyons and Brian Nolan (eds), The Economics of Disability (Manchester University Press 2015). [↑](#footnote-ref-7)
8. The implication of the Cost of Disability report which compares households with and without disabilities is discussed below. Indecon (2021) “The Cost of Disability in Ireland.” [↑](#footnote-ref-8)
9. Minister Jim Daly TD. Houses of the Oierachtas. (13th March 2019). Child and Adolescents Mental Health Services. Dáil Éireann Debate. https://www.oireachtas.ie/en/debates/question/2019-03-13/1 [↑](#footnote-ref-9)
10. HSE. (2019). Performance Profile July – September 2019: Quarterly Report. https://www.hse.ie/eng/services/publications/performancereports/july-to-september-quarterly-report.pdf. [↑](#footnote-ref-10)
11. Minister Mary Butler quoted in the Journal.ie “More than 8,500 young people on waiting list for primary care psychological services, Dáil hears” February 4th 2021. https://www.thejournal.ie/dail-mental-health-5345171-Feb2021/ [↑](#footnote-ref-11)
12. National Disability Authority (2015) Children’s Disability Services in Ireland. <https://nda.ie/publications/health/health-publications/children%E2%80%99s-disability-services-in-ireland.html>; HSE (2018) Transforming Lives, Working Group 1- Report on the Future Needs for Disability Services. <https://nda.ie/Publications/Disability-Supports/Transforming-Lives.pdf>; Department of Health (2021) Disability Capacity Review to 2032 - A Review of Social Care Demand and Capacity Requirements to 2032. <https://www.gov.ie/pdf/?file=https://assets.gov.ie/154163/8fe32ca7-2154-4fb0-8a41-6931c5f15471.pdf#page=1> [↑](#footnote-ref-12)
13. Gallagher S, Hannigan A. (2014) Depression and chronic health conditions in parents of children with and without developmental disabilities: the growing up in Ireland cohort study. **Research in Development Disability** [↑](#footnote-ref-13)
14. Greene, S., 2010, Growing up in Ireland **Literature Review Number 2 - Review of the Literature Pertaining to the First Wave of Data Collection with the Child Cohort at 9 Years.** https://www.esri.ie/system/files?file=media/file-uploads/2015-07/BKMNEXT260.pdf [↑](#footnote-ref-14)
15. Swift, A., et al (2021) Social-Emotional Difficulties in Irish Children Aged Five and Nine Years: A National, Longitudinal Study. **Children** 8, 656. [↑](#footnote-ref-15)
16. NDA (Collins G. and Doherty, C.) (2014) The effect of a disability on siblings. Presentation to the GUI Conference 2014. https://www.growingup.ie/pubs/the\_effect\_of\_disability\_on\_siblings\_Collins\_and\_Doherty.pdf [↑](#footnote-ref-16)
17. Minister for Children, Equality, Disability, Integration and Youth (2022) An Indicator Set for Better Outcomes Brighter Futures. https://www.gov.ie/en/publication/582092-better-outcomes-brighter-future-indicator-set/ [↑](#footnote-ref-17)
18. Duffy, N. (2021) Opening Statement on the provision of sport and physical activity for people with disabilities in Ireland in line with Article 30 of the UN Convention on the Rights of People with Disabilities. https://data.oireachtas.ie/ie/oireachtas/committee/dail/33/joint\_committee\_on\_disability\_matters/submissions/2021/2021-10-07\_opening-statement-niamh-daffy-et-al-ceo-cara-sports-inclusion-ireland\_en.pdf [↑](#footnote-ref-18)
19. National Disability Authority (2021) Discussion Paper – Supporting the Inclusion of Children with a Disability in Mainstream School Age Childcare [↑](#footnote-ref-19)
20. National Disability Authority (2020) Universal Design in Education and Training – policy landscape in Ireland <https://universaldesign.ie/awards/education/universal%20design%20in%20education%20and%20training%20%E2%80%93%20policy%20landscape%20in%20ireland.pdf> [↑](#footnote-ref-20)
21. National Disability Authority (undated webpage) European Union (Accessibility of Websites and Mobile Applications of Public Sector Bodies) Regulations 2020. <https://nda.ie/publications/communications/eu-web-accessibility-directive/> accessed on the 11 march 2022 [↑](#footnote-ref-21)
22. National Disability Authority (2019) Customer Communications Toolkit for the Public Service - A Universal Design Approach <https://universaldesign.ie/products-services/customer-communications-toolkit-for-the-public-service-a-universal-design-approach/> [↑](#footnote-ref-22)
23. NCSE (2019) Policy Advice on Special Schools and Classes: An Inclusive Education for an Inclusive Society? (progress Report). https://ncse.ie/wp-content/uploads/2019/11/Progress-Report-Policy-Advice-on-Special-Schools-Classes-website-upload.pdf [↑](#footnote-ref-23)
24. Ahead (2021) Students with Disabilities Engaged with Support Services in Higher Education in Ireland 2019/20. <https://www.ahead.ie/userfiles/files/AHEAD_Research_Report_21_digital.pdf> [↑](#footnote-ref-24)
25. Indecon (2019) Review of Career Guidance Final Reporthttps://assets.gov.ie/24951/dffde726604b451aa6cc50239a375299.pdf [↑](#footnote-ref-25)
26. Gallagher, A. et al (2020) The characteristics, life circumstances and self-concept of 13 year olds with and without disabilities in Ireland: A secondary analysis of the Growing Up in Ireland (GUI) study. PLoS ONE 15(3) [↑](#footnote-ref-26)
27. Cosgrove, J. (2018) Educational Experiences and Outcomes of Children with Special Educational Needs: Phase 2 – from age 9 to 13 A Secondary Analysis of Data from the Growing Up in Ireland Study. https://ncse.ie/wp-content/uploads/2018/03/03263-NCSE-EdExps-Children-SEN-FINAL-UPLOAD.pdf [↑](#footnote-ref-27)
28. Banks, J. et al (2016) Parental Educational Expectations of Children with Disabilities. ESRI. Dublin (Commissioned by the National Disability Authority); Mihut, G. (2020) Academic and Socio-Emotional Outcomes of Young People with Special Educational Needs and the Role of Parental Educational Expectations. <https://www.esri.ie/system/files/publications/WP692.pdf> (Commissioned by the National Disability Authority) [↑](#footnote-ref-28)
29. Smyth, E. (2018) The Transition to Primary Education: Insights from GUI Study. ESRI. Dublin (Commissioned by the NCCA) [↑](#footnote-ref-29)
30. Government of Ireland (2015) Comprehensive Employment Strategy for People with Disabilities 2015-2024. https://assets.gov.ie/18906/1120bc6ad254489db9571c74e8572f44.pdf [↑](#footnote-ref-30)
31. http://www.informingfamilies.ie/news/news.275.html [↑](#footnote-ref-31)
32. National Disability Authority (forthcoming) Report on the Operation of the Irish Sign Language Act 2017 [↑](#footnote-ref-32)
33. DCYA in collaboration with CEUD-NDA (2019) Universal Design Guidelines for Early Learning and Care Settings. https://aim.gov.ie/app/uploads/2021/05/universal-design-guidelines-for-elc-settings-introduction-1.pdf [↑](#footnote-ref-33)
34. Ombudsman for Children (2020) Molly Two Years On. Have Tusla and the HSE delivered on commitments to children with a disability in the care of the State? [↑](#footnote-ref-34)
35. NDA (2019) ‘Assessment of CES 2019 actions’ [↑](#footnote-ref-35)
36. Ibid. [↑](#footnote-ref-36)
37. The third and final CES 3-year action plan is currently under development led by DCEDIY disability unit. [↑](#footnote-ref-37)
38. Indecon (2021) “The Cost of Disability in Ireland.” [↑](#footnote-ref-38)
39. State of the Nation’s Children (2020) https://www.gov.ie/en/campaigns/1f703-state-of-the-nations-children/ [↑](#footnote-ref-39)
40. State of the Nation’s Children (2020) https://www.gov.ie/en/campaigns/1f703-state-of-the-nations-children/ [↑](#footnote-ref-40)
41. UNCRPD General Obligations, Article 4. https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities/article-4-general-obligations.html [↑](#footnote-ref-41)
42. UNCRPD General Comment 7 (2018) https://tbinternet.ohchr.org/\_layouts/15/treatybodyexternal/Download.aspx?symbolno=CRPD/C/GC/7&Lang=en [↑](#footnote-ref-42)
43. National Disability Authority (2002) Ask Me Guidelines for Effective Consultation with People with Disabilities. <https://nda.ie/nda-files/-ask-me-guidelines-for-effective-consultation-with-people-with-disabilities1.pdf> [↑](#footnote-ref-43)
44. Department of Children, Equality, Disability, Integration and Youth (2022) State of the Nation's Children. https://www.gov.ie/en/campaigns/1f703-state-of-the-nations-children/ [↑](#footnote-ref-44)
45. Department of Housing, Local Government and Heritage https://www.gov.ie/en/collection/80ea8-homelessness-data/#homelessness-data [↑](#footnote-ref-45)
46. Ahead (2021) Students with Disabilities Engaged with Support Services in Higher Education in Ireland 2019/20. <https://www.ahead.ie/userfiles/files/AHEAD_Research_Report_21_digital.pdf> [↑](#footnote-ref-46)
47. Department of Health, A Vision for Change (DOH 2006); Department of Health, Sharing the Vision: A Mental Health Policy for Everyone (DOH 2020). [↑](#footnote-ref-47)
48. Indecon (2022) Cost of Disability in Ireland (Commissioned by the Department of Social Protection) [↑](#footnote-ref-48)
49. Moloney, C. (2021) Mind the Gap Barriers to the realisation of the rights of children with disabilities in Ireland. Commissioned by the Ombudsman for Children.

    https://www.oco.ie/app/uploads/2021/03/MindTheGap\_OCO\_NUIG\_Disability\_Report.pdf [↑](#footnote-ref-49)
50. Department of Children, Equality, Disability, Integration and Youth (2021) An indicator Set For Better Outcomes Brighter Futures – 2021 Update [↑](#footnote-ref-50)
51. National Disability Authority (2021) Lockdowns Unlock Innovations Report. https://nda.ie/publications/others/research-publications/lockdowns-unlock-innovations-report.html [↑](#footnote-ref-51)
52. Nicholson, E (2021) Experiences of Conducting Remote Assessments for People with Disability. https://www.hse.ie/eng/about/who/cspd/ncps/disability/programme-publications/experiences-of-conducting-remote-assessment-for-people-with-disability.pdf [↑](#footnote-ref-52)