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Joint Committee on Autism
Final Report of the Joint Committee on Autism
June 2023

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- Pat Buckley TD, Sinn Féin
- Joe Carey TD, Fine Gael
- Joan Collins TD, Independents 4 Change
- Joe Flaherty TD, Fianna Fáil
- Joe McHugh TD, Fine Gael
- Marc Ó Cathasaigh TD, Green Party
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- Senator Catherine Ardagh, Fianna Fáil
- Senator Micheál Carrigy, Fine Gael (Cathaoirleach)
- Senator Eileen Flynn, Civil Engagement Group
- Senator Róisín Garvey, Green Party
- Senator Mark Wall, Labour Party

Notes:

Marian Harkin TD was discharged from the Joint Committee by Order of the Dáil on 8th November 2022 at her own request.

Upon her appointment as Minister of State, Jennifer Carroll MacNeill TD ceased to be a member of the Joint Committee on 22nd December 2022.

Joe Carey TD was appointed to the Committee on 7 March 2023.

The Committee wishes to also note its thanks to Ruairí Ó Murchú TD for his frequent attendance at the Committee's meetings and the contribution that he has made to its work.

Joint Committee on Autism



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FOREWORD



Following two Dáil motions calling for increased support for autistic people, the Houses agreed to establish the Joint Committee on Autism with cross-party support. The Joint Committee on Autism was established in February 2022 in the context of limited progress in improving services for autistic people. A number of key issues were identified by the Committee, including delays in Assessment of Need, poor access to assessments and services, the lack of inclusivity in education and a lack of employment supports.

From June 2022 to May 2023, the Joint Committee on Autism has had significant engagement with a variety of stakeholders regarding the provision of services to the autistic community.

Throughout the course of our 23 public meetings and 32 private meetings, myself and my fellow Committee members learned a great deal about the challenges faced by the autistic community and those who support them. The Committee was privileged to hear directly from autistic self-advocates and the families of young autistic people. On behalf of Committee members, we were moved by the honesty of the autistic community and their families as they shared their personal stories. We heard of the barriers that are faced by autistic people as they try to access the services and supports to which they are entitled and which they deserve. We heard of the struggles of autistic people who are confronted by a society which has for too long failed to consider their needs and has not facilitated their full participation. While the Committee is extremely grateful to these advocates, we are also disappointed that they have been forced to share details of their private lives and the challenges they experience with the public. The Committee urges the Government to adopt this report and to implement its recommendations.

The recommendations contained within this report were also informed by a broad range of witnesses including academics, service-providers, policymakers and more.

We are grateful for the considerable engagement which we had with all of our stakeholders. Their expertise is greatly appreciated and it is reflected in this report.

Throughout the course of the Committee's work, several themes emerged across departments and public sector organisations. Among them are an urgent need for greater cross-departmental collaboration, for joined-up service provision, for clear pathways and direct access to services, for accessible information, for comprehensive consultation with the autistic community and for well-resourced public services. More broadly, there is a need for a change in society's approach to autism and disability.

Fiacre Ryan, a young non-verbal autistic writer and student, addressed a public meeting of the Committee in December 2022. In his book *Speechless*, Fiacre writes: "It only seems appropriate to give the same rights given to those without autism to individuals with it. Needing some type of assistance does not make someone less of a person. Try to see past the autism and realise that we are the same inside as others."

There is a need for society to better understand and include autistic people. Moreover, there is a need for urgent action from the Government to address the stigma associated with autism and to improve the provision of services to autistic people.

I would like to thank my fellow Committee members, the Committee's Secretariat, Dr Emily Heery of the Library and Research Service and all of the witnesses who have contributed to the work of the Committee.

The Joint Committee requests that this report is debated in both Houses of the Oireachtas and that its recommendations are implemented by Government.



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SUMMARY

The Joint Committee on Autism has heard about the difficulties experienced by autistic people seeking access to supports and services in areas including disability services, education, social protection, employment, housing and more.

The Committee is concerned by the lack of basic services such as adequate school places, assessment of need and post-assessment supports. The Committee has found that many public services are completely inaccessible to autistic people due to a lack of availability or services that are not designed with autistic people in mind.

There is a clear need for better resourcing within the public sector. The Committee has heard about how understaffing in public disability services, education and planning have created barriers to accessing services which disproportionately impact upon autistic people and disabled people.

While addressing resourcing is an important step in establishing more comprehensive service provision, it is only one part of making services more accessible to autistic people. A change in mindset regarding autism is urgently required across society and in targeted key areas such as health and employment. The autistic community told the Committee about the lack of understanding of autism and the inaccessibility of services, including those which are adequately resourced. It is essential that services are designed with all neurotypes in mind and that services that directly impact on the lives of autistic people are designed in collaboration with the community.

The Committee heard from many advocates – including autistic people and their families – that they have been consistently let down by the State. The Committee recognises that it is difficult for the autistic community to trust that public services will improve when they have been failed so often.

In this context, it is necessary that legislation is enacted to underpin the Autism Innovation Strategy. It is essential that such legislation ensures that the State

publishes an Autism Innovation Strategy at regular intervals, includes the autistic community and their families in its design and that the Minister of the day addresses both Houses of the Oireachtas on its progress.

Introduction

The Joint Committee on Autism was established by Order of Dáil Éireann in December 2021 and by Order of Seanad Éireann in February 2022. The Committee was established to consider matters relating to the services and supports provided by the State for autistic people. As per its Orders of Reference, the Committee sought submissions and held public sessions relating to the following areas:

- Disability services
- Education
- Further and Higher Education
- Health
- Employment
- Social Protection supports
- Housing, public buildings and Universal Design
- Alternative and Augmentative Communication (AAC)

Under its considerations of education and disability services, the Committee also undertook site visits to Ballyowen Meadows Primary School and the Middletown Centre for Autism in Co Armagh. In addition, the Committee commissioned research into international best practice from the Oireachtas Library and Research Service. The Committee learned about the considerable work in relation to autism policy which has been undertaken by the Scottish Government. The Committee also met with representatives of the Scottish Government to discuss the learnings from their review of the Scottish Strategy for Autism and their on-going plans to make Scotland a more autism-friendly country.

Throughout its work, the Committee was honoured to hear the testimony of autistic people and their families. The Committee was privileged to welcome autistic self-advocates and the families of autistic people to an event in the Seanad chamber on 2 March 2023. Autistic self-advocates were welcomed to Leinster House to address Committee members as well as Members of both Houses of the Oireachtas. Autistic

people and their families highlighted the issues which they felt were important. This event encapsulated the need for inclusive engagement with the autistic community when creating policy and legislation that impacts upon their lives.

As the Committee began inviting autistic self-advocates and members of the autistic community to its meetings, it soon became apparent that the built environment of Leinster House was not accommodating of autistic people. Along with the Oireachtas Equality, Diversity and Inclusion team and AsIAM, the Committee began work on a plan to achieve an autism-friendliness accreditation for Leinster House. It is an on-going aim of Committee members and of the Houses of the Oireachtas Commission to make Leinster House one of the first autism-friendly parliaments in the world by December 2023.

The Committee held its first public meeting with representatives of the National Council for Special Education (NCSE) amid on-going public conversation about the lack of suitable school places available to autistic children and children with complex needs and the difficulties experienced by many parents in accessing a place for their child in the Summer Programme 2022.

It was in light of the latter debate that the Committee decided to publish an interim report in November 2022. This interim report made a series of recommendations to the Department of Education to encourage the participation of special schools in the Summer Programme in 2023. Aspects of the Committee's recommendations were implemented by the Department of Education after its own review into the Summer Programme. The Committee remains dedicated to ensuring that every autistic child, particularly those in special schools, secures a place in a school-based Summer Programme without difficulty.

The Committee also remains committed to ensuring that autistic children, adults and their families no longer have to fight or spend a sizeable portion of their income to access the basic services to which they are entitled.

The Committee is grateful to the many autistic people and families of autistic people who contributed to the work of the Committee. The Committee was privileged to hear

directly from people who have been underserved by the State and who advocate on their own behalf and on behalf of their families – in many cases because they have no other option available to them. The Committee heard about the challenges in accessing diagnosis, Assessment of Need (AON), therapeutic and clinical services, medical services, school places, AAC, employment, housing, social protection supports and more. The Committee also heard about the difficulties faced in trying to access some of these services privately as well as publicly, and the considerable personal costs associated with this.

The Committee was shocked and alarmed to learn of some of the statistics that have arisen from research into the costs associated with Autism Spectrum (AS) in Ireland and the effects of the State's failure to provide adequate public services to the autistic community. The Committee heard that 85% of autistic people are either unemployed or underemployed. Moreover, the Committee learned that, from data collected in 2014/2015, the average cost to families of autistic children was €28,464.89 per child per year due to accessing private services, loss of income and informal care. Moreover, data collected in 2014/2015 also showed that the average figure for debt incurred by the families of autistic children was €3,259.

In addition, the Committee also learned of the detrimental impact on the health of autistic people which occurs as a result of inadequate access to services and a lack of user-friendliness in service provision for autistic people. For instance, autistic people have a shorter life expectancy than their neurotypical peers. It is estimated that autistic people die between 16 and 30 years earlier than non-autistic people. Autistic people are also seven times more likely to die by suicide and are more likely to die by almost every common cause of death when compared with non-autistic people.

While the Committee has had ample cause for concern in respect of the provision of services to autistic people in Ireland, it also learned of instances of good practice and achievement in spite of the issues that impact upon service provision. The Committee was particularly impressed by developments in further and higher

education, where institutions are making strides in creating inclusive environments at third level campuses and supporting autistic students in accessing employment after college.

The Committee is also heartened by the autistic community's self-advocacy and interdependence in supporting one another where they have been underserved by the State. While the Committee is disappointed that so many autistic children and adults have not received the services and supports that they deserve, it commends the autistic community and those who support them for their proactive and positive approach to advocacy.

The Committee would also like to acknowledge the work undertaken by the Joint Committee on Disability Matters in its report *Aligning Disability Services with the United Nations Convention on the Rights of Persons with Disabilities*. The Committee welcomes the report's recommendations that a human rights-based approach to disability services be adopted, including in the provision of care to autistic people.

The Committee looks forward to the completion of the work that is being undertaken by the Minister of State with special responsibility for Disability, Anne Rabbitte and the Autism Innovation Strategy Oversight and Advisory Group. The Committee calls for the recommendations in this report to be reflected in the Autism Innovation Strategy and hopes that this strategy will deliver the much-needed commitment to planning and to implementing a cross-governmental approach to autism policy.

Furthermore, it is recognised that the recommendations and policy initiatives featured in this report and in the Autism Innovation Strategy merely represent the initial steps in improving the lives of autistic people in Ireland. The implementation of these policy initiatives will be key in ensuring that Ireland is a welcoming place for its autistic citizens to live in and that our society is one that includes and accepts autistic people for who they are. With this goal in mind, the Committee hopes that the Government will adopt a progressive, rights-based approach to autism policy hereafter. Further to this, the Committee wishes to highlight the importance of consulting with and including autistic people when formulating policy that impacts

upon their lives. It is essential that autistic people are given the opportunity to express their own views and ambitions and that these are accounted for fully in State policy concerning autism.

The Committee also calls for the establishment of an *ad hoc* committee or cross-party group to monitor the implementation of its recommendations and those of the Autism Innovation Strategy. The Committee recognises that the implementation of these recommendations will be key to improving the lives of autistic people in Ireland. For this reason, it is crucial that the implementation of these recommendations is monitored.

Moreover, the Committee calls for the implementation of legislation along the lines of Malta's Persons within the Autism Spectrum (Empowerment) Act, which was passed in 2016. Such a piece of legislation would require the State to publish an autism strategy at regular intervals, establish a committee or monitoring group featuring autistic people to participate in drafting and monitoring the strategy and require the Minister for Disabilities of the day to address both Houses of the Oireachtas on its progress. The Committee believes it is imperative that any autism strategy is underpinned by legislation to necessitate its continuous development and monitor its progress.

The need for further scrutiny

It is important to note that, as a time-limited Committee, some policy areas could not be examined in detail. One area which the Committee was unable to examine in detail is the inaccessibility of the legal system and the Courts Service.

At its public meeting in the Seanad on 2 March 2023, the Committee heard from Mr Nicholas Foote, who identified many of the challenges that inhibit autistic people from accessing the legal system and the lack of supports available.

The Committee notes the submission of AsIAM featured in the [Report on Courts and Courthouses](#) by the Joint Committee on Justice and calls for action to be taken to address the inaccessibility of the legal and courts systems.

Recommendations

The Committee calls on the Government to implement the following recommendations:

Whole of Government:

1. Enact legislation which requires the State to publish an autism strategy every three years, establish a committee or monitoring group featuring autistic people to participate in drafting and monitoring the strategy and require the Minister for Disabilities of the day to address both houses of the Oireachtas annually to provide an update regarding its progress
2. Initiate national autism acceptance campaigns to promote the participation of autistic people in all areas of social and cultural life along with targeted campaigns in key areas such as education, employment and health
3. Initiate consultation with the autistic community and their families to establish how best to collect disaggregated data for the purposes of forward-planning
4. Ensure that the needs of autistic people are taken into account when designing all public services and include the autistic community when designing autism-specific services
5. Establish a dedicated cross-departmental unit in the Department of the Taoiseach to facilitate a whole-of-government approach to autism and to embed joined-up cross-departmental services
6. Ratify the Optional Protocol of the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) without delay
7. Ensure that all government departments develop an autism policy
8. Develop a long-term workforce planning strategy to address staffing issues in disability services, including recruitment and retention of staff

9. Establish a 'One Stop Shop' programme wherein autistic people or those who think they may be autistic can receive information and can link in with the services that they require
10. Implement the recommendations concerning accessibility and disability featured in the Joint Committee on Justice's Report on Courts and Courthouses

Disability Services

11. Establish a single-entry point to children's disability services and Child and Adolescent Mental Health Services for autistic children and disabled children to ensure that children are no longer passed between services
12. Liaise with third-level institutions to develop work placement schemes to attract staff to disability services
13. Initiate a campaign in secondary schools targeting Leaving Certificate students to promote careers in disability services
14. Engage with the relevant professional bodies representing speech and language therapists, occupational therapists, physiotherapists, psychologists and nurses to inform a long-term strategy to address the staffing issues in disability services
15. Rebalance the distribution of resources between staff working on Assessments of Need and staff implementing therapeutic supports
16. Resolve pay parity issues for organisations who provide services under section 39 of the Health Act 2004
17. Attract staff in disciplines relevant to disability services who have the right to work in Ireland to return by subsidising travel costs to return to Ireland
18. Initiate a review of the practice of principals and teachers filling in the Educational section of the Assessment of Need form, taking into account the

views of stakeholders and ensuring that the practice complies with the spirit of the Disability Act 2005

19. Recognise the work of community groups who support autistic people by establishing a distinct funding stream to develop their work and to facilitate the establishment of new autism community groups across the country
20. Develop opportunities for career progression within public disability services for professionals in areas such as Occupational Therapy, Speech and Language Therapy, Physiotherapy, Psychology and more
21. Incentivise working within the public health sector to ensure that fewer professionals leave Ireland and that staff do not feel compelled to supplement their income by working in the private sector
22. Develop a plan that will ensure that public sector health workers are satisfied to work exclusively within the public health sector
23. Roll out suitable autism training for all public health staff to ensure that they can engage with and meet the needs of the autistic community
24. Develop clinical guidelines – along the lines of those developed by National Institute for Health and Care Excellence in the United Kingdom - for undertaking an autism assessment and ensure that they are adhered to by professionals within the public health sector and the private health sector
25. Liaise with the Department of Education and adopt an approach which integrates the School Inclusion Model and the Children's Disability Network Team model to ensure that in-school therapies are available along with community-based services for autistic people
26. Develop and enforce guidelines to ensure that interventions provided to autistic people and disabled people are evidence-based and rights-based

27. Provide adequate financial supports to families who access assessments and supports privately due to their unavailability in the public health system until such time as vacant positions within CDNTs have been filled
28. Increase the capacity within respite care across all Community Health Organisations
29. Provide additional funding to organisations who provide equine therapy and assistance dogs to scale up service provision across the country

Education

30. Provide funding and guidelines to all schools building new premises to ensure that they are built in line with the principles of Universal Design
31. Provide funding and guidelines to all schools to undertake an audit of their buildings and make them autism-friendly
32. Work to reduce class sizes to allow teachers the opportunity to better observe the development of pupils and to reduce distraction and distress for autistic pupils in overcrowded classrooms
33. Engage with the National Council for Special Education to develop a long-term plan to synthesise mainstream and special educational provision in line with the UNCRPD
34. Ensure that children in special classes, autism classes and special schools can participate in mainstream educational classes to end the practice of segregation based on neurotype
35. Update Continuing Professional Development (CPD) to ensure that education professionals, including teachers and SNAs, receive suitable autism training
36. Engage with the National Council for Special Education to establish the number of pupils on reduced school hours and implement measures to reduce the use of such measures

37. Engage with the HSE and the Department of Children, Equality, Disability, Integration and Youth to ensure that children in special schools can access clinical supports in schools until such time as CDNTs are fully staffed and access to services can be reviewed
38. Increase the pay offered to SNAs and teachers for participating in a school-based Summer Programme to incentivise participation
39. Engage with children's disability service providers to foster and encourage the participation of clinicians such as therapists and psychologists in the Summer Programme at an attractive rate of pay
40. Work with the Department of Health to amend the Disability Act 2005 in tandem with the Education for Persons with Special Educational Needs (EPSEN) Act 2004 and include a right to services as well as a right to Assessment of Need
41. Review established practices on transitioning to new schools throughout the education system and provide more guidance and supports for schools in assisting pupils to transition between schools
42. Establish a National Transitions Service to assist autistic children and adults as they transition into primary education, between schools, to secondary education, to university, to employment and all other areas of life
43. Establish a clear pathway to accessing Alternative and Augmentative Communication and assistive technology and ensure that autistic children and adults can access and retain AAC devices and supports throughout their lives
44. Increase the funding allocated to Alternative and Augmentative Communication and assistive technology to ensure that there are sufficient devices available to those who need them as well as training for the families of AAC-users

45. Review Department of Education policy in relation to the role and the priorities of the Middletown Centre for Autism
46. Liaise with the Department of Education in Northern Ireland to negotiate a mutual increase in funding to the Middletown Centre for Autism to expand their services and apply their best practice model nationally
47. Adopt a rights-based approach to the Summer Programme to ensure that it is regarded as an essential service for autistic children and their families
48. Establish an agency or a dedicated section of the Department of Education to manage the Summer Programme and ensure that it is made available in all schools, with the participation of trained external staff where internal staff are unavailable
49. Develop a clear policy to ensure that there is a requirement that interventions provided within the context of special education are evidence-based and rights-based
50. Liaise with the Middletown Centre for Autism to provide continuing professional development training for SNAs and encourage participation by regarding them as additional hours worked under the Croke Park Agreement
51. Include a mandatory module on autism training as continuing professional development for teachers
52. Ensure that all schools that are in receipt of public funding, whether public or private, foster more inclusive practices around autism, including the opening of special classes
53. Design a template or guidelines for schools clearly explaining the steps that should be taken if behavioural challenges emerge in an educational setting and ensure that protocols around restraint and penalisation are stated unambiguously, with a view towards eliminating these practices

Higher and Further Education

54. Liaise with the Department of Health to increase the number of places in third-level courses in occupational therapy, speech and language therapy, physiotherapy, psychology, social work and nursing and work to match these numbers with clinical placements
55. Increase the number of places in third-level courses in planning
56. Establish a scholarship scheme to fund students in third-level courses in disciplines relevant to disability services with a commitment from graduates to work in Ireland for a set number of years
57. Liaise with the Department of Education and Central Applications Office to provide prospective students with information regarding Leaving Certificate results and third level placements in sufficient time to allow for Higher Education Institutions to engage with students who may have need for additional supports
58. Provide funding to Higher Education Institutions to compile sensory maps and provide more autism-friendly tours of campuses throughout the year
59. Provide funding to allow for the model of the Trinity Centre for People with Intellectual Disabilities to be developed further and replicated across Higher Education Institutions
60. Liaise with Higher Education Institutions, the Department of Education, the Department of Health and the HSE to include autism training in Initial Teacher Education (ITE) as well as therapy, nursing and medical courses in third level institutions
61. Provide multiannual funding based on the academic calendar to allow Higher Education Institutions to undertake comprehensive, long-term planning to establish supports for disabled students as well as tailored supports for individual students before the beginning of the academic year

Social Protection

62. Introduce a non-means tested, targeted Cost of Disability Payment for autistic people and disabled people with high levels of expenditure due to their autism diagnosis or disability
63. Introduce a non-means tested, targeted Cost of Disability Payment for the carers to autistic people and disabled people with high levels of expenditure due to their autism diagnosis or disability
64. Introduce specific targeted supports for those with the highest additional costs due to disability, including autism
65. Increase the income disregard for the Disability Allowance and the Carer's Allowance to account for the high costs of disability
66. Recognise the work of carers and the services they provide the State by establishing a pilot scheme for a basic income entitlement or a participation income to replace the Carer's Allowance in line with the recommendations of Family Carers Ireland and the Joint Committee on Gender Equality
67. Establish a grant to assist autistic people and disabled people in paying for larger, one-off expenses
68. Benchmark the rate of the Disability Allowance and other social protection payments to ensure that autistic recipients can achieve a Minimum Essential Standard of Living
69. Undertake consultation with the autistic community on the accessibility of information regarding supports and services provided by the Department of Social Protection and ensure that there is no reduction in supports when those in receipt of Disability Allowance reach State Pension age
70. Undertake a review of the accessibility and user-friendliness of all application forms for disability supports with the autistic community

71. Initiate a review of application processes and their transparency to minimise the rate of rejection of applications for disability supports and care supports
72. Allow those who were previously in receipt of Disability Allowance and have subsequently entered employment to retain their entitlement to a Medical Card and Free Travel Pass, subject to certain limitations
73. Raise the age limit of Domiciliary Care Allowance to 18
74. Adopt a needs-based approach to the Disabled Drivers and Passengers Scheme

Employment

75. Undertake a review of public sector recruitment and employment practices to ensure that they are autism-friendly
76. Provide autism training to all public sector interviewers to address any biases against autistic people and ensure equality of opportunity for employment
77. Ensure that all environments where public employment processes are undertaken (interview offices, examination rooms, waiting rooms etc) are autism-friendly
78. Provide the option of remote job interviews by video call and other reasonable accommodations to prospective employees in the public sector
79. Develop a long-term plan for the State to provide a high-quality public employment service directly to autistic people and disabled people to ensure equal availability of employment services to disabled people across the State
80. Establish a State-run public employment service that builds on the good practice in the field of disability employment and which links autistic people to employers and offers support, guidance and information as well as tailored support services for participating employers

81. Engage with stakeholders including the autistic community and employers and review the Wage Subsidy Scheme and Reasonable Accommodation Fund with a view to promoting uptake of the schemes
82. Liaise with the Department of Enterprise, Trade and Employment to promote the availability and potential benefits of schemes such as the Wage Subsidy Scheme and Reasonable Accommodation Fund to employers
83. Amalgamate and streamline workplace support grants and the Reasonable Accommodation Fund under one fund which employers may draw down for the purposes of accommodating an autistic or disabled employee or prospective employee
84. Initiate a review of the Wage Subsidy Scheme through a rights-based, social lens and identify how best to update or replace the scheme
85. Remove the minimum work hours to access the Wage Subsidy Scheme to allow for people with disabilities to access part-time employment
86. Ensure that all Departments and State Agencies meet their targets to employ autistic people and disabled people

Health

87. Introduce mandatory autism training for all health and social care workers in the Health Service Executive and in Section 38 and Section 39 organisations who provide services on behalf of the Health Service Executive
88. Ensure that understanding autism training is a component in all higher education courses relative to health and social care, including medicine, nursing, dentistry, occupational therapy, speech and language therapy, physiotherapy, social work and psychology
89. Provide funding to health service providers (including general practice and dentistry) to make their services and built environment more autism-friendly

90. Formulate guidelines for autism-friendly service design and built environment design within health services, including general practice, physiotherapy, dentistry and mental health services
91. Direct Child and Adolescent Mental Health Services to cease its practice of refusing to serve children on the basis of an autism diagnosis or a suspected autism diagnosis
92. Initiate an independent review of CAMHS practices in respect of service provision to autistic children and investigate reports of discrimination against autistic children referred to CAMHS
93. Initiate meetings between CAMHS and disability services to establish how best to provide mental health services to autistic children, taking into account the current lack of capacity within CDNTs to provide multi-disciplinary supports including mental health interventions
94. Initiate plans to establish how best to create a pathway for autistic adults to access multi-disciplinary supports, including mental health interventions
95. Offer individual health plans to autistic people, including health check-ups, to ensure that they are supported in accessing health services

Housing, Planning and Built Environment

96. Increase resources for the Centre for Excellence in Universal Design to allow for the Centre to reach its full potential in assisting the State to embed the principles of Universal Design
97. Provide capacity to the National Disability Authority to review the accessibility of information on the websites of government departments and on application forms and support departments in changing or updating information

98. Review the application processes for social housing and other housing supports to ensure that they are accessible to autistic people and disabled people
99. Ensure that autism is regarded as a sensory disability by all Local Authorities for the purposes of accessing prioritised social housing provision
100. Provide adequate grants to allow for sensory rooms to be added to homes and the sensory-proofing of homes for autistic people
101. Ensure that Local Authorities engage with schools to assist in developing suitable sensory provision for autistic children
102. Provide designated funding to Local Authorities to add sensory areas and communication boards to all playgrounds
103. Provide autism training to staff in Local Authorities and ensure that autism is accepted as a condition which qualifies for housing support
104. Incentivise participation in continuing professional development courses in Universal Design and accessibility for architects and planners
105. Liaise with professional bodies within architecture and planning to promote education in Universal Design and the implementation of Universal Design practices
106. Engage with the Office of Public Works (OPW) to implement guidelines on making facilities and sites under their auspices more autism-friendly
107. Provide autism training to tour guides and other public-facing OPW staff at heritage sites and cultural institutions
108. Provide more opportunities for career development in public sector planning to retain planners

109. Recruit a designated Disability Officer in every Local Authority to advise autistic people and their families on accessing supports and assist them to complete the application process, where needed

CHAPTER 1 – Disability Services

Introduction

1. The unavailability of assessments, therapeutic supports and disability services has a wide-ranging impact on every aspect of the life of autistic persons with unmet service needs. While this report will consider a range of subjects including education, health, social protection and care, employment and housing, the Committee has seen that the absence of disability services impacts upon service provision in all of these sectors. While the lack of disability services does not account for all of the challenges that exist in these areas, it must be acknowledged that - by underserving or failing to serve autistic people altogether - there are knock-on effects throughout every aspect of an autistic person's life. This results in an undue burden being carried principally by autistic people and, particularly in the case of children and adults with high support needs, by their families and those, such as teachers, who try to cater for their needs with limited ancillary supports.
2. A range of services fall within the remit of disability services and primary care. These include diagnosis, Assessment of Need (AON) and therapeutic and psychological supports. Some of these services are the foundation upon which autistic persons may access other supports.
3. Autistic people and many organisations who serve the autistic community are welcoming of those who self-identify as autistic. However, there are also many autistic people who feel 'different' from the rest of society and believe that there is something 'wrong' with the ways they think and communicate as they are unaware that they are autistic. To achieve an understanding and acceptance of autism across society, it is essential that autistic people have access to a diagnosis to better understand their own identity and the society of which they are a part.
4. A diagnosis of autism, while not an integral part of the AON process, can also be an important factor when seeking to access services

Children's Disability Services Prior to PDS

5. Children's disability services emerged in an *ad hoc* fashion in Ireland. The majority of services were typically provided by voluntary organisations – sometimes referred to as section 38 and section 39 organisations – who work on behalf of the HSE under section 38 of the Health Act 2004 or ancillary to HSE services under section 39 of the Health Act 2004. Other services were provided directly by the HSE. As services emerged on this basis, the availability of particular services differed from one geographical location to another. As a result, there was an uneven distribution of services throughout the country and few areas in Ireland were in a position to offer the multi-disciplinary approach to therapeutic supports that is required by many autistic children. In essence, the principle underpinning the Progressing Disability Services for Children and Young People (PDS) model is to provide needs-led services as opposed to diagnosis-led services and ensure that there is no longer a 'geographical lottery' determining a child's access to disability services.

Assessments of Need (AON)

AON and the Disability Act 2005

The Disability Act, 2005

9. –(1) Where—

(a) a person (“the person”) is of opinion that he or she may have a disability, or

(b) a specified person (“the person”) is of that opinion in relation to another person and the person considers that by reason of the nature of that other person's disability or age he or she is or is likely to be unable to form such an opinion,

the person may apply to the Executive for an assessment or for an assessment in relation to a specific need or particular service identified by him or her.

6. Every child who suspects that they may have a disability - or is thought by another person that they may have a disability - has a statutory entitlement to an Assessment of Need under the Disability Act 2005.
7. AON is a process which seeks to identify the needs – both educational needs and health needs – of a child who is suspected of having a disability. Autism Spectrum is regarded as a disability for this purpose.
8. In 2020, the Office of the Ombudsman for Children published Unmet Needs¹, a report which was instigated by the large number of complaints received by the Ombudsman for Children in relation to difficulties in accessing AON.
9. In the report, Dr Niall Muldoon, the Ombudsman for Children, calls for a review of the Disability Act 2005 along with the EPSEN Act (The Education for Persons

¹ [Unmet Needs \(2020\) - OCO](#)

with Special Educational Needs Act 2004). In this report, Dr Muldoon states that the diagnosis-led model is incompatible with the holistic, needs-led approach recommended by the United Nations Convention on the Rights of the Child (UNCRC).

10. The report describes how the Disability Act 2005 prioritises the identification of a diagnosis for children over the identification of their needs:

“As enacted, the 2005 Act mechanism is an assessment of the need for services, rather than an assessment of the health and development needs of the child or young person. The only gateway to access these services is through a disability finding. For this reason, if an Assessment Officer finds that a child does not have a disability, a Liaison Officer cannot provide a Service Statement, regardless of the child’s other identified needs. The 2005 Act is a diagnosis led, rather than a needs led, model.”

11. As such, the Ombudsman for Children states that such an approach can reduce a child to their disability and the developmental needs of children are not prioritised.
12. Prof Malcolm MacLachlan of the HSE (Health Service Executive) echoed this point, stating that – notwithstanding the importance of diagnosis for one’s personal identity - “the latest research strongly suggests we should be addressing our people's needs rather than focusing more narrowly on their diagnoses.”
13. The Committee recognises the importance of diagnosis, including for children availing of the AON process, but affirms its view that a needs-led approach should be taken to AON.
14. The Committee echoes the Ombudsman for Children’s recommendation for a review of the Disability Act 2005 along with the EPSEN Act, particularly within the

context of the rights-based framework outlined in the UNCRC and the United Nations Convention of the Rights of Persons with Disabilities (UNCRPD).

15. Article 4.3 of the UNCRPD states that

“In the development and implementation of legislation and policies to implement the present Convention, and in other decision-making processes concerning issues relating to persons with disabilities, States Parties shall closely consult with and actively involve persons with disabilities, including children with disabilities, through their representative organizations.”

16. The Committee recommends that, as per Article 4.3 of the UNCRPD, the Disability Act 2005 is reviewed in close consultation with the autistic and disabled communities.

The Function of AON

17. At present, there is a perception that AON, as a process, should function as a key to unlocking services for autistic and disabled children. At a meeting of the Committee with representatives of the HSE, Mr Bernard O'Regan, Ms Mary Kelly, Mr Brian Higgins and Prof Malcolm MacLachlan told the Committee that there is a statutory right to AON but it is not a requirement for the purposes of accessing services.

18. Members have related instances in which members of the public have been informed that an AON is necessary for the purpose of accessing services or supports, for instance permission to utilise a technological support in State examinations.

19. However, representatives of the HSE maintain that an AON is not required to access services, however some services may wrongly be withheld by providers because a child has not received an AON. Prof Malcolm MacLachlan stated that a “custom” has developed wherein an AON is being pursued unnecessarily for the purposes of accessing services.

20. At a meeting of the Joint Committee on Children, Equality, Disability, Integration and Youth in 2022, Ms Angela O'Neill of the HSE told that Committee the following:

“It is really important that parents realise they do not have to go through an assessment of need to access services. It is not the gateway to services. With the assessment of need process, a desktop assessment lasting at least three months happens before any referral is made. Parents can pick up the phone and arrange a direct referral to any team. It is really important to get that message out to families. Assessment of need is not an absolute requirement. It is an option that parents may choose to avail of but they do not have to go through that route to access any of our health services.”²

21. It behoves departments and agencies of the State to clarify to public service providers what evidence is genuinely required where a child with a service need seeks to access that service. Services should not be withheld or delayed on the basis that a child does not have a completed AON report or diagnosis.

22. Notwithstanding that services should be easily accessible to those without a completed AON or diagnosis, it is also imperative that autistic children and their families are not discouraged from accessing an AON where it is suspected that the child may have additional support needs.

23. At a meeting of the Committee on 14 February 2023, Dr Muldoon said that “assessments of need are crucial to figuring out what children need to be the best they can possibly be and to allow them to thrive in life.” The Committee affirms its belief that children have an entitlement to access the highest possible standard of services and supports. Moreover, it affirms that any review of the Disability Act 2005 should not dilute or diminish the statutory entitlement to an AON nor should

² [Debate of the Joint Committee on Children, Equality, Disability, Integration and Youth - 22, March 2022](#)

it discourage young autistic people and those who care for them from seeking an AON.

Delays in Accessing AON

24. There are significant delays in accessing AON. There is a statutory entitlement to receive a completed AON report six months after it is first requested. However, the Committee has heard evidence that some applicants are waiting as long as three years to access AON. In December 2022, there were in excess of 4,000 assessment of need applications overdue. The Committee has heard that prior to the introduction of Preliminary Team Assessments (PTA) – which will be discussed in greater detail in the subsequent module - 91% of reports were completed outside of the six-month time limit.
25. The AON process appeals to autistic children and their families as – where a full assessment of the applicant’s developmental needs is undertaken – it provides for the identification of the supports a child requires to thrive. As stated by Dr Niall Muldoon, the AON is crucial in this regard. Ms Aisling Byrne of DCA Warriors told the Committee that the view that the AON process can provide the best outcomes for children is attractive to their parents: “It sets out the gold standard of service requirements. This allows a family to identify and plan for the needs of the child.” Irrespective of the ‘necessity’ or otherwise of AON when seeking services, high demand for AON is to be expected as parents go to great lengths to provide the best possible outcomes for their children. In addition, Ms Aisling Byrne identified that families feel more secure accessing services with a completed AON report due to its statutory footing.
26. In light of this, the Committee is disconcerted by reports that the HSE has made efforts to discourage autistic and disabled children and their representatives from accessing AON. As DCA Warriors told the Committee:
- “It is apparent from feedback we receive from parents that when they contact the HSE for advice on the assessment of need process they are being advised by HSE staff that they do not need to apply for assessments of need and that they

will receive everything they need from children’s disability network teams. This is a worrying development.”

27. While the Committee appreciates the scale of the backlog of AON applications and recognises a need to focus resources on service delivery, it is not appropriate for the HSE to discourage prospective applicants from making applications.

Preliminary Team Assessment (PTA)

28. The Committee wishes to voice its view that lessons must be learned from the High Court judgement on the Preliminary Team Assessment (PTA) process. It is imperative that the HSE consults with the relevant professional bodies when designing or restructuring models of service delivery. The need for consultation with professional bodies was made clear in the context of the PTA process. The PTA process was adopted by the HSE as a means to address a sizeable backlog of applications to the AON process. Over 10,000 assessments were completed under the PTA process and many of the children affected will require a full diagnostic assessment.³ As a result of the High Court decision that the PTA process does not fulfil the HSE’s obligations under the Disability Act, a number of these 10,000 children will need to be re-assessed. The Psychological Society of Ireland (PSI) advised the Committee that they understand that “just under 5,000 of these need an autism diagnostic assessment but there may be more.”

29. A Standard Operating Procedure (SOP) was introduced by the HSE in January 2020, which stated that the full diagnostic assessment of children would be replaced by a much shorter process. This new process was comprised of a desktop assessment, followed by a preliminary team assessment which was time-limited to 90 minutes. The resulting report did not provide families with a

³ [High Court Judicial Review C.T.M. \(A Minor\) Suing by His Mother and Next Friend v The Assessment Officer the Health Service Executive](#), Record No. 2021/405 JR

diagnosis and instead referred children on for further assessments in the majority of cases.

30. Many of the issues identified in the judicial review decision in the High Courts had been cited by the Association of Occupational Therapists of Ireland (AOTI), the Irish Association of Speech and Language Therapists (IASLT) and the PSI as concerns prior to the rollout of PTA. Dr Louise Higgins of the PSI told the Committee:

“All our professional bodies submitted serious concerns regarding the PTA. It was recognised that this was not compliant with the Disability Act and that a PTA is effectively a screening assessment. The Disability Act is designed to identify the support needs of a child. We knew the screening assessment was not in the best interests of children and that it would not answer questions or provide a comprehensive assessment of a child's needs. This was very clearly outlined by all our professional bodies. However, it was a system that was pushed through.”

31. In addition, Mr Odhrán Allen of the AOTI stated

“I will point out that nothing has happened since the High Court ruling that would in any way assure AOTI. I am sure our colleagues in the other professional bodies agree that something in a similar spirit with a different name could happen again. There is nothing that would reassure us that the same mistake will not be made by the HSE.”

AON and Access to Services

32. At present, the capacity of the HSE to complete AON applications is in tension with their propensity to deliver therapeutic interventions within disability services. Those staff who are qualified to perform AON are the same staff who provide interventions: psychologists, occupational therapists and speech and language therapists. As stated by Dr Karen McAuley of the OCO, the exigencies of the current situation have created “a narrative in broad terms which is about assessment versus services.” This narrative has emerged in large part due to the understaffing of CDNTs (Children’s Disability Network Teams) under the present

model of PDS (Progressing Disability Services), which will be discussed in the next module.

33. Bernard O'Regan of the HSE told the Committee that he would welcome a review of the Disability Act 2005, with the intention of providing a statutory right to services as this would establish a parity between a right to an assessment and a right to access services. Mr O'Regan suggested that due to the advantageous status of AON on as a statutory right, it is necessary for the HSE to prioritise it over the provision of therapeutic supports: "What we are suggesting is an enhancement of the Act so that it incorporates a right to services as well as a right to assessment." Mr O'Regan added that "until we equalise the right to an assessment with the right to a service, there will be a disproportionate orientation of one towards the other."

34. Ms Aisling Byrne of DCA Warriors suggested that the provision of assessments and the provision of services should not be pitted against one another as conflicting aspects of the HSE's responsibility and operations.

"DCA Warriors often hear complaints from clinicians that they spend too much time assessing children and not enough time providing services. Respectfully, this misses the point. The children who apply for assessments need them. Those assessments need to be done properly. After children's needs are identified, they need to be given appropriate services in a timely manner. Assessments of need and the provision of timely services are not mutually exclusive."

35. Dr Niall Muldoon shared his view that the "HSE has taken a certain interpretation that puts all the investment into assessments of need and services are not prioritised." Dr Muldoon continued "We need to move in a new direction whereby children get access to services while being assessed." The Committee has also received submissions and heard from parents who have indicated that rather than their children receiving supports directly from therapists, parents are being instructed by therapists on how to provide therapeutic intervention to their

children. The Committee is very concerned by this development as parents should not be expected to provide therapeutic interventions to their own children, particularly as they are not trained to do so.⁴

36. The Committee shares the views of the Ombudsman for Children that, notwithstanding the importance of AON, the HSE must begin to redirect some resources to service provision. Under the present model of HSE service delivery within children's disability services, those AON applicants who receive completed reports identifying their needs cannot avail of the therapeutic supports that they require due to under-resourcing in this area. While there is a statutory right to assessment and no statutory right to services at present, this should not be interpreted by the HSE as a mandate to neglect post-assessment service provision in favour of AON. The Committee welcomes the position of HSE representatives that the Disability Act 2005 should be reviewed and that a statutory right to services should be considered as a part of that review. However, the Committee does not accept that the statutory position of AON necessitates the neglect of service provision.

Provision of Children's Services

Progressing Disability Services

37. The Committee is concerned about the rollout of the 'Progressing Disability Services for Children and Young People' (PDS) model of service provision for children with disabilities. The Committee has heard from witnesses including the parents of autistic children, disabled persons organisations (DPOs), the professional bodies for therapists and psychologists, the Office of the Ombudsman for Children and the Office of the Ombudsman.
38. Many witnesses have praised the principles behind PDS and the aims of the plan on paper. Mr Ódhrán Allen of AOTI told the Committee that "In essence, we were supportive of the PDS model, but there was no fidelity to that model in its

⁴ Submission of the National Association Boards of Management in Special Education (NABMSE)

implementation.” Ms Rosalind Noël, senior Occupational Therapist (OT) and member of the AOTI management team, added

“The PDS model is based on a child- and family-centred approach. We feel that is a very good start for a model. We agree with that approach. However, it has not been implemented in such a way as to allow us to work within that model.”

39. Ms Áine Lawlor of the IASLT added “we would agree that the model which focuses on the child and takes away access based on a diagnosis is a good model... At its heart it is a model that supports the child and we all support that.”
40. However, witnesses including those quoted above were also in agreement that the implementation of PDS was unfaithful to the principles which underpin it and that sufficient planning had not taken place to allow the model to be successful.
41. In particular, a historic underfunding of disability services and the under-resourcing of the sector meant that there were insufficient levels of available staff to meet service demand. A lack of workforce planning and the lack of consultation with the relevant professional bodies have been identified as major flaws in the implementation of PDS by several witnesses. The Ombudsman for Children, Dr Niall Muldoon said of PDS that
- “Somebody decided to force it through regardless of the clear legal objections to it and the possible constitutional issues. It was forced through without extra support, resources and manpower to make it happen properly. That is where we find ourselves now. Some 4,000 people are waiting for an assessment of need.”
42. The comments made by the Ombudsman for Children in respect of a lack of adequate consultation regarding PDS echo those made by the professional bodies of therapy and psychology in respect of PTA.
43. Moreover, the same professional bodies told the Committee that there was a lack of consultation in the process of implementing PDS and, as a result, the programme has been unsuccessful for both service users and service providers.

The AOTI stated that as a result of the failure to plan the implementation of PDS, professionals are choosing instead to work in the private sector. Ms Áine Lawlor of the IASLT added that as a result of this exodus, more demand is placed on the therapists who remain in the public sector which, in turn, results in more difficulties in training graduates within disability services.

44. Understaffing is the primary reason for the lack of services under PDS. Mr Bernard O'Regan of the HSE told the Committee that there are between 830 and 850 vacant therapists roles within CDNTs in Ireland. Mr O'Regan added that this equates to a vacancy proportion of 28%. Greater workforce planning is required within the HSE to ensure that staffing levels are sufficient to meet future demand.

45. The *Disability Capacity Review to 2032* was published by the HSE in 2021.⁵ The Review states that

“HSE estimate that roughly 3.5% of the child population require specialist disability input from multidisciplinary children’s Disability Network Teams while a further 0.5% with non-complex needs (or complex needs requiring single discipline rather than interdisciplinary team input due to their disability) are likely to require Primary Care episodic interventions.”

46. The Review goes on to state that

“There is no comprehensive data on the number on people with a physical or sensory disability who get therapy services; on the number of staff delivering a specialist therapy service to adults; nor on access to primary care teams. So the principal approach has been to estimate what proportion of existing service levels would be required to tackle current unmet need and address the likely changes in the size and age composition of the disability population, and to apply that percentage change to the current therapy services budget.”

47. The lack of adequate data-gathering on the number of autistic people in Ireland and the lack of a reliable prevalence rate of autism limits the ability of the HSE to

⁵ [The Disability Capacity Review to 2032](#), HSE

install a programme of effective workforce management. However, based on the metrics utilised in the Review, it establishes that the highest service deficits are in dietetics, psychology and occupational therapy, where service needs to be doubled to satisfy current need. Additionally, services in speech and language therapy, physiotherapy and social work needs to increase by two thirds to address current unmet need.

48. Understaffing within CDNTs is a long-term problem which will require long-term solutions. It is also a problem which is cyclical in its nature – CDNTs are understaffed at present, creating more pressure on staff which results in an exodus from the public sector and makes it more difficult to train new staff into CDNTs and to have a positive experience of their work. While the extent of understaffing within CDNTs is a large issue, Dr Niall Muldoon has suggested that the HSE should embrace the opportunity to undertake strategic long-term planning as there is not a public expectation for an overnight solution or a quick fix. Dr Muldoon told the Committee:

“When we are talking about what good looks like in providing for our children with disabilities, whatever that disability is, we need to know what that is. What happens in the HSE, the Department of Health and whoever else is engaged with it is they look at what is good with what they have there. They try to build around the system and staffing they have. The pragmatism takes over from reality and what we want to move towards. Universal design, human rights and children’s rights are about providing the best possible system for those individuals. We need to get to a stage where we support and promote our civil servants and policymakers to decide what good is.

...

Invest now and look at the time and energy needed for what good looks like and then provide the money towards that. Then everybody has a clear path. The pressure on the HSE must be phenomenal if it is only trying to fix every three

months. However, what if someone says, “I have a bit of space because everybody knows I cannot fix it in three months, but I need this for the next five years”? There is a sea change to be made in that regard.”

49. The Committee believes that the HSE and the Department of Children, Equality, Disability, Integration and Youth (DCEDIY) must begin work immediately to assess the extent of staff shortages across disability services and make long term plans to resolve these issues.

Staff Shortages in CDNTs

50. There are 91 CDNTs across 9 Community Healthcare Organisations (CHOs) in the State. The average national vacancy rate of positions in CDNTs is 34%. Staff shortages across the health service have a consistent detrimental impact on service-provision. As mentioned in the previous module, staff shortages have had a significant impact on the roll-out of PDS.
51. The availability of services is also inconsistent across CDNTs at present. The lowest vacancy rate is 19% in CHO 3 whereas the highest vacancy rate is 43% in CHO 8. As a result, there are fewer services available in some CHOs compared to others. Moreover, different approaches are also taken to service delivery. For instance, within some CDNTs, there is a greater focus on upskilling and training parents compared to other CDNTs where there is more direct interaction between clinicians and children.
52. Difficulties in recruiting and retaining staff are impacting upon provision across the health service more generally. The HSE and many organisations which provide health services under section 38 and section 39 of the Health Act 2004 recruit from the same pool of professionals. As a result, there is a competition to recruit staff between children’s services, adult services, section 38 organisations, section 39 organisations and other sections of the HSE.
53. It is notable that some section 39 organisations experience particular difficulty in recruiting and retaining staff due to issues of pay parity. Mr Michael Hegarty of Liskennett Equine Therapy Centre told the Committee:

“Our teams are certainly down staff. We are down by possibly 25% to 30% of our workforce and the staff that are there are trying their best to plug that gap at this point in time. It is also fair to say that those staff are getting tired. In relation to section 39 workers, there is a 33% attrition rate each year.”

54. In addition, factors external to the health service are also impacting upon recruitment and retention within the area of services for autistic people. Mr Hegarty identified that “many therapists, newly qualified nurses, healthcare assistants, social workers, etc., are now heading to Australia and Canada. When we do exit interviews with staff we hear that they are going to travel.”
55. Staffing and recruitment are perhaps the largest challenges for the provision of services for autistic people and, for this reason, they must be prioritised by the HSE and the whole of Government.

Addressing Staff Shortages in the Health Service

56. The HSE and the DCEDIY must formulate plans for short-term and long-term solutions to the crisis in staffing within disability services immediately.
57. In the short term, the neglect of post-assessment services due to the prioritisation of AON must be addressed by redistributing resources into post-diagnostic service provision to ensure that more services are available after a child’s needs have been identified. Likewise, a targeted recruitment campaign must be undertaken to address the imbalance in staffing between CHOs. As mentioned previously in this chapter, there is a high vacancy rate in disability services across the country. However, areas such as CHO 8, which has only 57% of its vacancies filled, requires additional staff more urgently. For this reason, a targeted campaign should be undertaken to address the inequality of access to services due to geographical location.
58. Additionally, the HSE and the DCEDIY must review staffing within disability services for adults and evaluate the number of staff required in this area.

59. In respect of long-term plans to address the staffing shortage in disability services, it is essential that the HSE and the DCEDIY begin to consult with the relevant stakeholders, including professional bodies. Workforce planning must be undertaken in light of the *Disability Capacity Review to 2032*, taking a long-term approach to staffing needs rather than a reactive approach to problems as they emerge.
60. The two primary aspects of the staffing crisis are challenges in recruitment and challenges in retention. While these problems interface with one another, they will each require their own solutions.
61. An important step to addressing recruitment in the long term is increasing the number of places on third level courses in nursing, psychology, occupational therapy, speech and language therapy, physiotherapy and social work. An increase in graduates will go some way to ameliorating staffing issues in the coming years. However, it is also important that an equal number of clinical placements are developed in line with course places. For this reason, the HSE and DCEDIY must begin liaising with the Department of Further and Higher Education, Research, Innovation and Science and HEIs to plan for this. The Minister for Further and Higher Education, Research, Innovation and Science, Simon Harris, indicated a willingness to do so, telling the Committee:

“We agreed to increase the number of medicine places through the CAO, Central Applications Office, by 200 over the coming years. We provided 60 in September and another 60 are due to be provided next September. We have now agreed with the Department and with the Department of Children, Equality, Disability, Integration and Youth to do the same on therapy posts. That is absolutely vital. I am very much aware that there are issues with retention, but there are also issues to do with training enough people, which we are not doing currently. It is easy to create college places in some areas, but where a clinical placement is required, it does require my Department to do its bit in getting the universities to provide the place.”

62. Minister Harris also highlighted the importance of interdepartmental coordination when addressing the staffing shortage in disability services.

“We could fund the universities and they would create the places but... every place must be matched with a clinical placement and that is why it requires that working-together piece.”

63. In addition to these measures, the HSE, DCEDIY, DFHERIS and HEIs should consider the development of postgraduate programmes which would allow for quicker entry of graduates into areas such as psychology and therapy, as suggested in the final report of the Joint Committee on Disability Matters.

64. DFHERIS and the HSE may also consider incentivising enrolment in psychology and therapy courses by subsidising fees or remunerating students at an attractive rate for the duration of clinical placements. Moreover, the HSE may attract staff from abroad, including those who trained in Ireland, to work in the HSE by subsidising international travel to the country.

65. In respect of staff retention, consultation with professional bodies and other stakeholders is of particular importance. Increasing staffing levels and reducing the pressure on current staff will go some way to creating a more attractive work environment for psychologists, therapists, nurses and other staff.

66. In addition, the HSE must foster a culture of inclusion and consultation with staff in disability services and across the health service. Professional bodies have highlighted to the Committee that their members have raised concerns about expectations that they provide services that are not in line with their ethical standards. The views of professional bodies and their members must be taken into consideration when procedural changes are being devised.

67. It is also important that any anomalies concerning pay, particularly in respect of Section 39 staff, are addressed.

68. Workforce planning to address both recruitment and retention must begin urgently and must take into account the views of all relevant stakeholders, including professional bodies.

Other Children's Health Services

Animal-Assisted Intervention

69. Evidence-based alternative therapies and animal-assisted interventions should be better funded by the Government and should be widely available across the country. In particular, the Committee believes that increased funding should be made available to facilitate research into the benefits of alternative therapies, to potentially allow for the upscaling of animal-based therapies and supports and to facilitate a standardisation of processes.

70. A needs-based approach to autism necessitates investment in evidence-based supports which address the needs of a child, including animal-assisted interventions such as equine therapy or animal-assisted supports such as autism assistance dogs.

71. The inclusion of animals in interventions for autistic people is an increasingly common practice internationally. In recent years, more research into this area has been undertaken and certain benefits have been identified.⁶ It is noteworthy that, while several studies have noted the benefits of animal-assisted therapies, many of these studies also highlight that these are still emergent interventions that require greater scrutiny. Equally, it is notable that horses are the most researched species in this area, followed by dogs and that "All identified studies focused on children, with no research on adults."

72. In addition, it is noteworthy that animal-assisted interventions are not regarded as "stand alone" or "complementary" interventions, rather they are referred to as "potentially promising enrichment interventions" in one study. Additional research

⁶ [Research on animal-assisted intervention and autism spectrum disorder, 2012-2015](#), *Applied Developmental Science* (2017)

into the area is required before animal-assisted intervention can be established as an evidence-based practice.

73. Another matter raised in relation to animal-assisted interventions is the lack of standardisation among current practices. For instance, it is noted, in relation to equine therapy, that

“not only do practitioners and participants in such studies lack a shared agreement of what Equine Assisted therapy entails, there is also a lack of clarity between theoretical underpinnings of psychological theory behind the therapy and its practice. Therefore, it could be argued that until there is clearer understanding of the process and mechanisms of such therapies, it is not possible to test the interventions empirically.”⁷

74. In respect of the benefits for autistic people, the primary improvement that has been identified “unanimously” in 22 studies is increased social interaction. One paper by Dollion et al. states that:

“Reports on the effects of the addition of an animal to the therapeutic setting confirm that the presence of an animal facilitates interactions with a therapist, increases children with ASD’s social interactions and prosocial behaviours during a session, reduces their stress, anxiety and the expression of negative behaviours; improvement of the children’s language, communication and social skills can also be observed.”⁸

75. The Committee believes that the HSE should consider increasing investment in equine therapy. Moreover, the Committee believes that the HSE should engage with equine therapy providers and seek to collaboratively standardise their processes to ensure consistency of services.

⁷ [It’s not just about the horses at Equine!](#) Exploring perceptions of Equine Assisted therapy with adolescents with autism, their staff and therapy providers.

⁸ Dollion et al. ‘Characterization of Children with Autism Spectrum Disorder’s Interactions with a Service Dog during Their First Encounter.’ *Anthrozoös*, 2022.

76. The Committee believes that the State must also invest in organisations providing autism assistance dogs, such as Autism Assistance Dogs Ireland (AADI). Representatives of AADI told the Committee that they do not receive funding from the State. This is of particular importance as their services are oversubscribed. Nuala Geraghty of AADI told the Committee that 19 dogs were placed with families in 2022 while 199 applicants were unsuccessful. It is clear that State funding is needed to increase the capacity of organisations such as AADI to provide assistance dogs to autistic people.

Respite Care

77. Respite care is the temporary care of a person with support needs to provide relief to their usual caregiver or family. The purpose of respite care is to allow a disabled person's carer or carers to take a break and to mitigate the risk of burnout. Many carers have identified that care is a 24-hour job and respite is essential to ensuring that they are able to support the person for whom they care. There are several forms of respite care including residential care and non-residential care, such as day breaks and overnight stays. The Summer Programme is regarded as a form of respite care for many families of children with complex needs. Further information can be found regarding the Committee's work on the Summer Programme in Chapter 2: Education of this report as well as the Committee's Report on the Summer Programme 2023 and Report on the Survey of Special Schools about the Summer Programme 2023.

78. Respite care is typically provided by section 38 and 39 organisations. Respite provision is under-resourced and in high demand in Ireland, with very limited provision in some CHOs or no provision whatsoever in some areas. The Committee believes that there is a need for urgent action to increase the provision of respite care as well as a need for forward planning of respite provision across all of the CHOs in the State. The Committee believes that consideration must be given to how respite service capacity can be increased in collaboration with current service providers.

Adult Services

Access to Diagnosis as an Adult

79. There is no public pathway for adults to access an autism diagnosis except in very rare circumstances on an *ad hoc* basis. Cír Doyle of Neuro Pride Ireland described their experience of seeking a diagnosis as an adult as “very difficult and taxing”, adding that “You essentially have to be a suicide risk before it is considered.”

80. While the Committee welcomes the HSE’s move towards a needs-led model of disability service provision, it is important that access to diagnosis is not ignored in the process. As mentioned earlier in this chapter, an autism diagnosis can be of great importance to people as a matter of identity. This may be the case now more than ever before as many members of the autistic community in Ireland are vocal self-advocates and there are many active autism community organisations in the State – though many groups welcome those who self-identify as autistic as they have not received a formal diagnosis. Nem Kearns of Neuro Pride Ireland highlighted the importance of feeling accepted and valued by peers.

“Something we hear time and again from our new Neuro Pride Ireland members, whether they are in their teens or past retirement age, is that our community is the first place in their lives they have felt able to be truly themselves. Many cry or are overwhelmed at their first experience of something every person should experience by right – being accepted and valued for who they are.”

81. While the Committee is firm in its belief that all autistic people must be accepted and valued by society, it is aware that there is much work to do to achieve this goal. However, it is clear that understanding one’s diagnosis can be empowering and can encourage autistic people to engage with their community and seek their support.

82. Conversely, autistic people who have not been diagnosed can feel misunderstood and alienated from the rest of society. A particular challenge for

some adults who think that they may be autistic is the withholding of a diagnosis on the basis that they are perceived to be successful in certain aspects of their lives. Nem Kearns told the Committee:

“We still hear accounts from parents who are told by their GP that girls cannot get autism and, worryingly frequently, we hear from autistic adults, disproportionately women, who are informed that although they meet the diagnostic criteria during their assessment, their practitioners decided to withhold their diagnosis because they were in a romantic relationship, have children or have completed third level education.”

83. Davida Hartman added that:

“The issues Nem raised about GPs and other professionals having outdated views of the autistic experience is very much what we hear every single day. Many people coming to the practice would say they think they are autistic and asked their GP and various other people about it but all those professionals would have said they could not be autistic, that because they are married, have kids and are doing okay, they are not autistic, even if they tick all the boxes. There are very outdated views out there among professionals who actually really want to help.”

84. As Chapter Five of this report, on the topic of Health, will discuss in further detail, outdated views of autism among health professionals are of particular concern to the Committee as there are a range of health implications associated with autism. A lack of awareness of an autistic person’s neurology can result in a failure to identify increased health risks. Ms Davida Hartman of the Adult Autism Practice told the Committee that “Being diagnosed late in life has serious and life-threatening implications for this minority group who experience high rates of self-harm, eating disorders, and death by suicide.” For this reason, it is essential that clinicians are well-trained in autism and that barriers to accessing a diagnosis are removed.

Access to Disability Services as an Adult

85. There is no public pathway to access an assessment of needs or to access community-based disability services for autistic adults in Ireland. As Nem Kearns told the Committee

“There are no diagnostic services and if you are diagnosed, there is nothing after that. There are cross-disability things that a formal diagnosis can help you access but there are no guarantees. These could be accommodations in the workplace, in third level education or possibly when applying for disability allowance or something like that. However, there are no autistic supports beyond residential and disempowering, that is, institutional care, and institutional residential support. There is nothing to support autistic people in their communities and help them to live their best lives.”

86. As discussed earlier in this chapter, staffing deficits in children’s disability services has resulted in a tension between the completion of AON applications and the provision of services, which is weighted in favour of assessments due to its statutory footing. Similarly, the high vacancy rate within disability services has resulted in a situation wherein adult services are under-resourced as children’s services are prioritised. The *Disability Capacity Review to 2032* states that “Disability service providers report that children’s therapy teams under Progressing Disability Services have been staffed at the expense of adult services.” However, the same report identifies that there will be increased demand for adult services going forward due to an ageing population and demographic changes.

87. This issue is of particular concern as children face a cliff-edge when they enter adulthood, as the few services they may be able to access as children are no longer available to them as adults.

88. In 2017, the National Disability Authority (NDA) published a document titled *Good practice in supporting adults with autism*. In this report, they identify the

need to invest in children’s services and disability services to improve outcomes later in life: “There is currently an underdeveloped service response for adults with autism.”

89. The report continues:

“This is partly due to the lack of knowledge of the number of adults with autism, their location and their needs. Funding of services tend to be relatively short term without thinking of the longer term benefits that may accrue, for example, investing in a child with autism will pay dividends as an adult. The concept of spending now to save later or to achieve savings in another sector is not always encouraged and can be challenging for policy makers.”

90. While investment in the development of autistic children early on will benefit them later in life, it is still important to invest in adult diagnosis and adult service provision, particularly within the context of an ageing population. Many autistic adults have not been formally diagnosed and many autistic adults are unable to access services publicly or privately at present.

Improving Disability Services for Adults

91. As diagnostic and post-diagnostic services for autistic adults are largely non-existent in Ireland, there is an opportunity to design a new model of needs-led service provision. One such model identified by the NDA in their report on good practice is that of a ‘One Stop Shop’.

92. One of the issues facing autistic people and those who believe that they may be autistic is a lack of clarity around where they can go to access information, a diagnosis or other services. While charities such as AsIAM provide guidance, an information line and other supports to the autistic community, there is no public service where autistic people can get information on how to access other services in Ireland. One Stop Shops would allow autistic people and those who wish to access a diagnosis an easy access point for information on where to access services.

93. In addition, One Stop Shops could provide basic services to autistic people in the community. Autism is a heterogeneous condition wherein some autistic people may have higher support needs than others or a co-occurring intellectual disability while others may require minimal supports or live independently. It is estimated that 50% of autistic people have a co-occurring intellectual disability while another 50% do not. For this reason, a needs-led approach is required to ensure that all autistic persons can access the supports that they need at the right time and that specialist supports are reserved for those with high support needs.
94. Ms Davida Hartman of the Adult Autism Practice identified that it is very difficult for autistic people to identify and access the services they need at present. She told the Committee that
- “Autistic people are within every service. The line “We don’t deal with autism”, so frequently doled out, is exceptionally unhelpful not only for autistic people who are sent from one waiting list to another, but for the services themselves who could potentially see a reduction in the need for their services if people were correctly identified.”
95. A model has been piloted in Scotland wherein a ‘One Stop Shop’ offers advice and information to autistic people as well as linking in with other services. These One Stop Shops offer information, signpost or refer on to specialist services and also offer peer support groups.
96. A similar model of One Stop Shops across Ireland could also provide peer support groups and one-to-one appointments with autistic people to offer support to those with minimal needs and link in with specialist services for those who require them.
97. At present, Thriving Autistic offer a clinician-led model of peer support wherein an occupational therapist or psychologist facilitates weekly and monthly meetings. A similar model could be developed within a One Stop Shop service to

support autistic adults who do not require one-to-one support from clinicians on a frequent basis.

98. Moreover, a One Stop Shop model may also offer advice to parents on how to access services for children. The same lack of information and guidance which impacts those accessing adult services also impacts upon those seeking to access children's disability services. As Áine Lawlor of the AOTI told the Committee:

"We have pockets of services that work very well and we have excellent skilled clinicians who can provide fantastic services but it is about how families and people who have autism get to them. That is the challenge."

99. However, it is important that the development of such a model is undertaken in tandem with investment and resourcing in diagnostic and post-diagnostic services for both adults and children.

Chapter 2 – Education

Introduction

1. The Joint Committee on Autism was established with a broad remit – to consider services and supports for autistic people. The Committee agreed that Education would be the first area it would consider in its public meetings.
2. Many issues in the area of education – such as provision of services, the various types of educational provision, the Summer Programme and more – have long been of concern to autistic people and their families. However, there was an additional urgency to address issues within the sphere of education when the Committee sat for its first public meeting on 28 June 2022. Issues surrounding the lack of available places in special schools and classes were the subject of a report by the Office of the Children’s Ombudsman and a topic of debate within the Oireachtas and in the media. One specific issue which was gaining attention in the national media was the Minister for Education’s invocation of Section 37A of the Education (Provision in Respect of Children with Special Educational Needs) Act 2022, which allows the Minister to compel schools to provide additional school places for children with SEN. In addition, the difficulty for autistic pupils to access the Summer Programme was, and still remains, a source of frustration for many autistic young people and their families. The Summer Programme was the subject of an interim report published by the Committee in November 2022.

School Provision for Autistic Pupils

Introduction

3. There are three main types of public educational provision for autistic pupils in Ireland. There are mainstream classes, special classes in mainstream schools as well as special schools. Most special schools also provide autism classes and many special classes in mainstream schools are established to cater specifically to autistic pupils. There are no second-level special schools in Ireland, however

some second-level schools provide special classes for autistic pupils or pupils with other types of SEN (Special Educational Needs).

Plan for Places – Report by the Ombudsman for Children

4. In June 2022, the Ombudsman for Children – Dr Niall Muldoon – published a report on school places for children with SEN. In his foreword, Dr Muldoon states that the report was initiated “in anticipation of the review of section 37A of the Education Act 1998 that is currently underway, and following complaints to our Office in relation to children with Special Educational Needs (SEN) not being able to secure appropriate school places at both primary and post-primary levels in a timely manner, close to their homes.”⁹ The report notes a five-fold increase of places in special classes in the previous ten years. There were just more than 500 places in special classes in the 2011/2012 school year and just fewer than 2500 projected for the 2022/2023 school year.

Data Collection and Projecting Future Need

5. The Department of Education does not retain information on the number of pupils who have received a diagnosis of autism in schools. The State does not record data on the number of people who either have an autism diagnosis or identify themselves as being on the autism spectrum. Until recently, the prevalence of autism in Ireland was estimated at 1.5% of the population. This figure was said to be in line with the prevalence rate reported in other jurisdictions. However, other jurisdictions have more recently reported much higher prevalence rates of autism than the 1% to 1.5% that was common internationally and in Ireland. For instance, the prevalence rate of autism in Northern Ireland was estimated at 5% in 2022/2023.
6. At a public meeting on 5 July 2022, the Minister of State at the Department of Education with special responsibility for Special Education, Ms Josepha Madigan TD confirmed to the Committee that the NCSE uses a prevalence rate of autism of 1.55% for the purposes of forward planning. In the *Plan for Places* report

⁹ [Plan for Places \(2022\) - OCO](#)

published by the Ombudsman for Children, a prevalence rate of 1.5% is utilised - this report will be discussed in further detail later in this chapter.

7. However, in response to a parliamentary question by Deputy Holly Cairns on 2 February 2023, Minister of State Josepha Madigan indicated that a prevalence rate of 3.38% was published in research from 2020 and 2021. This prevalence rate is closer to the typical rate reported in jurisdictions such as Northern Ireland.
8. While the Committee hopes that this revised estimation of autism prevalence will be utilised by the NCSE for the purposes of forward planning and that this will improve outcomes for autistic children seeking to access suitable educational provision, it must be acknowledged that data on the prevalence of autism in Ireland remains sparse and unclear. The lack of disaggregated data on the prevalence of autism across a variety of backgrounds – including socio-economic, ethnic, gender and minority backgrounds – establishes a barrier to forward planning in education and disability services and prohibits efforts to address underdiagnosis in targeted communities.
9. The Committee believes that it is necessary for the State to collect disaggregated data on the prevalence of autism in the population for the purposes of forward planning. However, it is also essential that any plans to collect such data is not only done in consultation with the autistic community, but also fully includes the community and reflects the objectives they wish to achieve through such a process.
10. Ms Sinéad Gibney, Chief Commissioner of IHREC, highlighted to the Committee the need for inclusivity when collecting data on disability. She told the Committee that

“The denial of service to autistic people, regardless of whether it is defined by law as discriminatory, is a failure of the data to capture the different categories of people with disabilities and the different types of disabilities that people have. For example, I only learned in preparation for today's meeting that there is no

capacity for people to identify as autistic on the census form. There are different categories that people end up choosing because they are as close as they can get, around mental health and intellectual difficulties, but there is no category for autism. That is another example where the data collection issue is evident. It is the same in something like CAMHS where there is a broader definition of disability without the ability to specifically include autistic people.”

11. Dr Rosaleen McDonagh added that there is a further need to “desegregate” within data collection, stating that “There is a value in ethnic identifiers so that we can plan for a better Ireland where autistic adults and children, and all people with any impairment, can be part of the fabric of Irish life.”
12. It is important to fully include the autistic community and take account of their views when formulating any plans to collect data on the autistic population. For this reason, the Committee believes that consultation with the autistic community should begin as soon as possible with a view to determining the best method of collecting data for the purposes of forward planning and to address structural inequalities in access to diagnosis, assessment and therapies.
13. The projection of future need is integral to any forward planning programme. Therefore, it is an essential element in ensuring the availability of school places for autistic children in the years to come. At a public meeting of 28 June 2022, Mr John Kearney – CEO of the NCSE – stated the following:

“For the forthcoming school year, there will be 2,184 autism special classes providing places for more than 13,000 autistic students in our schools. This is an increase of 561% over the past decade. Some 306 new autism classes have been established for this coming September.”
14. While this represents a considerable expansion in provision of special classes over a ten-year period, it is not sufficient to meet current demand nor is it adequate in the context of a growing need for special classes for autistic pupils.
15. The Committee is concerned that there is inadequate data available to the NCSE and the Department of Education for the purposes of projecting future need.

While the next module will consider the need for integration in the Irish education system in further detail, the Committee affirms its view that data collection will be an essential component of projecting future need within the education system and beyond.

Integration and Forward Planning

Article 24 of the UNCRPD

1. States Parties recognize the right of persons with disabilities to education. With a view to realizing this right without discrimination and on the basis of equal opportunity, States Parties shall ensure an inclusive education system at all levels and lifelong learning directed to:

- a. The full development of human potential and sense of dignity and self-worth, and the strengthening of respect for human rights, fundamental freedoms and human diversity;**
- b. The development by persons with disabilities of their personality, talents and creativity, as well as their mental and physical abilities, to their fullest potential;**
- c. Enabling persons with disabilities to participate effectively in a free society.**

2. In realizing this right, States Parties shall ensure that:

- a) Persons with disabilities are not excluded from the general education system on the basis of disability, and that children with disabilities are not excluded from free and compulsory primary education, or from secondary education, on the basis of disability;**
- b) Persons with disabilities can access an inclusive, quality and free primary education and secondary education on an equal basis with others in the communities in which they live;**
- c) Reasonable accommodation of the individual's requirements is provided;**
- d) Persons with disabilities receive the support required, within the general education system, to facilitate their effective education;**

e) Effective individualized support measures are provided in environments that maximize academic and social development, consistent with the goal of full inclusion.

16. Article 24 of the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) is central to the matter of future planning for children with SEN in education. While there is a clear need for greater forethought in the Department of Education’s approach to the provision of school places to autistic children and children with other forms of SEN, any long-term plan must be fully in line with Article 24 of the UNCRPD..
17. The UNCRPD is clear in its position that persons with disabilities – including autistic people – be included in the general education system. It is also clear in its position that they must be fully supported within every model of educational provision. Many parents feel that their children have benefitted greatly from their enrolment in a special class or special school. At a Committee on meeting on 7 March 2023, Dr Mary Doherty – a medical doctor, autistic self-advocate and mother to autistic children – said:
- “The special class that my son attends is absolutely wonderful. Only for that he would simply not be able to access education. He is very bright but he cannot manage the sensory environment of a mainstream class. It is incredibly important.”
18. Some parents may feel that mainstream schools are unsuitable for children with complex needs. At a public meeting on 25 October 2022, Ms Miriam Kenny of Involve Autism D6/D6W told the Committee that “Parents recount stories of difficulties experienced when their child is considered to be in an inappropriate setting and how some children are managed out of schools due to those schools not having appropriate supports for the child.” The lack of supports and resources in mainstream schools can inhibit their ability to provide for autistic pupils. The current context of mainstream schools – one where few, if any, supports are

available to an autistic child – informs the view of some parents that mainstream schools are unsuitable for children with complex needs.

19. However, the current standard of inclusion within mainstream educational provision should not discourage ambition for full inclusion in future. It is important to be cognisant that fully inclusive education must be undertaken in tandem with adequate resourcing and training in mainstream education to ensure the highest standard of provision for children with SEN. At a public meeting on 14 February 2023, Ms Ann-Marie O’Boyle of the Office of the Ombudsman for Children responded to a question regarding the concerns of parents in respect of the inclusion of children with SEN in mainstream schools.

“The UN Committee on the Rights of Persons with Disabilities commented that simply putting a student with disabilities into a mainstream class without an accompanying structural change does not constitute inclusive education. In our research, such as Mind the Gap, we are cognisant of the investment that has been made by the Department of Education in special schools and special classes and that there are two parallel programmes of work - one on making mainstream classes more inclusive and the other on the special schools and special classes part. Our main ask is to have some sort of forward planning as to when these two parallel systems will converge and we might be able to achieve that inclusive model.”

20. At the same meeting, Ms Sinéad Gibney – Chief Commissioner of the Irish Human Rights and Equality Commission (IHREC) – commented that some parents are seeking special education options for their children rather than an integrative mainstream option because “mainstream education is not where it should be” and added that there is “a failure in services and a shortfall in the understanding of what inclusive education is and what our commitments under the UNCRPD are.” At the same meeting, fellow IHREC Commissioner, Dr Rosaleen McDonagh, described her personal experiences in education:

“I have experienced both segregated education and mainstream education. I was not very good in mainstream education because there were no supports. In segregated education, though, the syllabus was not what it should have been. It was not the same State syllabus. If we are to have supported education in whatever guise, I do not believe that segregated education serves anyone, be it the child, the parent, the wider community or citizens like us, as a society.

Nonetheless, some of us need extra support in the classroom. That support is not only about SNAs or specialised teachers. We also need to be on a par with our non-autistic or non-disabled peers.”

21. These sentiments were echoed by Ms Áine Jackson of the OCO:

“Article 24 of the UN Convention on the Rights of Persons with Disabilities proposes a model of inclusive education. The committee is in favour of this progressive realisation of rights and is against lifting children out of special classes or special education and putting them into mainstream settings without that broader systemic change because that does not represent the inclusive education model that it is proposing.”

22. Long-term planning for the full inclusion of children with SEN, including autism, must begin immediately to ensure that autistic children are not segregated from their non-autistic peers and that they receive a high standard of education and achieve the best possible outcomes. Moreover, this is necessary to ensure compliance with the UNCRPD.

Accessing Services in Special Schools and at Home

23. The crisis in disability services - which was discussed in the previous chapter – has a profound impact on autistic pupils in special schools. While therapeutic supports were previously offered in special schools, these supports were withdrawn under the PDS model. As therapies were no longer in place in schools, many autistic children and their families experienced considerable disruption as they attempted to access services in community settings outside of school.

24. On 1 September 2022, Minister Anne Rabbitte announced the phased re-instatement of health and social care supports, including therapists, to special schools.¹⁰ This was welcomed by the IASLT, however they voiced their concern that this action is being taken to the detriment of CDNTs and will therefore result in more restricted access to therapeutic supports for children who do not attend special schools.¹¹
25. Mr Bernard O'Regan of the HSE told the Committee that, while there should be access to therapists within special schools, it is important that “we have a way of working with families in order that we are also mindful of the other environments a child is in and we are providing wholesome and full support that is targeted not just on the educational needs of the child but on their broader needs as well.”
26. While it is important that there is equitable access to therapeutic supports in a variety of contexts for autistic young people, it is imperative that in-school services are available to those in all special schools and those who require services in their homes. The Committee is concerned that health and social care resources are still limited in special schools. In particular, the Committee is concerned about the lack of resources available to new special schools and to special schools with a high vacancy rate in their local CHO. For this reason, the Committee believes that it is necessary to redirect resources to those who require them most, both within special schools and to those with high service needs who receive home tuition.

¹⁰ Press release: [Minister for Disability announces re-instatement of therapists to Special Schools](#)
Department of Health, 1 September 2022

¹¹ Press release: [IASLT Statement on the Return of Speech and Language Therapists to Special Schools](#)

Augmentative and Alternative Communication and Devices

27. It is essential that there is free and straightforward access to Augmentative and Alternative Communication (AAC) as well as the relevant devices and training for families throughout the duration of the lives of autistic persons.

28. The Committee believes that access to evidence-based devices and practices to support autistic people and their families in communicating is a basic right. This right is laid out in Article 21(b) of the UNCRPD which states that:

“States Parties shall take all appropriate measures to ensure that persons with disabilities can exercise the right to freedom of expression and opinion, including the freedom to seek, receive and impart information and ideas on an equal basis with others and through all forms of communication of their choice, as defined in article 2 of the present Convention, including by:

...

Accepting and facilitating the use of sign languages, Braille, augmentative and alternative communication, and all other accessible means, modes and formats of communication of their choice by persons with disabilities in official interactions.”

29. At a public meeting of the Committee, Fiacre Ryan, a young non-verbal autistic writer and student addressed the Committee along with his mother, Carmel Ryan. In their opening statement, Ms Ryan told the Committee about the challenges of trying to access AAC for her son:

“Our children with autism deserve better. Assistive technology for each child should be a right, not something parents and schools have to beg for, requiring numerous letters of support, scrabbling to pay for appropriate training, struggling to pay for programmes and apps, and struggling for resources and equipment. Every child should have the right to communication and independence, with appropriate technological resources provided automatically by the Departments of Health and Education throughout his or her life.”

30. The Committee notes the concerns raised by the Irish Association of Speech and Language Therapists (IASLT) regarding a lack of evidentiary basis for the Rapid Prompting Method (RPM). The Committee believes that evidence-based AAC practices should be promoted by the State but maintains that where RPM is the chosen method of communication of an autistic person or disabled person, it is essential that they are facilitated in communicating using that method.
31. The Committee believes that the Department of Education should increase investment in AAC, including investment in training for families and caregivers to non-verbal autistic people, and ensure that that AAC devices are retained by users.
32. Moreover, the Committee believes that campaigns should be initiated to promote the understanding of AAC and acceptance of AAC users.
33. In their opening statement, Ms Ryan told Committee that her son “has struggled to complete his education due to a lack of understanding of autism, a lack of supports and resources, and the lack of access to, and training in, technology suited to his particular needs.” She also quoted from Mr Fiacre Ryan’s book *Speechless*:

“It only seems appropriate to give the same rights given to those without autism to individuals with it. Needing some type of assistance does not make someone less of a person. ... Try to see past the autism and realise that we are the same inside as others.”
34. The Committee believes that there is an urgent need for a greater understanding of non-verbal autistic people and for the alternative and augmentative forms of communication they may use. The Committee believes that the government should promote the understanding of non-verbal autistic people and AAC in public campaigns.

The Summer Programme

35. Throughout the course of the Committee's work, the Summer Programme has consistently emerged as a matter of concern. The Committee has received a considerable amount of correspondence from parents of autistic children which outlines their difficulty in securing a place on the Summer Programme for their autistic child or children, particularly in special schools. In November 2022, the Committee published an interim report titled [Report on the Summer Programme 2023](#). The interim report was published in the context of a low rate of school participation in the Summer Programme in previous years and the suggestion from some special schools that they would not participate in the Summer Programme in the year to come. This interim report was published with the purpose of establishing the barriers to special schools participating in the Summer Programme and how they can be removed by the Department of Education.
36. The Committee held a number of meetings which considered the Summer Programme and met with a variety of witnesses, including a number of parents' representative groups, the NCSE, Ms Josepha Madigan TD, the Minister of State for Special Education and Inclusion at the Department of Education, the INTO, the Teachers' Union of Ireland, the ASTI and Fórsa.
37. The report identified a range of key issues impacting autistic children and their families as a result of their exclusion from the Summer Programme. The report detailed the regression that children experience over the summer period, the lack of respite care and the resultant additional care costs. Witnesses also identified issues such as an increase in episodes of sensory overload, increased anxiety, aggression towards families, outbursts, absconding and strain on family relationships.
38. The Committee made a series of recommendations in its report including that the Department of Education establishes a liaison team to provide information and assistance to schools seeking to participate in the Summer Programme and an expansion of the range of professions that can participate in the Programme. The

interim report was debated in Dáil Éireann on 2 February 2023 and adopted by the House.

39. The Department of Education announced funding of €40 million for the Summer Programme 2023 alongside a review of the Summer Programme. Since the publication of the interim report, the Department of Education completed its review of the Summer Programme and published details of the Summer Programme 2023.

40. On 9 February 2023, the Minister for Education, Ms Norma Foley TD and the Minister of State for Special Education and Inclusion, Ms Josepha Madigan TD, announced details of the Summer Programme 2023. The theme of the 2023 Programme is “Building Confidence and Connections”. The accompanying press released placed an emphasis on supporting special schools, with a particular focus on ensuring the availability of a school-based programme in these schools. Minister Norma Foley stated that “The main focus for this year’s Summer Programme is that those children with the most complex special educational needs have access to a school-based programme.”¹²

41. The 2023 Programme features four strands:

- School-based programme in primary schools
- School-based programme in secondary schools
- Home-based programme
- School-based programme in special schools

42. There is also a Post-Primary Scheme.

¹² Press release: [Ministers Foley and Madigan announce 2023 Summer Programme](#), Department of Education. 9 February 2023.

43. The Department of Education published an Overview document¹³ providing further details of the School-based programme in special schools strand. The document states:

“This pilot programme is designed to ensure supports are targeted:

- to enhance the availability of school based programmes in special schools
- to coordinate and support children’s access to such a programme
- to assist with the identification of staffing needs and resources
- to reduce the administrative burden associated with leading and managing a school-based programme.”

44. Among the new features of this pilot programme are as follows:

- A Summer Programme National Coordinator – it is unclear who this will be, what position they hold in the Department of Education and whether they will be supported by a team.
- A new ‘Organiser’ role in schools to replace preparation hours – this role is specific to special schools. There will be one Organiser in each special school participating in the Summer Programme.
- The ‘Overseer’ role has been changed to ‘Summer Programme Manager’.
- “Each school must appoint a Manager for the Summer Programme. The role of Summer Programme Manager can be undertaken by any permanent or fixed term teacher, including the principal and Summer Programme Organiser in the participating school.
- The school day is shorter for the Summer Programme 2023 in special schools. The typical duration of a school day in a primary school is 5 hours and 40 minutes. The duration of the day is 10am to 2pm (4 hours). This

¹³ [2023 Summer Programme: ‘Building Confidence and Connections’](#), Department of Education.

shorter school day applies exclusively to those participating in the special school programme. The school hours within the mainstream school programmes remain unchanged. Staff participating in the Summer Programme 2023 in special schools will be paid the full daily rate. The Department's Overview document states that this "recognises the challenges associated with running the programme in a special school, including break time routines and transport concerns."

- "With regard to staffing, newly qualified teachers and undergraduate student teachers who have registered with the Teaching Council under Route 5 are eligible to be employed on the Summer Programme. It is also open to schools to recruit appropriately-qualified staff for the role of SNA. Another staffing resource available for special schools this year will be undergraduate students and other suitable workers, including early childcare workers who wish to work locally. A new portal, developed by the IPPN on www.educationposts.ie is available for students and other workers to register their interest in working on the Summer Programme. They will be able to submit preferences on location and availability."
- The rate payable to students and others, including early childcare workers and carers, will be the SNA rate of pay. Mainstream schools will also be able to avail of undergraduate and graduate teaching staff. It is unclear if they may participate in the Summer Programme 2023 in mainstream schools. It is also unclear if the services they would provide in these circumstances would be those expected of an SNA (e.g. non-therapeutic).
- An online portal will be made available to a child where they may register their interest in attending the Summer Programme in another school in cases where a place in a special school in their local area is not made available to them.

- Regarding payments, “Participating schools will utilise the Department’s Esinet system to submit claims. This will allow claims to be processed on an ongoing basis during the summer.”
- Additional funding will be provided to special schools. This includes a grant of €60 per pupil per week and additional grant funding of €2,000 per week to participating special schools.

45. Though some of the changes made to the Summer Programme 2023 are welcome, the Committee believes that the practical application of these changes is key.

46. The Committee undertook a survey of special schools with the intention of establishing whether or not they would participate in the Summer Programme in 2023. The survey asked school principals

- whether their school had participated in 2022
- whether they would participate in 2023
- if not, why they would not participate in 2023
- what improvements could be made to the Summer Programme going forward.

47. The responses demonstrate clearly that staffing issues – particularly difficulty in recruiting internal school staff – are the predominant factor in discouraging schools from participating in the Summer Programme 2023. While schools maintain that there is a lack of incentive for teachers to participate in the Programme, it also appears that the School Organiser role is not wholly attractive to staff either.

48. Contributions from special schools identify issues such as a lack of funding for transport and a lack of funding for specialist training as prohibitive to their participation in the Summer Programme. The further information section also

allowed respondents to develop on the main barrier to participation in the Programme, namely staffing issues.

49. Staffing issues are cited by special school principals as the primary deterrent to participation in the Summer Programme 2023. While the Department of Education sought to address staffing issues by allowing students from fields such as psychology, therapy and teaching to participate in the Summer Programme, special schools appear to regard students and external staff as an unviable staffing resource.

50. A number of respondents indicated that a sizeable core team of internal teaching and SNA staff would be required to support children with complex needs. The following reasons were cited:

- Staff require specialist training to support children with complex needs in their schools (FEDS¹⁴, tracheostomy care, client manual handling,¹⁵ how to administer medication, how to manage behaviours of concern etc.)
- Children require support from familiar staff
- Unsafe to run the Summer Programme without a core team of internal staff
- Unsafe for new staff due to an increase in behavioural incidents¹⁶ and lack of familiarity with specific triggers, handling needs and medical needs
- Too costly and time-consuming to try to train new staff in managing the issues listed above

51. In respect of internal staff, responses to the survey have identified a number of issues prohibiting their participation in the Summer Programme, chief among

¹⁴ Feeding, Eating, Drinking, Swallowing

¹⁵ Handling children who require the use of hoists, slings etc

¹⁶ Some schools have cited the lack of therapists/psychologists for a rise in behavioural incidents

which are the staff burnout after the school year and inadequate or unattractive pay.

52. A number of respondents indicated that teachers and SNAs are dealing with an increase of behavioural issues as pupils are not receiving therapeutic supports. In addition, many SNAs cannot cover their own childcare costs and the pay rate is unattractive to teachers who wish to spend time with their own families. Home-based provision is much more appealing at this pay rate.
53. It is particularly noteworthy that the unsuccessful roll-out of PDS is a larger issue behind the unwillingness of internal staff to participate in the Summer Programme. Responses to the survey on the Summer Programme have indicated that the wider context of disability services, supports for children with complex needs and supports for special schools throughout the school year have a profound impact on the propensity of schools to provide the Summer Programme.
54. Throughout the course of the Committee's work, it has become evident that many of the issues concerning assessments, diagnoses, supports and services for autistic children are interconnected with one another and can be traced to the deficits within the rollout of PDS.
55. Responses to this survey seem to suggest that the same is true of the Summer Programme.
56. Several survey responses in respect of staff burnout cite the lack of multidisciplinary services as a reason for a much more challenging caseload for staff in special schools throughout the year. Many responses state that staff must avail of the full summer break to be able to work for the coming school year.
57. In addition, the increase in behavioural incidents not only contributes to the exhaustion of internal staff, but also establishes a barrier to external staff participating in the Summer Programme. Increased behavioural incidents can occur as a result of a lack of support for children who require therapeutic intervention.

Transitions

Introduction

58. Points of transition are crucial milestones in the development of all people, including members of the autistic community. Day-to-day transitions, such as the transition from the home to school in the morning can cause considerable difficulties for families. The Committee believes that the Department of Education must consider how families can be supported in managing transitions such as these. However, this section of the report will consider in greater detail the issues concerning larger transitional milestones, such as graduating from secondary school to third level education or employment.

Managing Transitions

59. Transitions can produce a mixture of emotions in people irrespective of neurotype. Excitement, anxiety, apprehension and happiness are among the many feelings that people with and without an autism diagnosis can experience when they take a step into an unfamiliar world such as a new school, graduation to secondary or tertiary education or when starting a new job. The experience of making a large life change can present even more opportunities and challenges for autistic people when compared with their non-autistic peers.

60. Among the traits often associated with autism is a preference for fixity and a difficulty in navigating changes in routine, however it is important to acknowledge that there are many autistic people to whom this does not apply. As a result of this, often those who work with the autistic community approach periods of transition with a negative mindset – viewing transitions as a challenge to be overcome. As alluded to already, there can be challenges associated with points of transition, however, transitions for autistic persons should be embraced with a positive attitude just as they are for their neurotypical peers. In fact, this section will refer to recent research which demonstrates that, with the right supports, autistic people can flourish as a result of a successful transition. This section will also consider some points of transition which are particularly relevant to the area

of education as well as the need for a centralised National Transitions Service to support autistic people and their families as they prepare to make an important life transition.

Starting or Switching Schools

61. Starting preschool and primary school are important milestones in the early development of children. These periods are regarded as critical points which are potentially indicative of future experiences of academic learning.¹⁷ They are also important stages in respect of the development of social skills. Children who have reached preschool age (from two years and eight months old) can avail of the Early Childhood Care and Education (ECCE) Scheme until they begin to attend primary school. At present, autistic children may access either universal or targeted supports in preschool through the Access Inclusion Model (AIM) irrespective of whether or not they have a diagnosis. Under AIM, some guidance and supports are provided to parents to plan for the transition of their child into primary school. Moreover, the National Council for Curriculum and Assessment (NCCA) have also compiled reporting templates and suggested transition activities for preschools to use when planning for the transition of children into primary schools. While these supports are welcome and demonstrate a coherent approach to the transition into primary school, greater participation from the receptive primary school in the transition process may be of benefit to children as they transition into school. For instance, school visits and an opportunity to meet their new teacher, SNA and other staff may benefit autistic children as they make the transition into primary education.

62. There is little guidance available to families who wish to move their child to a new school at primary or secondary level. Aspects of other school transition materials – such as the pre-school materials mentioned above or other guidance documents – may be applicable to some degree in these cases. However, the Department of Education and the other bodies under its aegis should endeavour

¹⁷ Connolly, Micaela Maria. *Experience of parents whose children with autism spectrum disorder are starting primary school*. 2015. Doctoral Thesis, University of East London Psychology.

to establish supports for parents of autistic children who seek to make such a transition.

Transitioning to Secondary Education

63. Progressing to post-primary education often involves a shift to a larger and more diverse school with more complex social and educational systems.¹⁸ The student population is different from that of the pupil's primary school and the teaching staff is different. As a result, support systems, communication tools and other mechanisms which had been in place in primary education are not automatically available to pupils. For some pupils with complex needs, this transition will also entail a shift from a special school to a mainstream school as there are no post-primary special schools in Ireland.
64. Changes in routine – including larger changes such as progressing to secondary education – present a greater challenge to many autistic pupils. Autistic pupils have been identified as a population which is particularly at risk of making an unsuccessful school transition.¹⁹ Additionally, the transition to secondary school can also include more minor changes throughout the school day. For instance, pupils in secondary school must become accustomed to a more varied class schedule, movement between classrooms and different teachers throughout the school day. Moreover, secondary schools can present an entirely different sensory environment from that of primary school.²⁰
65. However, despite the challenges that may exist when some autistic children transition to secondary education, recent research indicates that this transition – with the correct planning and supports – can result in improved outcomes for

¹⁸ Whelan, Moira et al. 'The Association Between Autism Spectrum Traits and the Successful Transition to Mainstream Secondary School in an Australian School-Based Sample', *Journal of Autism and Developmental Disorders*. 2021.

¹⁹ *ibid*

²⁰ *ibid*

autistic pupils.^{21 22} For this reason, it is essential for the Department of Education to establish a protocol to assist schools in establishing and implementing transition programmes for children who will benefit from such a service.

66. At present, there is a guidance document available to schools online.²³ This document was published by the NCSE in 2016. Additionally, the NCSE provides a guideline document for parents which was also published in 2016.²⁴ Both documents, along with the school transition process, should be reviewed by the NCSE and the Department of Education.
67. The purpose of the guidance document is to support schools in assisting children with SEN in transitioning from primary to post-primary education. The document states that:
- “Many schools have now excellent practices in place to support students at various transitional points... These guidelines are intended to share this good practice so that more students with special educational needs, and their families, can be supported to make transitions with greater confidence and ease.”
68. However, the document lacks detail and does not amount to a coherent transition programme. The guidance document for schools is 11 pages long, including two pages with links to additional references, whereas the guidance document for parents is 20 pages long. This reflects an expectation that the onus is on parents to initiate preparations at school-level to ensure that their child has a positive transition from primary to secondary school. This expectation does not constitute good practice, as a transition programme should be established by the primary school and secondary school for autistic children who would benefit from it and should guide parents in navigating the process.
69. As autism is a heterogeneous condition and the needs of children can vary dramatically, it is important that schools tailor such a programme to the needs of

²¹ *ibid*

²² Stack et al. [The perspectives of students with Autism Spectrum Disorder on the transition from primary to secondary school: A systematic literature review](#). 2021.

²³ [Supporting Students with Special Educational Needs to make Successful Transitions](#). NCSE, 2016.

²⁴ [Changing Schools: Moving from Primary to Post-Primary School](#). NCSE, 2016.

the child. As suggested in the report by Stack, Symonds and Kinsella, the best way to design such a programme is with the input of the child.

70. It is essential that autistic people, including autistic children, are consulted and that their views are taken into account when designing any process or plans which concern them. Dr Karen McAuley, Head of Policy at the OCO, highlighted the particular importance of consulting autistic children in such processes.

“Regarding participation, crucially, the right to be heard is a core principle of children’s rights which applies to all children. We know an overarching finding from the research we published, which was undertaken for us by experts in NUI Galway in 2021, called *Mind the Gap*, was that children with disabilities, including autistic children, are not heard. We need to acknowledge with regard to some our approaches to consulting, to hearing the views of children and young people, and facilitating their participation, that while Ireland has been progressive in this area and has done much commendable work, we still have a long way to go.”

Transitioning to Higher Education

71. While there are no official figures for the number of autistic people in third level education in Ireland, it is thought that there are at least 1,400. On 2 June 2022, the Minister for Further and Higher Education, Research, Innovation and Science, Mr Simon Harris TD, announced new initiatives to support autistic students and those with an intellectual disability in accessing third level education.²⁵ Funding of €12m is being made available to third level institutions between 2022 and 2025 to improve services for autistic people. This initiative forms part of PATH 4 of the National Access Plan (NAP). One aspect of Phase 1 of PATH 4 is “To support an evidenced-based whole-of-tertiary, whole-of-education and whole-of-Government

²⁵ Press release: [New third-level access support for autistic students and students with an intellectual disability announced by Minister Harris](#). Department of Further and Higher Education, Research, Innovation and Science, 2022.

approach, which will inform future policy on successful transitions to and within higher education for students with intellectual disabilities.”

72. In 2013, the NCSE published a report titled *Moving to Further and Higher Education: An Exploration of the Experiences of Students with Special Educational Needs*.²⁶ The report engaged directly with autistic people to investigate their experiences when transitioning to tertiary education and the barriers they face. The report also sought to establish what instances of good practice exist and how they can be developed further.
73. The Committee believes that this work should be built upon and that its findings should inform a long-term plan to address the challenges experienced by autistic people transitioning to further and higher education.

Possible Challenges of Transitioning to Third Level Education

74. The transition from secondary education to further education can present considerable challenges to autistic people. As Elias et al write:
- “The transition from secondary to postsecondary education is a period of both great intellectual, social, and increased quality of life opportunities as well as heightened risk for skill loss, societal isolation, and increased separation from same-aged peers with respect to adaptive skill growth.”²⁷
75. Tertiary education presents new challenges and opportunities in respect of academic life, social life and new responsibilities. For many students, including autistic students, they must reckon with greater independence in managing accommodation, finances, catering as well as increased academic demands.²⁸ For some students, travel to and from university and developing new social relationships will also pose challenges and opportunities.

²⁶ [An Exploration of the Experiences of Students with Special Educational Needs](#). NCSE, 2013.

²⁷ Elias et al. ‘Brief Report: Creation of a Transition Readiness Scale for Adolescents with ASD’, *Journal of Autism and Developmental Disorders*, 2022.

²⁸ Lai et al ‘Evaluation of a Transition to University Programme for Students with Autism Spectrum Disorder’, *Journal of Autism and Developmental Disorders*, 2020.

76. These challenges, among others, can result in fewer autistic people participating in third level education as well as a less fulfilling academic and social experience of higher education. In a study by Lai et al²⁹ the authors write that, for autistic people, “the number of enrolment, retention, academic achievements, and employment rate following graduation is still relatively lower compared to students with other disabilities, as well as their typically developing peers.” The study goes on to state that

“Given the potential additional complexity of challenges faced by autistic students, it is essential for university stakeholders and transition services to be aware of the potential needs of autistic students, to facilitate preparation for university life, and to provide informational, practical, and emotional support during the transitional process.”

77. The possible challenges for autistic people attempting to access third level education are complex and varied. As autism is a heterogenous condition, individualised planning is required to address the specific needs of autistic people who are seeking to enrol in third level education.

78. There is a clear need for transition planning for all autistic students who are considering third level education.

Pre-Transitional Planning for Third Level Education

79. While there is a need for dedicated transition services in the long term, there are steps that can be taken now to ease transitions for autistic people attending third level education institutions. Ms Julie Tonge of UCD identified the need for dedicated transition services:

“Supporting students to transition to third level cannot be the responsibility of third level institutions alone, not least as they remain unknown to us until the point of access. We recommend that a dedicated transition service be established to

²⁹ *ibid*

support autistic people to prepare for the transition to third level and to collaborate with third level institutions to assist with this.”

80. While dedicated transition services will be discussed later in this chapter, there are short term changes that can be made to improve the experiences of autistic people transitioning from secondary education to tertiary education. For instance, earlier access to Leaving Certificate and CAO results would allow for more lead-in time for autistic students to make contact with their prospective HEI.

81. In addition, providing information to autistic students and their families early on may help them in deciding what supports they made need throughout college life.

82. Ms Tonge elaborated that

“For autistic students in particular, it can be challenging to be told that they will be meeting with an occupational therapist and that they have to make their own decisions. Often, they will not have been asked to make decisions for themselves up to this point. It is a question of providing some support for students at pre-entry stage to discuss with people what college will be like, what they will be offered and what will help them in that college environment, and enabling them to be thinking of all of those things at pre-entry stage. We do not know these students at the pre-entry stage so we cannot do the work with them almost until they arrive with us. The late leaving certificate in the past number of years has even made that more challenging. Students are transitioning into university and within a couple of days they are in classes, so there is no opportunity for us to meet with them earlier on before they start.”

Benefits of Transition Planning

83. Transition planning has been shown to bear positive outcomes for autistic people progressing to third level education. A paper by Chiang et al found that young autistic adults who participated in transition planning or received instruction on transition planning were up to three times more likely to progress to third level

education than those who did not.³⁰ In the study by Lai et al, the authors consider some of the focuses of transitional programmes that are currently available in some universities:

“Common themes emerging from qualitative studies [of transition planning programmes] have included coursework requirements, disability awareness on campus, social skills and social relationships, availability of practical and emotional support, organisational difficulties such as time-management and problem-solving skills, sensory challenges and mental health concerns.”³¹

84. The same study also identifies issues concerning disability awareness on campuses and disclosing diagnoses for autistic students. It is essential for any transition planning programme to identify the challenges that autistic people face when attending university to ensure that they can be mitigated. However, it is also important that transition planning is a positive process which includes the autistic person and recognises the opportunities that participation in third level education can offer.

Models of Transition Planning

85. Among the aspects of transition planning programmes that have been trialled abroad are ‘Autism Summer School’ in the University of Bath in the UK. This summer school was trialled over several years and comprised of two overnight stays in student accommodation and a curriculum delivered across 3 days.

“The curriculum was designed to prepare autistic students for typical university life and promote self-care and wellbeing when at university. Upon arrival, each student received a package containing a detailed timetable and brief outline of session contents, as well as printed session hand-outs. Sessions were structured across three strands ‘work’, ‘rest’, and ‘play’. All sessions were delivered face-to-

³⁰ Chiang, HM et al. ‘Predictive factors of participation in postsecondary education for high school leavers with autism’. *Journal of Autism and Developmental Disorders*, 2012.

³¹ Lai et al ‘Evaluation of a Transition to University Programme for Students with Autism Spectrum Disorder’, *Journal of Autism and Developmental Disorders*, 2020.

face in a group. The sessions taught included introducing students to the nature of academic life at university such as experiencing a typical lecture, socialising students to the role of staff and tutors, accessing student support and disclosing your diagnosis ('work' theme). There were also sessions about stress reduction, management of situational anxiety and the role of physical wellbeing with information about sporting facilities ('rest' theme). The strand of sessions about 'play' included information about clubs and societies at university, experiencing shared meals on campus, social outings and opportunities for informal socialising."³²

86. The study by Lai et al found that the results of this programme have been "very positive." The study states that

"Overall, the autism summer school identified concerns of potential autistic students who are thinking about attending university, and highlighted that these concerns can be significantly reduced through a pre-transitional autism summer school. Social, non-social, and anxiety-related concerns can be addressed with short pre-transitional programmes in a manner that potential autistic students find both helpful and enjoyable and enhance perceptions about successfully starting university."³³

Transition to Employment

87. Transitional supports are also important for autistic people who wish to enter employment, whether they are entering from third level education or upon completion of secondary level education. While chapter four of this report will consider the need for public employment supports in greater detail, a transitional support into employment is one possible feature of a potential plan of action to address the issue of unemployment and underemployment in the autistic community.

88. At third level, the Committee has seen instances of good practice. The Trinity Centre for People with Intellectual Disabilities (TCPID) has developed a

³² ibid

³³ ibid

programme wherein an interdisciplinary team supports young people with intellectual disabilities – some of whom are also autistic – to transition into employment. Through this programme, students develop independent learning skills and employment skills with the support of occupational therapists, an employment pathway co-ordinator, a mentor and employers. The course is two years in duration and includes a work placement programme and typically results in a six-month paid internship after two years. Mr Hugo MacNeill of TCPID told the Committee that there is an appetite among employers to foster greater inclusivity and diversity in their staff and that there is an opportunity and a willingness to expand programmes such as TCPID to this end. This programme also includes some training for mentors and employers who work with participants. Training consists of an online presentation which gives employers a better understanding of the participants who will be working with them, such as differences in communication styles.

89. The Committee believes that programmes similar to that which is available at the TCPID should be developed across HEIs to support autistic people and disabled people in accessing employment.
90. In addition, the Committee believes that autistic people should have access to supports that help them to develop employment skills and other skills outside of the academic and research sphere. Ms Julie Tonge of UCD told the Committee of the need to support autistic students in developing self-advocacy and communication skills.

“An additional need is support for the development of life skills. A programme tailored to the needs of autistic people to develop skills that would benefit them, regardless of whether they continue in education or seek employment would be useful. There is also a need for adequate support to prepare autistic people for the workplace and for workplaces to practise inclusive recruitment and employment practices. Accessing reasonable accommodations in an employment context can be much more complex than in an educational environment and

autistic people need to be supported to develop self-advocacy and communication skills and to identify suitable reasonable accommodations. Specialised career consultants with a deep understanding of autism, and who can build relationships with employers are needed.”

91. The Committee believes that DFHERIS should provide funding to HEIs to develop modules to encourage the development of autistic people who require additional support in communication and self-advocacy and other life skills.
92. Moreover, the Committee believes that DFHERIS should provide funding to HEIs to replicate the model which is utilised by TCPID as well as provide more multiannual funding to allow for greater forward planning.

An Inclusive Transitions Service

93. A National Transitional Service would benefit those autistic people who do not make an immediate transition from secondary education into tertiary education. Any such service should be mindful of those autistic people who may attend third level education as mature students or go directly into employment or an apprenticeship after completing secondary education. Such a national service that links in with an autistic person and their own support services allows for greater inclusivity and does not favour those who undertake third level education straight from secondary school over those who feel unprepared to enter third level or wish to enter employment.
94. Such a service would benefit those who wish to attend HEIs as mature students, for instance, and could provide assistance to autistic people when making transitions throughout their lives. Jessica Doyle of Thriving Autistic told the Committee

“I am probably repeating what others have said. Rather than thinking of specific areas where autistic people are present, it is probably more important to think that autistic people are present in all areas and in all contexts of life. We are everywhere. We think a great deal about transition, and transitioning from primary school to secondary school, or from secondary school out to college. We also

need to think about all of the other transitions, such as becoming a parent, going into work or going into retirement. It is very important that we think about all of the different transitions in a full lifespan - which may not be the right word - or throughout life.”

95. The Committee believes that a cross-departmental approach should be taken to establishing a National Transitions Service to support autistic people as they move between services and progress throughout their lives.

Strategic Disability Funding for Higher Education Institutions

96. The National Access Plan 2022 – 2028 (NAP) was published by the Department of Further and Higher Education, Research, Innovation and Science (DFHERIS) in August 2022. The Programme for Access to Higher Education (PATH) Fund was announced under the NAP. This fund has been made available to third level institutions in multiple strands to support time-bound programmes and projects which address the aims of the NAP. The fourth funding strand – PATH 4 – has been instated in two phases specifically to address Universal Design needs and to provide more opportunities for students with intellectual disabilities to engage with third level education.

97. Under PATH 4, funding of €12m has been made available to higher education institutions (HEIs) over a four-year period starting in 2022 and will be implemented on a phased basis as follows:

- Phase 1 (2022) – Universal Design Fund, to support inclusive universally designed higher education environments for all (once-off fund of €3m based on allocation/approved project plan basis to HEIs funded under PATH.)
- Phase 2 (2023-2025) – Proposals for course provision for Students with Intellectual Disabilities. Funding under this phase is subject to a competitive proposals process.

98. At a meeting on 22 November 2022, the Minister for Further and Higher Education, Research, Innovation and Science, Mr Simon Harris TD told the Committee that funding under Phase 1 is underway and would be allocated in the following month. The Minister indicated that 19 universities and HEIs had submitted project plans at that date. Funding of €3m has now been provided to HEIs under phase 1 of PATH 4.³⁴ Funding under phase 2 of PATH 4 has not yet been provided to HEIs.

99. Funding for HEIs to implement Universal Design practices and infrastructure is welcome, as is funding to make third level courses accessible to those with intellectual disabilities. In particular, Prof Michael Shevlin of the TCPID welcomed the provision of dedicated funding for people with intellectual disabilities – of whom some have a co-occurring autism diagnosis:

“The big breakthrough has been the programme for access to higher education, PATH, developed by the Department. That is going to bring about dedicated funding for these types of programmes next year. We see this as very positive. This is the real breakthrough. This has not happened anywhere else in Europe that we are aware of, and we are part of Erasmus programmes. This is the first time dedicated State funding has been provided for young people with intellectual disability to attend higher education. That is a massive breakthrough.”

100. However, universities and HEIs have also voiced their view that more multiannual funding is required to embed Universal Design in third level institutions and to ensure that autism-friendly practices and infrastructure are maintained. Dr Mary Rose Sweeney of DCU told the Committee that PATH 4 funding for Universal Design “is not sufficient”, adding that DCU is “trying to tap into that but it would not be enough to meet the needs of all of the universities currently.”

³⁴ Press release: [PATH 4 project roll-out for universal design, autistic students and students with an intellectual disability announced by Minister Harris](#). Department of Further and Higher Education, Research, Innovation and Science, December 2022.

101. Ms Julie Tonge of University College Dublin told the Committee that UCD is utilising funding from phase 1 of PATH 4 to embed sustainable solutions, but advised that there are other aspects/features, such as sensory rooms, that the funding cannot cover as multi-annual funding would be required to ensure its upkeep. Instead, UCD is utilising funding to create a support toolkit for HEIs, which will be welcomed by many institutions, however the provision of sensory spaces and changes to other aspects of the built environment must also be supported financially by the Department of Further and Higher Education, Research, Innovation and Science.

102. Along with an increase in funding, more freedom to spend funding is also required by HEIs to improve accessibility and fully include autistic students in higher and further education. Ms Tonge identified the need for strategic, multiannual funding:

“If I had a magic wand, I would do something about strategic funding. We get funding on an annual basis and it all needs to be spent within a year. It can only be spent on very restricted things. The money not spent in the year gets returned. However, if that money could go into a strategic fund, we could start planning additional services, looking at the needs of the students and what other things we could put in place. For some time, we have had occupational therapists but we could be doing many other things as well. It is very difficult to get time and resources to look at other projects that could be done. The Deputy mentioned the grants that come in for projects but that money needs to be spent in a very short space of time. It would be good to have funding on a rolling basis allowing us to retain some of the funds. We could roll it up over time and do something. Perhaps at different times we could apply for additional funding to do certain things based on students' needs, which change all the time.”

103. While HEIs welcome project-oriented funding, such as that provided under PATH 4, it is clear that they require funding on a rolling basis to provide services to autistic and disabled students.

104. In addition, there are timing issues regarding the disbursement of existing supports for students with disabilities. The Fund for Students with Disabilities (FSD) is available to HEIs to provide supports to students with disabilities to enable access to third level education and participation in courses. The fund covers the following areas:

- assistive technology equipment and software
- non-medical helpers (e.g. personal assistants, notetakers)
- academic/learning support
- deaf supports (sign language interpreters, speedtext)
- transport support

105. Funding is disbursed according to the calendar year rather than the academic year. Therefore, it is challenging for HEIs to plan appropriately. Ms Tonge said:

“Obviously, some students have a high cost implication. We have students with very high support needs - things like personal assistants, transport requests, sign language interpreters and everything else. It is very difficult to manage a fund like that on an annual basis. We do not want to spend all the money we have because we do not know who is coming in September. There are three months left and if we have budgeted for more than we actually need, there is no way to ring-fence that money and keep it for something we could use in the future. Even if we thought we could afford an additional person to provide support for these students, it is very difficult to do that on that annual-funding basis.”

106. In the short term, the Department of Further and Higher Education, Research, Innovation and Skills should engage with HEIs to offer funding in accordance with a more suitable timescale that takes into consideration the academic calendar and the planning which must be undertaken by institutions to ensure the easy transition of students into third level education. Moreover, the Department should adopt a long-term goal of providing multiannual funding to universities to allow for

greater freedom to improve upon service provision and make the necessary structural changes that HEIs identify within their own institutions.

107. It is imperative that the Department adopt a strategic approach to provide rolling, multiannual funding to HEIs to allow for them to develop long-term plans to promote the full inclusion of autistic and disabled students through a framework of Universal Design. Dr Mary Rose Sweeney of DCU told the Committee

“I wish to make a comment on how we grow the overall framework at DCU. The engagement so far has been organic in that people who are interested in that area reached out to us with organisations such as AsIAM. We have done good work with it to support it to get up and running. It would be nice to see a more coherent, strategic or systematic approach to all of the higher education institutions, HEIs, in embedding this type of an approach.”

108. The Committee would welcome a commitment from the Department of Further and Higher Education, Research, Innovation and Skills to augment the NAP with a long-term strategy to embed Universal Design in HEIs.

Chapter 3 – Social Protection

Introduction

1. Social Protection supports have an important part to play in ensuring that autistic people are fully included in society. Social Protection supports can ensure that the families of, and carers to, people with additional care needs do not experience poverty and can participate in their communities.
2. However, the Committee heard from witnesses that disability supports and supports for carers fall short of these aims. Inclusion Ireland stated in 2022 that one third of disabled people in Ireland are at risk of poverty and that the cost of disability is a significant contributor to this risk.³⁵ Moreover, the *Roadmap for Social Inclusion 2020-2025* states that poverty rates among disabled people in Ireland are among the highest in Europe. The Committee firmly believes that it is essential to eliminate the risk of poverty faced by the autistic community and the wider disabled community to ensure their full participation in society. At present, as many public services remain unavailable to many autistic people and costs associated with autism and other disabilities are rising, the purchasing power of those in receipt of Social Protection supports is reducing. Urgent action from the State is required to address the increasing risk of poverty faced by autistic and disabled people.
3. The Committee also believes that in the longer term, a social and human rights-based approach must be taken to how Social Protection supports can enable participation in society. Some disabled people in receipt of Social Protection supports feel threatened that the supports they have may be curtailed or taken away, particularly if they seek to enter the workforce. It is essential that the State ensures that autistic people who wish to work are not inhibited by concerns that they may lose supports such as the Medical Card or Free Travel Pass.
4. Moreover, the Committee contends that a new approach must be taken to supports for carers. Under the present model, the work of carers goes

³⁵ [Inclusion Ireland Response to Budget 2022](#)

unrecognised by the State. According to the most recent census of 2022, there are almost 300,000 unpaid carers in Ireland. While supports are available, many carers find them to be inadequate in light of the additional costs associated with autism and other disabilities. The Committee echoes the recommendation of the Joint Committee on Gender Equality that carers must be recognised for the service that they give to society and should be compensated for their work.

The Cost of Autism

The Cost of Childhood Autism for Families

5. Families supporting autistic children are subject to a higher risk of poverty due to the lack of State support for autistic people. The Committee is very concerned by the additional costs incurred by families due to a child's diagnosis of autism or indeed multiple diagnoses within the one family. The Committee heard evidence from Dr Áine Roddy of Atlantic Technological University (ATU) when she appeared before the Committee, alongside Inclusion Ireland, on 24 January 2023. In 2018, Dr Roddy and Prof Ciarán O'Neill published 'The economic costs and its predictors for childhood autism spectrum disorders in Ireland: How is the burden distributed?', a study which sought to establish the additional costs incurred by families as a result of an autism diagnosis. The study found that the average cost to families was €28,464.89 per child per year due to accessing private services, loss of income and informal care. In contrast, the average annual State expenditure on autism-related health, social and educational resources was €14,192 per child.³⁶ Dr Roddy informed the Committee that "The figure of €28,000 is exceptionally high. It is the highest internationally in terms of out-of-pocket expenditure and overall in terms of the cost for families." However, she added that this specific area of the cost of autism is under-researched internationally. Dr Roddy added that despite this, existing evidence suggests that the cost of autism is higher in Ireland than other countries.

³⁶ Roddy, Áine; O'Neill, Ciarán. ['The economic costs and its predictors for childhood autism spectrum disorders in Ireland: How is the burden distributed?'](#). 2019.

6. This study – the only Irish study of its kind into the costs associated with autism – divides the expenditure of families into ten categories including living costs, care costs, educational costs, medical costs and travel costs. Due to the heterogeneity of autism, autistic people can have a broad range of needs which can result in substantial additional costs. Under the category of living costs, those surveyed reported an annual expenditure of up to €23,920 with a mean cost of €2795.67 per annum. These costs included expenses such as special diet, repairing damage, continence care and extra heat and electricity. Expenditure on the care costs of those surveyed ranged from €0-23,400 with a mean cost of €1564.14 annually. Money spent on educational costs were as much as €10,438.75 per year with a mean cost of €1043.93 per annum. Medical costs were as high as €17,140 per year with a mean cost of €1835.97 annually. As much as €14,400 per year was spent on private therapeutic interventions and assessments alone. Travel costs were as high as €4,800 a year and there was a mean cost of €873.98 annually.³⁷ Moreover, it is important to note that for families in which more than one child has an autism diagnosis, the associated costs are significantly higher.

7. Many of these additional expenses for families arise due to a lack of State services. At her appearance before the Committee, Dr Roddy stated that “it is important to note in the papers I supplied that most of that expenditure related to education and special needs assistants. It was not exceptional services by any means. They were very basic State services.”

8. While studies such as this have considered the amount of money that is spent by families on private services to bridge the gaps where public services cannot be accessed, there has been little research into the spending needs of families that go unmet. In her 2022 thesis, Blackwell notes:

“Autism studies have tended to approach daily living costs with an actual expenditure approach whereby parents complete spending diaries and/or retrospectively list what they spent on different goods and services, usually over

³⁷ *ibid*

a six or 12-month period, and therefore the expenditures studies aim to measure families actual spending rather than what they need to spend.”³⁸

9. Therefore, though the average cost to families of an autistic child is €28,464.89 per child per year, this figure does not account for the needs of an autistic child that go unmet due to a lack of available public services or a lack of finances to access services privately.
10. However, Dr Áine Roddy and Prof Ciarán O’Neill also examine the issues of unmet needs and debt for families of autistic children in their 2020 paper ‘Predictors of unmet needs and family debt among children and adolescents with an autism spectrum disorder: Evidence from Ireland’.³⁹ The authors state that

“The findings from parental reported responses show over 74% of children did not receive one or more services in the previous 12 months. Average debt per year per family was €3259. Regression analyses showed that families that had two or more children with an ASD were more likely to experience unmet needs and incur debt specifically because of the child’s condition than families with one child with an ASD.”⁴⁰
11. The authors also note that there was a broad range in figures relating to the debt incurred by the families surveyed for the study. In some instances reported debt was as high as €150,000. Of the parents surveyed, 73.87% stated that their autistic child had an unmet service need in the previous 12 months. Of that cohort of parents, 38.74% stated that the reason their child had an unmet service need is because they could not afford to pay for the service, 55.41% of respondents with unmet needs were on a waiting list and 60.81% stated that the relevant care, therapy or intervention was unavailable to them.⁴¹ Moreover, of those parents whose child had an unmet service need, 81.08% of them indicated

³⁸ Blackwell, Chloe. [The needs of children on the autism spectrum and their families](#). 2022.

³⁹ Roddy, Áine; O’Neill, Ciarán. ‘Predictors of unmet needs and family debt among children and adolescents with an autism spectrum disorder: Evidence from Ireland’. 2020.

⁴⁰ *ibid*

⁴¹ *ibid*

that the relevant service or services had been recommended to them by a health professional.⁴²

12. The study also identifies that 30.85% of respondents indicated that their child has unmet service needs because private services are unavailable in their area. This further highlights the challenges for autistic people and their families that are presented by a reliance on private healthcare services where public services are unavailable, as these services are overburdened in cities and unavailable in many rural places. Moreover, trying to access services outside of one's area adds to the additional costs paid by parents in the form of travel costs and taking unpaid leave to travel on top of the cost of accessing a private service.
13. As well as factors such as geographical location and multiple diagnoses of autism within a single family unit, Dr Roddy highlighted to the Committee that one parent families often face particularly acute challenges when trying to meet their child's needs.
14. At the same Committee meeting, Ms Angela Locke-Reilly, Advocacy Project Worker at Inclusion Ireland and a parent to an autistic child, identified some of the "hidden costs" of autism which may sometimes be overlooked. Speaking of her son's experience and that of her family, she said:

"My son might go for two months at a time only sleeping for two hours per night. We are up, as a family, for 22 hours. We are using electricity, eating and watching television. We have the lights on. He also has loads of extra gadgets because he would not play with toys or anything like that... My electricity bill is a great deal higher than that of any of my friends."
15. The many and diverse costs that are incurred by families as a result of a child's autism diagnosis are substantial. Some of these costs are hidden costs; such as additional home repair costs, additional energy costs due to a child's difficulty sleeping or additional waste costs due to continence issues. Other costs are incurred as families try to access assessments and therapies privately where

⁴² ibid

public services fall short. Some costs take the form of lost income as parents take unpaid leave to care for their children. Studies by Roddy and O'Neill have shown that these costs amount to an average of €28,464.89 per child per year and that families incurred an average of €3,259 per year in debt.

16. Families of autistic children in Ireland are at an increased risk of poverty and debt due to the costs associated with autism. For this reason, an improvement in public services and better access to better social protection supports are necessary to ensure that autistic children and their families do not live in poverty and may participate fully in society.

The Cost of Autism for Autistic Adults

17. Autistic adults are more exposed to the risk of poverty than their non-autistic peers as a result of the additional costs their diagnosis incurs. This area is under-researched and would benefit from further examination, particularly from the standpoint of policy-making in Ireland. However, research internationally suggests that many autistic people carry an additional financial burden when compared with their neurotypical peers. In research which has been undertaken, attention has focused primarily on costs related to healthcare.⁴³ A literature review by Rogge and Janssen of the available research into the costs of autism identified that one common finding is that “the medical and healthcare costs are significantly higher for individuals with ASD than for the general population.”⁴⁴ Citing a study from 2006⁴⁵, the authors state that the healthcare costs of an autistic person are twice as high as those of a neurotypical person.⁴⁶ In November 2021, the Department of Social Protection published a report undertaken by Indecon International Research Economists titled *The Cost of*

⁴³ Rogge et al. ‘The Economic Costs of Autism Spectrum Disorder: A Literature Review.’ *Journal of Autism and Developmental Disorders*, 2019.

⁴⁴ *ibid*

⁴⁵ Croen, L. A. et al. ‘A comparison of health care utilization and costs of children with and without autism spectrum disorders in a large group-model health plan.’ *Pediatrics*, 2006.

⁴⁶ Rogge et al. ‘The Economic Costs of Autism Spectrum Disorder: A Literature Review.’ *Journal of Autism and Developmental Disorders*, 2019.

Disability in Ireland. Respondents who identified themselves as having “A developmental disability like autism or ADHD” reported average annual additional costs of €14,428 due to their disability in 2020.⁴⁷ It is important to note that many autistic people have co-occurring disabilities and conditions which can result in further costs in addition to those related to autism services.

A Multi-Faceted Approach to Supporting and Including Autistic People

18. A multi-faceted approach is required to address the issues of poverty and the marginalisation of autistic people. While this chapter refers specifically to Social Protection, it is important to note that the provision of high-quality and accessible services across the public sector will reduce costs for autistic people and disabled people. Moreover, for autistic people who can obtain work, equitable access to education and employment supports will also go some way to addressing poverty and social exclusion.

19. The Indecon report suggests that a multi-faceted approach to disability supports is necessary. The survey undertaken for the report found that there was no definitive consensus among respondents as to what form disability supports should take; whether income supports, grants or additional services. Instead, responses reflected a desire for a mixture of supports. The report states that “[A] basic standard income support for all individuals with a disability is unlikely to appropriately address the costs incurred by those most severely limited by their disabilities. In order to effectively support those living with disabilities in Ireland, ongoing state support via income supplements as well as grants and direct service provision is likely to represent the most cost-effective means of achieving policy objectives in relation to reducing poverty, improving income equality and the quality of life of people with a disability in Ireland.”

⁴⁷ The Cost of Disability in Ireland. Report by Indecon International Research Economists for the Department of Social Protection, 2021.

20. The report suggests that “Measures to address the additional costs of disability should be based on a multifaceted approach involving increased cash payments, enhanced access to service provision and specific targeted grant programmes.”
21. The Committee believes that a new approach to disability services must be taken and that it must incorporate the elements of income supports, grants and an improvement in services.

Addressing the Cost of Disability for Autistic Adults

22. The additional costs associated with autism can vary significantly depending on an autistic person’s support needs and whether or not they can be accessed publicly. The Indecon report states that
- “The extent to which additional costs are incurred depends on the nature of an individual’s disability. While it is useful for policymakers to consider the average cost of disability, there is a need for recognition that the actual cost to some individuals who require specific expenditures may be significantly higher than the average.”
23. The Committee believes that a comprehensive approach must be taken towards mitigating the high expenditure associated with autism in Ireland. Along with the aforementioned need for improved public services, there is also a need to increase pre-existing disability supports and consider means testing in the context of the cost of disability.

Disability Allowance

24. Disability Allowance is an allowance for disabled people aged 16 years to 66 years. Disability Allowance is established on the premise that those with a disability are restricted in their ability to work to the same extent as those who are non-disabled. It is paid on a weekly basis. The Department of Social Protection states that:
- “To qualify for Disability Allowance, you must:

- have an injury, disease or physical or mental disability that has continued, or may be expected to continue, for at least one year
- be substantially restricted from doing work that would otherwise be suitable for a person of your age, experience and qualifications
- be aged between 16 and 66. When you reach 66 years of age you no longer qualify for Disability Allowance, but you are assessed for a State Pension.
- satisfy a means test (a test of your income and any income from your spouse or partner, and the results will be used to work out your rate of pay) and habitual residence conditions”

25. The personal rate of Disability Allowance is €220 per week. Additional payments can be paid in cases where the recipient has adult dependents or dependent children.

26. The Disability Allowance is means tested, meaning that those with an income derived from work receive a reduced payment and those who earn in excess of €375 per week cannot access the payment.

27. According to the Disability Federation of Ireland (DFI), more applications for Disability Allowance were refused in 2021 than there were applications allowed. The DFI stated that 13,989 applications were rejected, whereas 13,298 were granted.⁴⁸ Moreover, the DFI stated that, of the 5,575 appeals that were made, only 2,178 appeals were rejected. As such, there is a high rate of appeals that are subsequently allowed, partly allowed or result in revised decisions. Mr Rónán Hession of the Department of Social Protection told the Committee that one reason for the high rate of appeals is the high volume of incomplete applications that are submitted. Mr Hession told the Committee that eligible applicants often submit partially completed applications earlier on and seek to appeal their refusal

⁴⁸ ['More people were refused Disability Allowance than number granted the payment'](#). Irish Examiner, 13 February 2022.

after they have collated the relevant supporting documentation to avail of backdated payments.

28. While this may account for a section of the applications that are allowed on appeal, the Committee believes that it is important for the Department of Social Protection to review its application forms and its methods in consultation with the autistic community and the disabled community to ensure that they are accessible and transparent.
29. The Department of Social Protection must also adopt a rights-based approach to autism and social protection. In effect, this means increasing social protection payments, including disability allowance, in line with a Minimum Essential Standard of Living (MESL).
30. This is of particular importance at present as the purchasing power of those in receipt of social protection supports has declined as costs rise. The purchasing power of those in receipt of social protection supports has declined even further than the purchasing power of those in employment. In April 2023, the Economic and Social Research Institute (ESRI) published a report titled *The Impact of the Irish Budgetary Policy by Disability Status*. The report states that
- “Since the onset of the financial crisis, the rate of payment of disability-related schemes has not kept pace with growth in market income. When social welfare payments do not keep pace with market income growth, the purchasing power and standard of living of welfare recipients fall compared to that of workers. Given barriers to employment, social welfare represents a larger component of income for those with disabilities. For this reason and because they also have higher costs of living compared to those without disabilities, the stagnation of social welfare payment rates is likely to impact them more.”
31. As costs rise, so too does the risk of poverty for autistic people and disabled people in receipt of social protection supports. It is necessary to mitigate these rising costs, including those associated with disability, to ensure that more autistic

people do not experience poverty. The benefits of an increase in social protection supports are also referred to in the Indecon report:

“The Department of Social Protection currently administers several income support payments for individuals with disabilities (disability allowance, illness benefit, invalidity pension, carers allowance, blind pension, partial capacity benefit, and disablement benefit). These programmes can be efficiently used to provide income supplements to individuals with disabilities in Ireland to address rising costs of disability. There would be limited additional administrative costs in providing additional support in this manner.”

32. The Committee believes that increasing the Disability Allowance to supplement income, in tandem with improving public services and introducing targeted supports, to would go some way to addressing the rising cost of disability.
33. Moreover, further consideration should be given to the level of income disregards for supports such as Disability Allowance. While the income disregard for Disability Allowance was raised from €140 per week to €165 per week in Budget 2023, the possibility of further increases should be considered in light of the cost of disability. As stated in the Indecon report:

“Eligibility requirements can be adjusted to account for extra costs of living associated with disability. This could be undertaken with the help of recalculation of the means testing of public benefits to be sensitive to the reduced value of income and assets due to disability costs.”

34. The Committee believes that increases in income disregards should be considered in light of the increasing costs associated with autism and with disability.

Targeted Cost of Disability Payment

35. A targeted cost of disability payment is needed to address the substantial additional costs which arise as a result of the lack of adequate public services for autistic people and disabled people. As stated in previous modules, based on a

survey undertaken in 2018, the cost of autism to families in Ireland was €28,464.89 per child per year. As per the Indecon report, the average annual disability costs for those with developmental conditions such as autism was €14,428 in 2020. Moreover, the Indecon report notes that disability costs vary considerably depending on factors such as the condition in question and the extent of one's support needs. The Indecon report states that

“The evidence presented by Indecon has illustrated that the costs of disability vary significantly by type and severity of disability. The analysis has also shown that extra costs of disability are incurred across a wide range of areas and can include expenditure such as medicines, care and assistance, transport and mobility, costs of social engagement, home adaptation, and day-to-day expenses on items like food and heating the home.”

36. This is of particular importance in light of Indecon's findings that those with developmental conditions such as autism were more likely to live in a household in which family members reduced their work hours or did not work due to care responsibilities. In effect, those with higher support needs often have increased disability-related expenditure as well as less income available to their household to meet these costs. For this reason, targeted supports are required to address the cost of disability for those with the highest disability-related expenditure.

37. The Indecon report also states that

“Concentration of any additional supports should be targeted on those most in need and who face the greatest additional costs of disability. This would be more effective in meeting policy objectives and in enhancing value for money than in introducing additional small scale supports for those who face minor additional costs of disability.”

38. The Committee affirms its view that a payment which targets those with the highest expenditure on autism and on disability is necessary to address the high cost of autism in Ireland.

Supports for Carers

Introduction

39. The Department of Social Protection provides supports to carers to compensate for loss of income due to the inability to work and to pay for care-related expenses. Among the supports available to carers are Carer's Allowance, Carer's Benefit, Domiciliary Care Allowance and the Carer's Support Grant. The Carer's Support Grant is an annual payment which is available to those in receipt of any of the other three supports.

Domiciliary Care Allowance (DCA)

40. Department of Social Protection guidelines describe the Domiciliary Care Allowance (DCA) as

“a monthly payment for a child, aged under 16 with a severe disability who requires ongoing (continual or continuous) care and attention, substantially over and above the care and attention usually required (in excess of that required) by a child of the same age. The child is likely to require full-time care and attention for at least 12 months. There are no PRSI conditions and it is not means tested.”

41. The guidelines state that “The definitions used for terms such as severe or substantial in this qualifying condition are detailed in the DCA Medical Guidelines used by the department in assessing applications for DCA.”

42. The DCA Medical Guidelines document was published in 2014. It defines ‘disability’ as “Any restriction or lack (resulting from an impairment) of ability to perform an activity in the manner or within the range considered normal for a child compared to a child of the same age.”

43. The guidelines do not clearly define the term ‘severe’, instead stating the following:

“The Oxford English Dictionary descriptions of “severe” were discussed – serious, critical, extreme in an unpleasant way. These phrases could be used in the proposed guidelines to describe the nature of eligible disabilities.”

44. There is a lack of transparency around the target population for whom DCA exists. This is likely to cause confusion for applicants as they seek to determine their own eligibility and may cause difficulty for those who wish to apply to understand the process. This is of particular relevance in light of the high rate of applications which were initially refused and later approved on appeal.
45. In 2021, 38.5% of appeals made against DCA rejections were allowed. A further 1.8% were partially allowed and 34.9% of them resulted in revised decisions by the Deciding Officer. Only 24.4% were disallowed and 0.4% were withdrawn. This constitutes a sizeable proportion of rejected applications which were later won on appeal and may raise questions as to why it is so difficult for carers to access this payment.
46. More generally, the Committee has heard from witnesses that the Domiciliary Care Allowance is difficult for carers to access. The DCA application form is an 18-page document featuring a range of highly personal questions pertinent to a child's disability and the extent to which they are disabled. It must be completed in part by the applicant's general practitioner.
47. Many applicants find it very distressing to fill out the document and sometimes seek assistance from parents' groups and charities to do so. In addition, difficulties in accessing GPs can further frustrate the process for carers.
48. This also constitutes an undue burden on applicants. At an appearance before this Committee, Ms Ciara Jones of Autism Support Hub described the DCA application process in the following terms:
- “It is traumatic. They have to put in everything. It is so much information. It is almost like a counselling session for parents when we take them through the form, because they have to verbalise the reasons they feel they are entitled to DCA.”
49. Mr Rónán Hession of the DSP told the Committee that

“We certainly want to try to rationalise the forms wherever we can. Of course, when you have a means test and the added complexity of the medical conditionality, there is a limit to how far you can reduce the application requirements. However, we try to keep the forms readable and short.”

50. However, it is clear that the DCA form remains a challenging and distressing document for carers to complete.
51. The Committee believes that the Department of Social Protection must ultimately move away from a charity model and instead adopt an approach that recognises carers as workers who provide the State with a service. However, until this long-term aim is realised, it is imperative that application processes and application forms – including those for Domiciliary Care Allowance – are reviewed and updated in light of the difficult and upsetting experiences of applicants who engage with them.

Care Beyond Social Protection

52. The Committee believes that care must be recognised as work and that carers must be recompensed for the work they undertake and the services they provide. In line with the Committee’s views that a social model must be applied to autism and to disability, care must be designated as a right for autistic and disabled people with care needs and it must be regarded as a form of labour undertaken by carers rather than an act of charity.
53. ‘Care’ has a broad meaning which encompasses a diverse array of areas such as respite care, foster care, professional care and care for family or loved ones. While this chapter has thus far identified aspects of the various care supports which should be reformed or amended by the Department of Social Protection, the Committee wishes to state its belief that the Carer’s Allowance must be considered beyond the scope of Social Protection and instead viewed as a basic income payment for the work that is undertaken by carers.
54. Many carers and representatives of carers’ organisations have called for a removal of the means test of the Carer’s Allowance.

55. Mr Rónán Hession expressed to the Committee the view of the Department of Social Protection that there is insufficient budget within the Department to remove the means test and that such a policy decision would be beyond the scope of the Department:

“I know what the carers' groups are calling for. They are essentially looking for non-means-tested payments at the same level as the artists' basic income. A bit like with the additional needs payment, our solutions are social welfare-shaped and sized. We have scarce resources which are targeted and we have to use means-testing as a way to target resources at those who have the greatest income need.”

56. The Committee recognises the limits of the scope of the Department of Social Protection to provide non-means-tested compensation for carers. Moreover, the Committee believes that care should not be regarded as a social protection support arising from an inability to work, rather it should be viewed as a form of work in itself.

57. The Committee believes that the Government should apportion a budget to establish a basic income payment or participation income for carers which will mitigate the substantial loss of earnings for the families of those with care needs, recognise the work performed by carers and the savings in expenditure which has benefitted the State due to the labour of carers.

58. The National Economic & Social Council (NESC) published *The Future of the Irish Social Welfare System: Participation and Protection* in November 2020. In this report, NESC proposes that a pilot ‘participation income’ scheme be established. Participation income refers to a payment which compensates those who provide a valuable service to society which is otherwise financially unrewarded or under-rewarded.⁴⁹

⁴⁹ [The Future of the Irish Social Welfare System: Participation and Protection](#). National Economic & Social Council, 2020.

59. Moreover, the Indecon report states that “There is a need to recognise the impact on families of individuals with a disability and in particular, the loss of earnings and sacrifices made by families in caring for those most in need.”

60. In the final report of the Joint Committee on Gender Equality, *Unfinished Democracy: Achieving Gender Equality*, the Committee on Gender Equality also recommended a participation income approach to Universal Basic Income (UBI). It is also noted in the final report of the Committee on Gender Equality that Family Carers Ireland (FCI) endorse an increase to €325 per week to Carer’s Benefit and Carer’s Allowance as well as an increase to the income disregard to €1000 for a couple and €500 for an individual.⁵⁰

⁵⁰ [‘Unfinished Democracy: Achieving Gender Equality’](#). Joint Committee on Gender Equality, 2022.

61. The report by the Committee on Gender Equality states

“FCI suggest that at a minimum, Carer’s Allowance should be an equivalent level to payments made under the foster care scheme. The Committee heard that adults looking after foster children who have additional needs can receive supplementary financial supports from Tusla in addition to the Foster Care Allowance of €325 per week (for a child under 12 years of age) or and €352 per week (for a child aged 12 years and over). However, a family providing care for their own child with serious needs receive a maximum of €302, subject to a means test. As an interim measure, FCI suggest that the Carer’s Benefit and Allowance should be increased to €325 per week, bringing it in line with the Basic Income for the Arts, and the weekly means test disregard should be increased to €1000 for a couple and €500 for an individual. Stakeholders propose the introduction of a participation income’ approach as a potential income support that acknowledges the contribution carers make to society. This would not be means tested and, as distinct from a Universal Basic Income (UBI), would recognise care as a socially valued activity.”⁵¹

62. Family Carers Ireland re-affirmed this view at the final public meeting of the Joint Committee on Autism on 30 May 2023.

63. This Committee supports the view of the Committee on Gender Equality that care should be valued by the State and that carers should be properly compensated for the service which they provide to those for whom they care.

⁵¹ ibid

Chapter 4 – Employment

Introduction

1. Access to employment is an important component of inclusion in society. Moreover, it is a “key determinant of health and life outcomes”, with implications for relationships, housing, physical and mental health, financial security, quality of life, reduced anxiety and depression. Stable employment for autistic in particular has shown to improve health outcomes and life outcomes and to reduce the cost of hospitalisations and supports.⁵²
2. In addition, for many autistic people, employment offers a sense of belonging, an opportunity to develop confidence in a social setting with others and an opportunity to practice interacting with other people.⁵³
3. The right for disabled people not to be discriminated against when seeking employment is laid out in the Employment Equality Acts 1998 – 2015 and is underpinned by the UNCRPD.

⁵² Raymaker et al. “[I] don’t wanna just be like a cog in the machine:” Narratives of Autism and Skilled Employment’. *Autism*, 2023.

⁵³ Chan et al. Beyond Friendship: The Spectrum of Social Participation of Autistic Adults.’ *Journal of Autism and Developmental Disorders*, 2023.

Article 27 of the UNCRPD – Work and Employment

States Parties recognize the right of persons with disabilities to work, on an equal basis with others; this includes the right to the opportunity to gain a living by work freely chosen or accepted in a labour market and work environment that is open, inclusive and accessible to persons with disabilities. States Parties shall safeguard and promote the realization of the right to work, including for those who acquire a disability during the course of employment, by taking appropriate steps, including through legislation, to, inter alia:

Prohibit discrimination on the basis of disability with regard to all matters concerning all forms of employment, including conditions of recruitment, hiring and employment, continuance of employment, career advancement and safe and healthy working conditions;

Protect the rights of persons with disabilities, on an equal basis with others, to just and favourable conditions of work, including equal opportunities and equal remuneration for work of equal value, safe and healthy working conditions, including protection from harassment, and the redress of grievances;

Ensure that persons with disabilities are able to exercise their labour and trade union rights on an equal basis with others;

Enable persons with disabilities to have effective access to general technical and vocational guidance programmes, placement services and vocational and continuing training;

Promote employment opportunities and career advancement for persons with disabilities in the labour market, as well as assistance in finding, obtaining, maintaining and returning to employment;

Promote opportunities for self-employment, entrepreneurship, the development of cooperatives and starting one's own business;

Employ persons with disabilities in the public sector;

Promote the employment of persons with disabilities in the private sector through appropriate policies and measures, which may include affirmative action programmes, incentives and other measures;

Ensure that reasonable accommodation is provided to persons with disabilities in the workplace;

Promote the acquisition by persons with disabilities of work experience in the open labour market;

Promote vocational and professional rehabilitation, job retention and return-to-work programmes for persons with disabilities.

States Parties shall ensure that persons with disabilities are not held in slavery or in servitude, and are protected, on an equal basis with others, from forced or compulsory labour.

4. Autistic persons have the right to an equitable opportunity to work. This right is laid out in Article 27 of the UNCRPD. This section of the UNCRPD requires states to prohibit discrimination against autistic people in employment, protect their rights and promote employment opportunities within the public and private sectors as well as in self-employment.

Autism and Employment in Ireland

5. At present, 85% of autistic people in Ireland are unemployed or underemployed.⁵⁴ Moreover, a report published in 2021 by the Organisation for Economic Co-

⁵⁴ [Autism in the Workplace](#). AslAm and Irish Jobs, 2023.

operation and Development (OECD) stated that “The disability employment gap is much larger than in most other OECD countries and twice the OECD average.”⁵⁵

6. In March 2021, AslAm and IrishJobs published their first report into Autism in the Workplace.⁵⁶ In 2023, AslAm and IrishJobs published a follow-up report.⁵⁷ While the second report showed some minor improvements in some areas compared to the results of the first report, it is clear that considerable work is required to address the inequalities in accessing employment that exist between non-autistic people and autistic people. Among the findings of the report are that 60% of autistic people either don't believe or are unsure that they have the same chance of career progression as non-autistic employees. In addition, 84% of autistic people do not feel confident that employers, managers, colleagues and clients know enough about autism to support them in the workplace. From the perspective of recruiters, 67% of them said they believe it would be more difficult to hire an autistic person or are uncertain about the process.
7. In addition, another study found that disabled people are discriminated against at work at twice the rate of non-disabled people.⁵⁸

Challenging Negative Perceptions and Resisting Stereotypes

8. There are a number of stereotypical ideas applied to autism which the autistic community can find limiting. Some of these stereotypes concern the kinds of work that autistic people may or may not be suited to. While some autistic people find employment in STEM (Science, Technology, Engineering and Mathematics), autistic people are the same as their neurotypical peers in that they can make valuable contributions within all fields of work such as the arts, politics, law, the

⁵⁵ [Disability, Work and Inclusion in Ireland : Engaging and Supporting Employers](#). OECD, 2021.

⁵⁶ [Autism in the Workplace](#). AslAm and Irish Jobs, 2021.

⁵⁷ [Autism in the Workplace](#). AslAm and Irish Jobs, 2023.

⁵⁸ McGrath, Donie; O'Sullivan, Michelle. What is Reasonable? The Operation of 'Reasonable Accommodation' and 'Disability' Provisions Under The Employment Equality Acts 1998–2015. *The Irish Journal of Management*, 2022.

service industry, advocacy, academia and many more. Throughout the course of the Committee's work, autistic witnesses provided insights from perspectives in psychology, academia, medicine and more. It is important that the choices of employment that are available to autistic people are not limited by stereotypical views of autism.

9. Other negative perceptions of autistic people can impact upon their ability to access employment and their satisfaction at work. The 2023 AsIAM/IrishJobs report notes that 62% of respondents to their survey agree that organisations believe that employing and/or supporting autistic employees would be too costly. Furthermore, almost 80% of respondents agree that the majority of employers believe that it is too high risk to employ autistic people.
10. Negative perceptions and stereotypes are a society-wide issue for autistic people. While awareness of autism has grown, it is essential that acceptance and understanding of autism and autistic people is now prioritised across society, including in employment. For this reason, cross-society campaigns must be led by Government to destigmatise autism and promote the inclusion of autistic people within every aspect of life. In addition, targeted campaigns should be rolled out in key areas such as the public and private employment sectors.

Fostering a Culture of Inclusivity in Work and Employment

11. The OECD report *Disability, Work and Inclusion in Ireland: Engaging and Supporting Employers* identifies two primary reasons for the underrepresentation of disabled people in employment; inaccessibility of education for disabled people and a general lack of inclusivity in the Irish labour market. While the chapter of this report on Education seeks to address the issue of inaccessibility in that sphere, this module will consider the barriers that inhibit access to employment for autistic people within the Irish labour market.

12. The OECD report states that

“Other disadvantaged groups, such as older workers, mothers with young children, migrants or Travellers, also struggle to access the labour market – a

labour market geared towards mainstream full-time employment and offering limited work time and work place flexibility. Persons with disabilities are those facing the largest employment disadvantage of all groups.”

13. There is a clear need for a cultural shift in how autism and disability is viewed by society, including employers. Moreover, there is a need to take practical steps to embed a culture of inclusivity in workplaces, wherein autistic people are valued as an asset and differences are accommodated and accepted.
14. As mentioned in other sections of this report, public campaigns are required to promote the understanding and acceptance of autism and autistic people. The State should initiate plans to roll out such campaigns immediately. Likewise, the State must engage with employers through stakeholders such as the Department of Enterprise, Trade and Employment, the Irish Business and Employers Confederation (IBEC) and trade unions to promote the acceptance of autistic people. The State must make employers aware of how autistic people can contribute to their workplaces and promote the subsidies and grants that are available to employers to include and support autistic people.
15. Targeted campaigns should also promote the roll-out of autism training to Human Resources (HR) and management staff in businesses, as well as offering funding to employers to make such training available.

Policy Context

16. There are no autism-specific employment supports provided by the State at present. Employment supports for autistic people are delivered through the same schemes and mechanisms as those for the wider disability community. While the social model of disability informs laws prohibiting the discrimination against disabled people in employment, the approach to employment supports for disabled people in Ireland has historically been in line with the medical model of disability. It is invaluable that Ireland approaches employment and autism with a positive and pragmatic framework underpinned by the social model of disability.

Ms Deirdre O'Connor of the INTO highlighted to the Committee that expectations for young autistic people can often be limiting. She told the Committee that “A lot of the time it is about what [disabled school-leavers] cannot achieve. It is really important that people have good expectations and expect that people with disabilities generally will go into employment.” The Committee affirms its view that it is vital that a social model which enables autistic people to participate in employment should underpin Government policies on employment supports for disabled people.

17. In 2021, the Department of Social Protection published the *Pathways to Work 2021-2025* strategy. The Department states that “the strategy is designed to support those unemployed before the pandemic, those looking to return to work or join the workforce and those facing additional barriers to work, in order to promote better job opportunity outcomes for all.”⁵⁹
18. The *Pathways to Work 2021-2025* guidance document identifies the “binary manner” in which disabled people are treated within the welfare system – “either they are disabled and therefore cannot work (to any significant degree) or they are not disabled.” The document also notes that the welfare system fails to recognise that there is a continuum or spectrum of abilities/disabilities. Importantly, the Department notes that an inconsistent approach is taken to towards the facilitation of those in receipt of Disability Allowance to work. Each support operates with a different set of conditions and a distinct approach to facilitating recipients in earning an income from employment.
19. The OECD report on disability and employment in Ireland notes that employer engagement and outreach “is a weak element in Ireland’s policy landscape”. However, the report goes on to state that
- “the Department of Social Protection has taken steps in the right direction in the past few years through the implementation of an employer outreach unit. Its reach and resources, however, remained rather minimal. To fill this gap and

⁵⁹ [Pathways to Work Strategy 2021 - 2025](#). Department of Social Protection, 2021.

pushed by the CES, the Employer Disability Information (EDI) service was introduced in 2016, as a peer-to-peer service through which employers can obtain the information they need in recruiting and retaining workers with disabilities. This was a timely step as the need for peer support is often expressed, including in the employer survey conducted as part of this project in which peer-to-peer support was found to be the most requested approach. However, the EDI remained small and without impact as it failed to reach small and medium sized businesses, and its funding ended after only a few years. A new contracted-out service was introduced in March 2021, under a new name (Employers for Change) but with a similar objective to provide an effective peer-to-peer service for employers. At this moment, it is too early to tell where the journey will go. The success of the new service will depend predominantly on the amount of resources attached to it: with a current budget of EUR 150 000 per annum, its impact ought to be limited.”

20. Echoing the report of the OECD, ICTU’s submission to the Committee calls for more sustainable funding for Employers for Change as their work has been impactful in building awareness of disability and in supporting employers.
21. The Committee also joins the call for greater and more sustainable funding for Employers for Change to maximise the work they have undertaken thus far in providing information to employers on how to hire and retain disabled staff.
22. This chapter will discuss in greater detail the need for an adequately-resourced public employment service to provide information to employers and disabled jobseekers as well as to link the two groups.

State Employment Supports

23. State supports for autistic people seeking employment and for autistic people in employment are an important way of ensuring that autistic people have equitable access to work and feel supported by their colleagues, management and other support services in their workplace.

24. EmployAbility is a service contracted by the Department of Social Protection. There are 26 EmployAbility offices in Ireland. The purpose of the service is to assist people with a health condition, injury, illness or disability to access employment and to assist employers in recruiting from this pool of jobseekers.⁶⁰ The Department states that the service also includes “in employment support for both the employer and the employee”, “a professional job-matching service to help ensure successful recruitment” and “advice and information on additional employment supports and grants”.⁶¹
25. There are a number of criteria which one must satisfy before accessing EmployAbility. EmployAbility Galway provide the following criteria on their website:
- “Clients must be willing and able to work a minimum of 8 hours per week, and able to progress to independent employment by the end of an 18 month period...We are required to exit people at the end of the 18 month period so we can work with new clients who are also waiting on support from us
26. Clients are required to be job ready, as our goal is to support you in finding a paid job, and help you become independent in that role so you are able to work independently without our support.”⁶²
27. The website also states that “Job readiness is defined by the Department as having the necessary, training, motivation, education and ability to progress to work.”
28. As education and training are regarded by the Department of Social Protection as basic criteria for support through EmployAbility, it is particularly important that autistic people can access those services with support from the State.
29. Furthermore, it is of concern to the Committee that disabled people and autistic people have their support from EmployAbility withdrawn in its entirety after an 18-

⁶⁰ [EmployAbility Services](#)

⁶¹ [EmployAbility Services](#)

⁶² [EmployAbility Galway Website](#)

month period. One of the objectives of the Department of Social Protection's *Pathways to Work 2021-2025* is to ensure that "the wraparound supports are in place to facilitate the participation and employment of people with disabilities." To achieve such a goal, it is important that extensive planning is undertaken before any State supports are withdrawn and that there is a transition to the next phase of employment. Unless an adequate support network has been developed around autistic jobseekers throughout this 18-month period, this deadline represents a cliff edge to service users. It is essential that a support network and a managed transition into the next stage of employment is undertaken with the involvement of the autistic employee, the employer and EmployAbility.

30. The Committee also wishes to voice its concerns about the potentially unnecessary subjection of EmployAbility to a public procurement process. Ms Geraldine Hurley of the Department of Social Protection told the Committee that the service is being tendered on advice "from the Chief State Solicitor's office saying that the current contractual arrangements are not in line with EU procurement rules and legislation."
31. The Committee is concerned that the privatisation of the only available public employment service for autistic people and disabled people may result in a diminished and inaccessible service for those whom it is supposed to serve. The Committee maintains that the profit incentives for private organisations may divert from the primary focus of a human rights-compliant, socially-oriented model of service provision for autistic people and disabled people. It is essential that a community-based public employment service provision is retained and that the support needs of autistic and disabled jobseekers are not superseded by private commercial interests.
32. Moreover, the Committee notes that the Department of Social Protection has obtained the advice of the Chief State Solicitor, however the Committee believes that there is an arguable case that the directive should not apply in this instance

and that further scrutiny should be undertaken to determine the necessity or otherwise of subjecting this vital service to a public procurement process.

33. The Department of Social Protection also provides other employment supports which may benefit autistic people and their employers. For instance, the Wage Subsidy Scheme (WSS) is a financial incentive for private sector employers to employ disabled people. The scheme is available to employers to employ a disabled person whose disability may impact upon their productivity. The State-subsidised wage effectively compensates the employer for any loss in productivity.
34. In addition, the Reasonable Accommodation Fund helps employers and employees with a disability to access, improve or retain their employment through the provision of four grants:
- the Workplace Equipment Adaptation Grant (WEAG)
 - the Job Interview Interpreter Grant (JIIG)
 - the Personal Reader Grant (PRG)
 - the Employee Retention Grant (ERG).
35. At a public meeting on 21 February 2023, representatives of the Department of Social Protection informed the Committee that the Reasonable Accommodation Fund is currently under review. Additionally, the Disability Awareness Support Scheme (DASS) is also made available by the Department of Social Protection to support employers in the private sector in providing training to employees of those who work with disabled colleagues.
36. However, the uptake of these schemes is poor. Mr Rónán Hession, Assistant Secretary General at the Department of Social Protection, told the Committee that:
- “There is a very low level - an unfeasibly low level - of claiming on things like the reasonable accommodation fund and wage subsidy schemes. Clearly, therefore,

they are not working in their current form and we need to change them to make them more user-friendly. We have some ideas on that that I think would help, and we have got a lot of good input from AsIAm and other autism groups.”

37. The lack of uptake and awareness of these schemes is also borne out in the *Autism in the Workplace 2023* report. The report found that 58% of businesses are unaware of the current supports and schemes available to assist them in recruiting or retaining autistic talent. Furthermore, 60% do not believe that there are sufficient supports and information in place for businesses to recruit autistic talent. The report also states that “Many respondents say they don’t know what reasonable accommodations an autistic staff member might require.” It is plain from this report that employers are unsure of what supports are available to them from the State to accommodate autistic staff and that there is uncertainty around how such supports can be accessed. Moreover, it may be that the supports that are available at present are not sufficient in incentivising employers to better consider and accommodate prospective autistic staff.

Wage Subsidy Scheme for Disabled People (WSS)

38. The Wage Subsidy Scheme (WSS) is a financial incentive for employers in the private sector to employ disabled people, including autistic people. The base payment rate is €6.30 per hour, which is paid to employers to subsidise the employee’s wage. In situations where an employer employs between three and six employees, a further 10% is applied to the hourly rate. In these cases, the payment rate is €6.93 for each employee. In the case of an employer who has more than 23 employees, the payment rate is €9.45 per hour for each employee.
39. The Committee believes that the WSS should be reviewed and that changes to the scheme should be implemented to incentivise employers to employ more autistic people. Mr Peter Brabazon of Specialisterne Ireland told the Committee that he believes the WSS is “excellent”, however it is “administratively difficult” and “needs some improvements.” He elaborated that

“We provide support from a financial expert on how to apply for it. Smaller companies find it difficult to apply. Even larger companies find it difficult. We have submitted our ideas on how the process might be streamlined. The wage subsidy support scheme is an excellent system under which a company can get €12,000 plus per year for each person with autism or another disability it employs.”

40. However, the Open Doors Initiative in their Budget 2023 submission indicated that they view the WSS as “outdated” and that it “focuses on the medical model of disability.” The submission states that “The terminology is off putting to both employers and people with disabilities. It also fails to take into consideration people with disabilities who are capable of working to the same level as non-disabled peers but at reduced hours.”⁶³
41. The Committee feels that the WSS should be reviewed through the lens of the social model of disability to ensure that it aligns with the ambition of adopting a rights-based social approach to services and supports for autistic people and disabled people. It is important that such a review results in a scheme which empowers autistic people of varying support needs to obtain employment. The WSS must incentivise employers to employ autistic people and disabled who may work part-time, or work fewer hours or in different work patterns based on the needs and capacity of the person. A review of the WSS should seek to empower autistic people to work in organisations and workplaces which accept them as they are.

Employment Support Models

42. A new model of support for employers and autistic and disabled jobseekers should be established. The Committee believes that pre-existing services for autistic people who wish to work can be developed further and can offer a basis for an updated model of State-provided employment support.
43. The Committee was pleased to learn about instances of good practice in the area of employment for autistic people, which it hopes can be developed and

⁶³ [Budget 2023 Submission. Open Doors Initiative.](#)

replicated across the country. The Committee heard from and received submissions from a range of stakeholders who addressed the matter of employment, including DPOs such as AslAm and the DPO Network as well as other stakeholders such as Specialisterne Ireland, The Irish Congress of Trade Unions (ICTU) and the Trinity Centre for People with Intellectual Disabilities (TCIPD).

44. The Committee welcomes the work of Specialisterne Ireland, which in some cases provides services which complement those available through publicly contracted providers such as EmployAbility. The Committee believes that social enterprises such as Specialisterne Ireland could scale up their operations with multiannual funding from the State.

45. Mr Peter Brabazon of Specialisterne Ireland told the Committee about the growth of the organisation in the ten years since its foundation and identified that there is a high demand for the services they provide:

“In the first year of operation, Specialisterne Ireland placed four people in employment. Last year, we placed 85 people. We have registered almost new 200 candidates this year, which represents an increase of 25% on last year, and we currently have over 1,000 candidates. One of the big issues out there is the demand for the service.”

46. Mr Brabazon also discussed the difficulties which are presented for the organisation as a result of time-bound and restricted funding:

“The main challenge for us is the lack of multi-annual funding. If a charity gets support from Pobal, it might only be for a year and a half. Our main challenge is retaining the employees we have.”

47. The Committee endorses the work of Specialisterne Ireland calls on the Government to provide more sustainable funding on a multiannual to organisations in this area to ensure that they can meet the high demand for their

services and scale up accordingly. Moreover, the Committee believes that experts such as those at Specialisterne Ireland can assist the Department of Social Protection in developing its model of service-provision disability employment.

48. Among the gaps identified by Specialisterne Ireland is the need for training in self-advocacy and “employment etiquette” for autistic people. While a previous chapter on education has considered this issue in relation to students in third level education, the Committee believes that training for the same skills should be provided to those outside of third level education by a State employment service.
49. Likewise, under the model utilised by the TCIPD, support in developing life skills, work skills and self-advocacy skills is provided. Both the model employed by Specialisterne Ireland and TCIPD can be developed further and made available through a public sector service.
50. Another beneficial aspect of the Specialisterne Ireland and TCIPD models is the continued support offered to autistic and disabled employees. As noted above, supports are withdrawn from autistic applicants to the EmployAbility scheme after 18 months. While this may be suitable for some autistic people, others may still require support after this time period, albeit on a less frequent basis. Mr Brabazon told the Committee that while the majority of the autistic people they support go on to work independently, some require a degree of continued support after several years. The Committee believes that publicly provided supports for autistic people seeking to enter employment should be tailored to their needs and that on-going supports should be provided in cases where it is deemed necessary by the autistic employee.
51. More information on the work of the Trinity Centre for People with Intellectual Disabilities in Education - Chapter 2 of this report.

Accommodations in Workplaces

52. A review of the available supports in respect of reasonable accommodation practices in workplaces should be undertaken by the Department of Social

Protection. Instances of good practice in respect of reasonable accommodations should be developed further and should inform such a review.

53. Reasonable accommodation practices – much like Universal Design practices – often benefit whole organisations, including neurotypical and non-disabled staff as well as neurodivergent and disabled staff. ICTU note in their submission the Committee that

“Reducing possible stress points in the workplace is good for everyone. It is also good for business outcomes, as a stress-free workplace helps employers to maintain maximum productivity and to retain staff.”

54. Among the proposals made by ICTU is the ‘reasonable accommodation passport scheme’ which it developed in collaboration with IBEC. Mr David Joyce of ICTU told the Committee about how the scheme functions and its potential benefits:

“The passport scheme provides a confidential live record of adjustments agreed with an employer. The passport is for workers to keep and share with anyone whom they think may need to know about the barriers they face within or outside the workplace, and the adjustments that have been agreed to prevent or reduce its impact in the workplace. A passport system would ensure that everyone is clear about what has been agreed, and reduce the need to reassess these each time an employee changes role or has a change in line management. It can act as a tool to support individuals in fulfilling their potential and contributing to their own success and that of the organisation. We believe that its adoption by employers could encourage the employment of people with autism and open up conversations around reasonable accommodation.”

55. Mr Joyce explained that this scheme not only provides clarity to both employer and employee of what has been agreed in respect of accommodations, but also opens up the opportunity to the employee to discuss reasonable accommodations and matters pertaining to their employment.

“They allow time for employees to explain the kinds of changes or adjustments they might need in order to perform their roles efficiently and productively. The passport might also explain the barriers they encounter so everyone understands the reasons for them. Also, the passport might set out the terms for a review because, obviously, people's conditions change over time. The advantage of this is that the passport is an agreement between a person and his or her line manager, so if the line manager changes or the person's role changes, the latter has this passport that shows what has been negotiated and agreed with a previous line manager.”

56. The Committee endorses the approach taken by ICTU and IBEC in developing a passport scheme, as it represents an opportunity for autistic people to discuss the accommodations that they may need, which employers and employees may both feel challenging to broach otherwise.

57. The responses to the AslAm/IrishJobs survey have demonstrated that employers are not confident in how to approach accommodations for autistic people. In addition, the OECD report, *Disability, Work and Inclusion in Ireland: Engaging and Supporting Employers*, found that:

“Only 10% [of employers] are aware of Ireland’s Reasonable Accommodation Fund while 70% say they have never received any advice from, for example, other companies, employer associations or organisations delivering disability services on how to integrate and retain people who identify as having a disability, but would like to know more about this type of support. All this suggests that disability and disability supports have not arrived in the employment mainstream.”

58. For this reason, it is important that information, advice and support is readily available to employers in respect of the adjustments they can make for autistic staff and it is also essential that information is available to autistic people in respect of what they can request and how to be confident in making these requests. Deirdre O’Connor of the INTO, speaking on behalf of ICTU, told the Committee that

“People need to have information about how to go about putting reasonable accommodations in place. There has to be good information systems regarding support for employers in accessing the funding that is available and in the practicalities of putting reasonable accommodations in place. There have been several initiatives under the comprehensive employment scheme to put employer information services in place but these have not succeeded. There have been pilots that have not succeeded.”

59. The Government should establish a dedicated website to provide information to employers online as well as provide a contact for employers to obtain advice about accommodating autistic and disabled employees in their place of work.

Deirdre O'Connor added that

“One of the other pieces of the comprehensive employment strategy relates to transitions from one stage of life to another such as the transitions from preschool to primary school, from primary school to secondary school and from secondary school into the college or the workplace. Supports need to be targeted there.”

60. There is further information available in the Education chapter about the Committee's recommendation that a dedicated National Transitions Service be developed to assist autistic people in this area.

61. The principal support available to employers for the purposes of making accommodations for autistic and disabled staff is the Reasonable Accommodation Fund. As mentioned previously in this chapter, this fund is under-utilised by employers. The Committee believes that the Reasonable Accommodation Fund and all other funds relating to accommodating disabled staff should be reviewed together. ICTU proposes that all funds pertaining to reasonable accommodations should be amalgamated into a single fund for employers to draw down on the basis of an employee's needs. Such an approach would benefit the employee, whose needs can be addressed in a tailored fashion, and would benefit the employer by providing a single point of contact for the purposes of reasonable accommodations.

62. In addition, it is important that reasonable accommodation funding and other funding for employers should be promoted as a part of a targeted, employer-focused autism acceptance campaign. The Committee believes that for any funding scheme for reasonable accommodations to be successful, autistic employees must feel comfortable disclosing their adjustment needs to their employer. As such, the Government must take leadership in initiating a shift in how autism and autistic people are viewed in workplaces and in society.

63. Along with a cultural shift in the way autism and other disabilities are perceived, the Committee believes that it is essential that self-advocacy skills are taught to autistic people throughout school and third level education. Deirdre O'Connor of the INTO highlighted to the Committee that it is important that children learn these skills in school so that they understand and can advocate for the accommodations they require in the workplace.
64. It is imperative that self-advocacy skills are taught to autistic people and that an understanding and acceptance of autism is promoted across society. These initiatives will benefit autistic people in accessing employment and in other areas of their lives.

Towards a New Model of Employment Supports

65. The Committee recommends that planning is undertaken by the Department of Social Protection and the Department of Enterprise, Trade and Employment to establish a new model of employment support underpinned by the principles of the UNCRPD and a social model of disability. The instances of good practice that are evidenced in the work of the TCIPD, Specialisterne Ireland and Employers of Change must be maximised and made publicly available throughout the State through a reconfigured public employment service.
66. The high rate of unemployment for autistic people and the low uptake of employment supports and incentives demonstrate that the current system of service provision is failing autistic and disabled jobseekers as well as potential employers. As such, the Committee believes that a well-resourced, comprehensive public employment service is needed to provide information and assistance to employers and disabled jobseekers, signpost the available supports and link employers to disabled jobseekers.
67. The OECD report on disability and employment highlights the need for a well-resourced structured employment service to attract employers to hire and retain autistic people and disabled people:

“Successful employer engagement needs a well-embedded and well-accepted structure, i.e. a service that employers know and can access easily and at no cost. The non-existence of such a structure is a major weakness in the Irish system, and finding the right place for it will be critical. In many OECD countries, the Public Employment Service (PES) has a twofold role as a provider of services for jobseekers and employers (and in some countries even threefold because the PES is also responsible for the training of employees). While Ireland’s PES struggles with its legacy as a service for hard-to-employ workers, it has changed remarkably in the past decade and has the potential to transform into a service for all jobseekers and all employers. The key issue is to resource an employer service appropriately, ideally ensuring every employer has a dedicated contact person to turn to in the nearest Intreo office.”

68. When considering the establishment of such a service, the Department of Social Protection must take into account the matters raised in this report, in particular the models utilised by other service providers in the area.
69. Such an employment service should initiate targeted campaigns to highlight the benefits of employing autistic and disabled people, address the need for skills development and job coaching for autistic and disabled people, provide training for employers who wish to employ autistic and disabled staff and provide in-job supports for jobseekers and employers, including a key contact person in the service.
70. The Committee believes that such a public service should be developed in collaboration with pre-existing service providers in this area to ensure that autistic and disabled jobseekers are given the same opportunity to access employment as the rest of society.

Chapter 5 – Health

Introduction

1. This chapter of the final report of the Joint Committee on Autism will consider the issue of health and accessing healthcare for autistic people. While the first chapter of the report considered disability services, the purpose of this chapter is to identify issues - and make recommendations - relating to healthcare outside of disability services.
2. The Committee is deeply concerned by the high rates of serious illnesses experienced by autistic people, the lower rates of life expectancy and the social and structural conditions that have given rise to adverse physical and mental health outcomes for autistic people.

Autistic People, Health and Wellbeing

Overview

3. Autistic adults have poorer health outcomes in comparison with the general population.⁶⁴ A study by Doherty et al frames the issues around autistic people and health in stark terms:

“Autistic adults have poor physical and mental health compared with the general population. Most medical conditions are more prevalent in the autistic population, including diabetes, hypertension and obesity. Autistic people experience premature mortality. Life expectancy is potentially reduced by 16–30 years, with increased mortality across almost all diagnostic categories. In-hospital mortality is also increased. Autistic people are over two times as likely to use emergency departments and to die after attending emergency care and three times as likely to require inpatient admission.”⁶⁵

⁶⁴ Doherty et al. [Barriers to healthcare and self-reported adverse outcomes for autistic adults: a cross-sectional study](#). *BMJ Open*, 2022.

⁶⁵ *ibid*

4. Other medical conditions are also more common in autistic people in comparison with the general population. For instance, between 20% and 40% of autistic people have epilepsy – this rate also rises with age. In comparison, the prevalence rate of epilepsy among the general population is 1%.⁶⁶ The UK autism research charity Autistica published a report that states “Autistic adults who also have a learning disability have been found to be almost 40 times more likely to die from a neurological disorder relative to the general population – with the leading cause being epilepsy.” The report also states that autistic people are “at increased risk of dying younger from virtually every cause of death.”⁶⁷
5. In addition, autistic children also have poorer health outcomes than their neurotypical peers, with a disproportionate rate of obesity having been identified in autistic children as young as 2.⁶⁸
6. Additionally, mental health issues are more common in autistic children and adults in comparison with the rest of the population. In the HSE’s *National Clinical Programme for Self-Harm & Suicide-related Ideation*, the autistic community is identified as a group with specific needs in respect of self-harm and suicidal ideation. The report states that “Suicide, self-harm and non-suicidal self-injury are major health concerns for autistic people. Suicidality is exceptionally common, occurring in 66% of autistic individuals.”⁶⁹ The report also states that suicide risk is seven times higher in autistic people and that estimates of suicidal ideation among autistic young people ranges from between 10.9% to 50%.
7. Despite the need for further research into autistic people in Ireland and their health, it is clear that both autistic adults and autistic children experience a higher incidence of many physical and mental health issues when compared with the general population.

⁶⁶ *Personal tragedies, public crisis*. Autistica, 2021

⁶⁷ *ibid*

⁶⁸ Ketcheson et al. ‘Promoting Positive Health Outcomes in an Urban Community-Based Physical Activity Intervention for Preschool Aged Children on the Autism Spectrum’. *Journal of Autism and Developmental Disorders*, 2021.

⁶⁹ ‘Groups with Specifically Identified Needs’. *National Clinical Programme for Self-Harm & Suicide-related Ideation*, Health Service Executive.

Causes of Increased Health Risks

8. There are a range of factors that contribute to poorer health outcomes for autistic people when compared with the general population. In 2022, Doherty et al published 'Barriers to healthcare and self-reported adverse outcomes for autistic adults: a cross-sectional study'.⁷⁰ The study considers the factors which impede autistic people in accessing health services and the resultant adverse health outcomes. While further research into this area is required, this study is important as it allowed for autistic people to self-report the difficulties that they themselves experience when trying to access healthcare and contrasted this data with self-reported information from a cohort of non-autistic respondents.
9. The study groups the barriers to accessing healthcare thematically: "communication", "sensory processing", "perceived stigma", "planning and organising" and "predictability and control".
10. Under the theme of communication, 62% of autistic respondents indicated that they have difficulty using the telephone to book an appointment, whereas 16% of non-autistic respondents had the same issue. Additionally, 78% of autistic people who were surveyed indicated that they would avoid using the telephone. In addition, 46% of autistic respondents experienced difficulty in communicating with reception staff, whereas 8% of non-autistic respondents experienced the same difficulty.
11. In respect of sensory processing, 51% of autistic respondents said that the waiting room environment was a barrier to accessing healthcare in contrast with 8% of non-autistic respondents.
12. Stigma associated with autism also featured as an obstacle to accessing healthcare. 67% of autistic respondents indicated that they felt they that they would not be taken seriously when describing symptoms, 66% were concerned

⁷⁰ Doherty et al. [Barriers to healthcare and self-reported adverse outcomes for autistic adults: a cross-sectional study](#). *BMJ Open*, 2022.

that they would waste the doctor's time and 63% indicated that they had difficulty in asking for help.

13. Regarding planning and organising, 66% of autistic respondents found it difficult to summarise their medical problems and over 50% found it challenging to make an appointment in advance, prioritise health issues and make changes to their lifestyle or habits.
14. Regarding predictability, 70% of autistic respondents advised that not knowing the wait duration was a particular concern for them, in contrast with 30% of respondents who are not autistic.
15. Evidently, this report identifies a range of barriers for autistic people when accessing primary care services, such as GPs.
16. Saliently, the study also identifies the detrimental effects of such barriers. The report states the following:

“Autistic respondents reported adverse consequences more frequently than non-autistic respondents, including untreated mental (69%) and physical (63%) health conditions. Notably, 60% were told they ‘should have seen a doctor sooner’ and 47% ‘did not attend referral to a specialist’. Thirty-six per cent ‘required more extensive treatment or surgery’ and 34% did not access treatment for a ‘potentially serious or life-threatening condition’. Additionally, they were less likely to ‘attend on schedule for screening programmes’ than the non-autistic respondents.”

17. There are a range of causes of increased incidence of mental health issues for the autistic community, many of which overlap with causes of physical health issues. The study by Doherty et al does not distinguish between mental and physical health issues when collecting data, however it notes that “Autistic individuals were more likely [than non-autistic individuals] to attend for mental health difficulties (61% vs 27%)”.

Access to Mental Health Services for Autistic Children

Child and Adolescent Mental Health Services (CAMHS)

18. The Committee is deeply concerned by the low acceptance rates of referrals to Child and Adolescent Mental Health Services (CAMHS) in some Community Health Organisations (CHOs). In particular, the Committee is alarmed by reports from parents that their child has been refused access to CAMHS services due to their autism diagnosis or their presentation of autistic traits.
19. At a public meeting of the Committee on 23 May 2023, Mary Butler TD, Minister of State with special responsibility for Mental Health and Older People at the Department of Health told the Committee that she does not accept that autistic children are subjected to discrimination when accessing autism services. The Minister of State said that there had been an increase in referrals to CAMHS of 33% between 2021 and 2022, with the Covid-19 pandemic being the driving factor. Minister of State Butler told the Committee that children with a primary diagnosis of autism are typically referred to a CDNT as they require multidisciplinary support. She elaborated that those with a primary diagnosis of a mental condition, such as depression, and a secondary diagnosis of autism generally receive support from CAMHS.
20. However, Adam Harris told the Committee that autistic children seeking to access mental health supports in Ireland are subjected to “structural discrimination”. Mr Harris elaborated:
- “I will give two examples of [structural discrimination] in terms of mental health services. This is very real. If an autistic person and a neurotypical person sit next to each other in school and both of them break their arm, both can go to an accident and emergency department tonight and get that resolved. If they both begin to self-harm and, statistically, the autistic young person will be more likely to do so, the autistic person cannot go to child and adolescent mental health services, CAMHS, in many instances. The bureaucracy and red tape and, really,

the lack of coming to the table and taking responsibility by mental health services has been absolutely devastating for our community. It is a community of people who, when we talk about children, are 28 times more likely to consider suicide.”

21. At the meeting with Minister of State Butler, she acknowledged difficulties in recruitment and retention of staff and highlighted the particular set of challenges that have arisen due to different sections of the HSE, such as CAMHS and primary care, each seeking to recruit from the same pool of potential staff along with the voluntary sector. Mr Bernard O’Regan of the HSE told the Committee that recruitment to CDNTs and to CAMHS are being prioritised in the current HSE recruitment drives.
22. Minister of State with responsibility for Disability, Ms Anne Rabbitte TD told the Committee that a national access policy must be developed to address difficulties in accessing mental health services for children. The Minister of State elaborated that there should be integrated access to primary care, mental health and disability services.
23. The Committee also wishes to note its concerns about parents’ reports of the lack of supervision of their children under CAMHS and the inadequacy of the supports they have received. Ms Karen O’Mahony of the Rainbow Club in Cork told the Committee

“The current provision of Child and Adolescent Mental Health Services needs to be examined, and there are many teens like my son Sean on medication that is not being monitored appropriately.”

24. She elaborated that

“Mine is one of many families in Cork whom this has happened to. Sean was put on medication at the age of six. He was monitored every three months for his weight, blood pressure and height, which is part of being overseen by CAMHS. GPs cannot do that because, obviously, they are not registered psychiatric professionals. It is now more than five years since Sean has seen any doctor. He is now 6 ft 2 in. and very big.

He is on the same level of medication and our doctor cannot interfere with that.”

25. The Committee calls for a review of CAMHS services and a full investigation of reports from autistic people and their families that they have been refused services on the basis of an autism diagnosis or the presentation of autistic traits. The Committee wishes to firmly state its view that any discrimination against autistic children seeking to access mental health supports is unacceptable.
26. While the Committee understands that autistic children with complex needs require multi-disciplinary supports, CAMHS should not refuse to accept referrals of autistic children in the absence of such multi-disciplinary supports.
27. The Committee affirms its view that capacity must be built within the health service to ensure that the best possible services and interventions are provided to those who need them. However, the Committee also understands that multi-disciplinary supports are not readily available throughout Ireland at present. As such, the Committee maintains that mental health services must be provided to autistic children as readily as they are provided to their non-autistic peers through CAMHS. While the Committee accepts that multi-disciplinary supports should be available to children in schools and in their communities through local CDNTs, it must be acknowledged that these services are not yet adequately staffed to provide the multi-disciplinary supports that are regarded as best practice. For this reason, autistic children should not be refused services by CAMHS on the basis of their autism diagnosis.

Mental Health Services for Autistic Adults

28. Some general mental health services for adults are typically provided by voluntary organisations with support from the HSE, although targeted public supports are available for particular groups who are particularly at risk of having a mental health condition. Limited Counselling in Primary Care (CIPC) is available to medical card holders experiencing mild to moderate conditions such as depression, anxiety and stress. There are no autism-specific mental health

services in Ireland, however mental health services tailored to those with an intellectual disability are being developed throughout the country and will also provide some services to autistic people seeking access to mental health supports.⁷¹ Mental health supports are also available privately.

29. At present, there are very few mental health supports available to the autistic community to access publicly. In light of the high rates of mental health conditions and suicidality among the adult autistic community, the Committee believes that it is essential that public mental health supports are clearly sign-posted and are easily available to the autistic community.
30. The Committee believes it is essential that significant investment is made in mental health services for autistic people and for disabled people. In addition, the Committee affirms its view that a diagnosis of autism must not prohibit access to services and that underlying mental health conditions are not dismissed by service providers on the basis of a primary diagnosis of autism.

Mandatory Training for Health Service Staff

31. The difficulties experienced by autistic people seeking to access healthcare demonstrates the need for autism training for all staff who work in healthcare settings. In England, mandatory training for all staff – including administration and support staff – in the National Health Service (NHS) in England was introduced after a sustained campaign by the family of Oliver McGowan, a young autistic person who died in an NHS facility. The Oliver McGowan Mandatory Training programme is run by Health Education England (HEE) and “is designed to provide staff with the knowledge and skills to make reasonable adjustments as well as challenge their preconceptions of learning disabilities and autism.”⁷²

Training for staff is split into two tiers:

- Tier one training is provided to staff who require a general awareness and understanding of the support required by autistic people. These staff

⁷¹ [Mental Health Services for Adults: National Model of Service](#). Health Service Executive.

⁷² Nick Evans. ‘Training nurses in learning disability and autism: Oliver McGowan programme aims to address health inequalities and prevent avoidable deaths.’ *Nursing Management - UK*. 2023

members do not make decisions in respect of an autistic person's care but will likely encounter autistic people in the course of their work.

- Tier two training is provided to all staff who are directly involved in the provision of care to people with learning disabilities or autism.

32. Both tier one and tier two training begin with an e-learning module. The second phase of tier one training is comprised of interactive online training whereas the second phase of tier two training features a one-day in-person training course. Tier two training features information that is particularly pertinent to clinicians and other health staff, including reasonable adjustments, co-occurring conditions and how to avoid “diagnostic overshadowing.”⁷³

33. The Committee calls on the Health Service Executive (HSE) to roll out autism training to all HSE staff and staff in organisations who provide services on behalf of the HSE. The training programme should include comprehensive specialist training for clinicians and staff who care for autistic people, similar to training provided for NHS staff in England.

Autism-Friendly Provision in Primary Care and Private Healthcare

34. Measures must be taken by the State to remove the barriers to accessing healthcare which autistic people encounter. Targeted campaigns within the area of health should be undertaken by the Government and funding should be provided to make changes to the built environment and the modes of service provision.

35. This chapter has considered the factors which deter autistic people from accessing healthcare, including communication methods, inaccessible healthcare facilities and anxieties regarding stigma. It is essential that targeted campaigns and training are provided to general practitioners (GPs), dentists, therapists and other staff who provide private healthcare to address the stigma associated with

⁷³ *ibid*

autism and to make those who work in healthcare aware of the changes and adjustments that they can make to their services and the built environment to be more inclusive of autistic people. Such changes may include the facility to make appointments through an online form rather than by phone, reducing time spent in waiting rooms, making waiting rooms more autism-friendly and providing autism training to GP's secretaries and administrative staff.

36. In addition, guidance should be made available online and funding should be provided to make such changes.

Chapter 6 – Housing, Planning and the Built Environment

Autism, Housing and Homelessness

Introduction

1. Autistic people face the same challenges in accessing housing as their neurotypical peers, as well as additional difficulties that arise as a result of their diagnosis. The Committee has heard from a range of witnesses in previous sessions about the difficulties which autistic people can encounter when trying to navigate complicated processes and complete complex forms to access services and other entitlements. Likewise, many of the same challenges exist when autistic people try to access housing supports. As the processes of accessing social housing supports can differ from one local authority to another, it can be particularly difficult for autistic people.

2. AsIAM states the following in relation to accessing Social Housing Support:

“The complicated nature of the process can be especially taxing for autistic adults, who may be uncomfortable with phone calls and face to face interaction. It can also be a source of distress for parents of autistic children who will likely be involved in similar long-term applications for diagnosis, clinical supports, and education.

Even after the application process, challenges can emerge. The offered housing may not be suited to the autistic person’s sensory needs or can be distant from their place of work or (if children) the specific school which matches their support needs.”⁷⁴

3. It is important to address any barriers which inhibit autistic people in accessing housing support from the State and from Local Authorities, particularly as autistic people are overrepresented in homelessness figures.

⁷⁴ [Housing - AsIAM](#)

4. In the 2020 study *Adult Autism in Homelessness*, the National Disability Authority write:

“The recent Disability and Discrimination in Ireland report (IHREC, 2018) reveals that people with a disability are more than twice as likely as people without a disability to experience discrimination in access to housing and are 1.6 times more likely to experience housing deprivation. Thus, autistic adults are at increased risk of homelessness due to the association between Autism spectrum disorders (ASD), poor socio-economic outcomes and discrimination.”⁷⁵

5. The report continues to state that:

“Homelessness is not an outcome of autism, but of the disabling barriers autistic adults face throughout their lives’ ... Homelessness both arises from and contributes to vulnerability and that the complex interrelationship between autism and homelessness has been under explored. Social isolation, poor skills, lack of community understanding and support, employment disadvantage and discrimination are likely to be key reasons why autistic adults may be more at risk of homelessness.”

6. In addition, the report by the National Disability Authority highlights the particular challenges faced by autistic people when trying to transition out of homelessness:

“Cognitive impairment, difficulties in social skills, dealing with bureaucracy and complex access systems can significantly affect an individual’s ability to obtain and maintain stable housing, and to benefit from supportive services ... Sensory difficulties mean that many autistic people are unable to tolerate noisy, busy housing offices and accommodation where there is a disorganised, unpredictable, or chaotic atmosphere ... Executive function is often impaired in people with ASD and this could make a transition to independent accommodation especially difficult.”

⁷⁵ [Adult Autism in Homelessness: Prevalence, Experiences and Support Needs in an Irish Context - A Mixed Methods Study](#). National Disability Authority, 2020.

7. As autistic people are at a higher risk of homelessness than non-autistic people, it is essential that housing supports and homelessness supports are made more easily accessible to autistic people.

Policy Background

8. *The National Housing Strategy for Disabled People 2022 – 2027* was developed by:

- The Department of Housing, Local Government and Heritage;
- the Department of Health and;
- the Department of Children, Equality, Disability, Integration and Youth.

9. The plan was published in January 2022. This strategy follows on from the *National Housing Strategy for People with a Disability 2011 – 2016*, which was extended to 2021.

10. The 2022 – 2027 Strategy is aligned with *Housing for All*. The Strategy adopts a human rights approach based on the UNCRPD. It identifies six key themes:

- Theme 1 – Accessible Housing and Communities
- Theme 2 – Interagency Collaboration and the Provision of Supports
- Theme 3 – Affordability of Housing
- Theme 4 – Communication and Access to Information
- Theme 5 - Knowledge, Capacity, and Expertise
- Theme 6 – Strategy Alignment

11. The Implementation Plan was due to be published in June 2022, however it has not yet been published. Inclusion Ireland welcomed the publication of the

Strategy, particularly as it utilises a human rights approach. However, Ms Derval McDonagh, CEO, highlighted the need for an implementation plan:

“Now what we need is a concrete implementation plan which will mirror the inclusive process to date and continue to keep disabled people at the centre of the implementation and monitoring of the strategy at local and national level.”⁷⁶

12. The Committee calls for the publication of an implementation plan as soon as possible and believes it should be considered in detail by the Committee on Housing, Local Government and Heritage.

Accessing Social Housing

13. Social housing support is provided by local authorities and approved housing bodies. There is an extremely limited stock of social housing in Ireland and long waiting lists to access it. Moreover, there is an over-reliance on residential care for those with intellectual disabilities, many of whom are also autistic. Ms Derval McDonagh, CEO of Inclusion Ireland told the Committee that there are 2,400 people living in institutional settings and 1,300 disabled people under the age of 65 living in nursing homes and that “thousands of people are living at home with their families and have never had an opportunity to have their own front door key.”

14. Ms Sarah Jane Lavin, an autistic self-advocate and Director at Inclusion Ireland, told the Committee that she lives with her mother at present and wishes to live independently. She added:

“About a year ago, my mother rang the local Deputy to ask where we were on the housing list. She was told that I was on it and that there were places in Naas, but I would have to be aged over 65 to avail of them. The Deputy said “hang on a minute”, there were places in Celbridge for which I needed to be aged over-55.

⁷⁶ [Inclusion Ireland Welcomes National Housing Strategy for Disabled People 2022-2027](#). Inclusion Ireland, January 2022.

What could my mum say? She explained that I do not want to go into residential care. That was the alternative.”

15. The Committee is concerned by the lack of social housing available to autistic people and disabled people. Moreover, the Committee is particularly distressed that residential care is presented as the only available option to many autistic people and disabled people.
16. Additionally, the Committee heard from witnesses that information regarding social housing supports is inaccessible. Ms McDonagh told the Committee about the importance of accessible information:

“Giving people information is about giving people power. Ultimately, one of the biggest barriers autistic people and people with intellectual disabilities face is the lack of accessible information and the lack of accessible processes such as those relating to applying for housing. We need to look at it in a layered way so that accessible information and communication are seen as human rights. It is the bit that gets you the seat at the table. If that is not there to begin with, that barrier has removed you from housing and so many other aspects of civil life so it is a really important point.”

17. In addition, Ms Angela Locke Reilly, Advocacy Project Worker at Inclusion Ireland, told the Committee about the difficulties associated with the application form for social housing support, including the challenges for disabled people in filling out the application form:

“The application process for housing is horrendous. One of my tasks last year was to do research into housing and to look at the practical things we could do to support people. The number one thing that people said was that the application process is a nightmare. When I looked at the application I could not believe that it was over 25 pages. It is ridiculous to expect a person who has an intellectual disability to complete such a form and get all the documents together. It is an ableist system that puts up barriers to prevent people getting access to housing.

Many people did not even know they were supposed to go on the housing list or could go on it. There seemed to be a lack of information for people. If people look for it, they will find it on different Government websites but that is not an option for some people. They need information to be more accessible to them.”

18. The Committee believes that there is an urgent need for a review of the social housing application process as well as the application forms associated with it. Information regarding supports must be accessible to autistic people and disabled people and any barriers which inhibit their access to applying for social housing must be removed.

Universal Design and Accessible Housing

19. Accessible housing must be provided to autistic people and disabled people. Social housing should be built in line with the principles of Universal Design. By developing houses with the principles of Universal Design in mind may prove to be more cost effective than making alterations to homes after they have been built. The Committee looks forward to the cost-benefit analysis report of the National Disability Authority (NDA) regarding Universal Design. Moreover, by embedding Universal Design within housing construction practices, the need to alter buildings is reduced for those who may become disabled later in life or go on to later have an autistic child.
20. Long-term planning is required to ensure that sufficient social housing is built in line with the principles of Universal Design.
21. Moreover, the Committee believes that funding must be made available to families to make the necessary alterations to their homes to accommodate autistic family members. Ms Norma Purtill, Senior Staff Officer at Limerick City and County Council, addressed the Committee on behalf of the City and County Management Association (CCMA). She told the Committee that

“There is currently no provision for people to apply for grants for extensions of private houses to accommodate autistic needs, for example, as allowed for under housing aid for older people, HOP, housing adaptation grants, HAGs, and

mobility aid grants, MAGs. Limerick City and County Council has used the disabled persons grant scheme, DPGS, to provide additional space for autistic needs. However, this would not normally be facilitated due to cost and budget allocation.”

22. The Committee believes that it is essential that provision for housing adaptation is made available to autistic people and their families on the basis of their needs. Moreover, sufficient funding must be provided to Local Authorities to ensure that demands for such adaptation grants can be met.

23. In addition, there is a need to integrate the process of obtaining social housing for autistic and disabled people with the process of obtaining home-based supports. Cross-departmental collaboration between the Department of Housing, Local Government and Heritage and the Department of Health must be embedded. Ms McDonagh told the Committee that:

“A house is absolutely useless unless you have the supports to live there. When we talk about supports it may be personal assistant hours or intensive supports. Some people just need a small bit of support to live independently while others need around-the-clock nursing support.”

24. The Committee hopes that the implementation of the *National Housing Strategy for Disabled People 2022 – 2027* will result in the integration of the provision of housing for disabled people with the provision of home-based supports. Moreover, the Committee believes that it is essential that autistic people and disabled people are provided with social housing which meets their needs.

Public Spaces

Universal Design in Public Spaces

25. Many public spaces are not accommodating of autistic people. The Committee is concerned that issues such as visually cluttered or over-stimulating sensory environments can deter autistic people from visiting public spaces including city

centres, sports stadiums and more. Mr Brendan Allen of the Irish Planning Institute (IPI) told the Committee of recent CPD opportunities that it has developed to promote the implementation of Universal Design and inclusivity in designing public spaces. Mr Allen also told the Committee that, while the IPI is happy to assist in building the capacity of planners to design more autism-friendly spaces, there are resource constraints which limit planners in developing specialist skills in areas such as Universal Design and sensory awareness. Mr Allen said that

“the overall quantum of planners in the public and private sectors must increase to deliver current roles and responsibilities. Only this will allow our members and other built environment professionals specialise further in urban design and neurodiversity issues. Creating obligations without adequate resources will risk raising expectations without necessarily improving outcomes.”

26. However, Mr Allen also indicated that neurodiversity awareness could feature as components of planning programmes in third-level institutions when undergoing accreditation in future.
27. The Committee endorses the work of the IPI in developing and providing CPD within the areas of Universal Design and inclusivity of public spaces. The Committee would welcome the continued cooperation of the IPI in providing and promoting CPD in these areas. The Committee believes that Universal Design, inclusivity and autism-friendliness should form a component of all accredited planning programmes in third-level institutions. Moreover, the Committee notes the need for an increase in the number of planners within the public and private sectors. Additional places in planning programmes in HEIs should be funded and efforts should be made to retain planners in Ireland through measures such as increased options for professional development in the public sector.

Autism-Friendly Public Buildings

28. It is essential that plans are put in place to ensure that public buildings across the country are autism friendly. At present, some organisations in the State have taken the initiative to seek accreditation as autism-friendly buildings and others

have made adjustments to make their buildings more accommodating of autistic people. However, most public buildings remain inaccessible to many autistic people.

29. The Committee has demonstrated its commitment to this issue by working to make Leinster House an autism-friendly complex by December 2023 in collaboration with the Equality, Diversity and Inclusion (EDI) team at Leinster House, the Houses of the Oireachtas Commission and AsIAM. A sensory audit of Leinster House was undertaken by AsIAM and the EDI team. Furthermore, staff in Leinster House – including Members of both Houses of the Oireachtas – are encouraged to undertake autism training. It is imperative that the Oireachtas demonstrates that it is an open and accessible environment that welcomes autistic visitors, staff and parliamentarians alike.
30. The Committee calls on the Government to ensure that all public buildings are made autism-friendly. Moreover, the Committee believes that that departments and other public organisations should seek to make their buildings more accessible to autistic staff. The Committee also hopes that private sector organisations will implement autism-friendly measures in their workplaces.
31. The Committee welcomes the work of other organisations to make their built environment more welcoming of autistic people. The Committee commends the work of Limerick City and County Council in developing an autism-friendly library service. The Committee heard from Ms Patricia Cusack, Executive Librarian at Watch House Cross Community Library in Moyross, who told the Committee about the process of making libraries in Limerick more autism-friendly and how their work has benefited the autistic community. Ms Cusack told the Committee

“I feel that the positives from it have been tremendous. I hope that we will become more and more inclusive going forward. I feel that we saw and are seeing a community that was invisible in a certain sense, particularly in terms of people coming from the Brothers of Charity Services and care in the community

groups. In my experience, they had not been coming into the library in significant numbers before that. It is a wonderful thing that they are now able to come into the library.”

32. The Committee believes that it is essential that public buildings are made inclusive of autistic people. The Committee calls on the Government to provide funding to allow departments and public organisations - including arts, cultural and sports organisations - to access autism training for staff and make adjustments to public buildings to ensure that they are welcoming of autistic people.

Appendix 1 - List of Public Meetings

28 June 2022

National Council for Special Education

- John Kearney, Chief Executive Officer
- Paula Prendeville, Principal Officer, Policy & Practice,
- Mary McGrath, Principal Officer, Operations

[Transcript available here](#)

5 July 2022

Department of Education

- Josepha Madigan TD, Minister of State with responsibility for Special Education and Inclusion

Association of Secondary Teachers in Ireland

- Moira Leydon, Assistant General Secretary, Education and Research
- Miriam Duggan, President-Elect

Irish National Teachers Organisation

- Máirín Ní Chéileachair, Assistant General Secretary and Head of Education and Research
- David O'Sullivan, Assistant General Secretary, Legal, Industrial Relations and Equality Section

[Transcript available here](#)

12 July 2022

Department of Health⁷⁷

- Anne Rabbitte TD, Minister of State with responsibility for Disability

AsIAm

- Adam Harris, Chief Executive Officer

[Transcript available here](#)

20 September 2022

Autism Support Hub

- Ger Kenny
- Ciara Jones

D12 Campaign 4 Inclusion

- Margaret Lowndes

Rainbow Club

- Karen O'Mahony

⁷⁷ Minister Rabbitte, along with responsibility for Disability, has since transferred to the Department of Children, Equality, Disability, Integration and Youth

Special Needs Schools and Classes

- Sarah Murphy
- Miriam Jennings
- Elaine Jenkins

[Transcript available here](#)

29 September 2022

Joint Meeting with the Joint Committee on Disability Matters

Centre for Excellence in Universal Design and the NDA

- Dr Aideen Hartney, Director of the NDA
- Dr Gerald Craddock, Chief Officer of the CEUD
- Dr Dónal Fitzpatrick, Senior Design Adviser of ICT of the CEUD

Independent Living Movement

- Desmond Kenny, Chairperson
- Catherine Gallagher
- James Crawley

AsIAm

- Adam Harris, Chief Executive Officer

[Transcript available here](#)

4 October 2022

The Teaching Council

- Phil Fox, Acting Director
- Bríd Murphy, Acting Head of Initial Teacher Education

Teachers' Union of Ireland

- David Duffy, Education and Research Officer

Fórsa

- Linda Kelly, National Secretary, Health and Welfare Division
- Andy Pike, Head of Education

Irish Primary Principals' Network

- Páirc Clerkin, Chief Executive Officer
- Caroline Quinn, Leadership Team Support

[Transcript available here](#)

18 October 2022

Health Service Executive

- Bernard O'Regan, Head of Operations, Disability Services
- Prof Malcolm MacLachlan, Clinical Lead, National Clinical Programme for People with Disability
- Brian J Higgins, Head of Change, Planning and Delivery, Disability and Mental Health Services

- Mary O’Kelly, Chief Officer, Community Healthcare Office – Dublin South, Kildare and West Wicklow
- Dr Graham Connon, Principal Clinical Psychologist, Community Healthcare Office – Dublin North, North Central and North West

[Transcript available here](#)

25 October 2022

Cavan Autism Parents Support

- Noeleen Smith
- Trina Boylan

Dedicated Children’s Advocacy Warriors

- Aisling Byrne

Involve Autism Dublin 6/Dublin 6W

- Miriam Kenny
- Alan Power

Get Autism Active

- Dr Susan Crawford

Adult Continuing Education at University College Cork

- Eleanor McSherry

[Transcript available here](#)

8 November 2022

Autism Assistance Dogs

- Nuala Geraghty, Chief Executive Officer
- Debbie Carr, Client and Parent

St Joseph's Foundation – Liskennett Farm Equine Therapy Centre

- Michael Hegarty, Chief Executive Officer
- Dr Barry Coughlan, Principal Psychologist
- David Doyle, Project and Services Development Officer

Special Needs Action Group, Athy

- Geraldine Murphy, Chairperson
- Deirdre Archbold, Treasurer

Cara Darmody and Mark Darmody

[Transcript available here](#)

22 November 2022

Solas

- Alan McGrath, Executive Director of Delivery
- Roisin Doherty, Director of Learning Support

Trinity Centre for People with Intellectual Disabilities

- Prof Michael Shevlin, Director
- Hugo MacNeill, Ambassador
- Marie Devitt, Employment Pathways Coordinator
- Barbara Ringwood, Senior Occupational Therapist

Dublin City University

- Fiona Earley, Autism-Friendly University Coordinator
- Dr Mary Rose Sweeney, Head of the School of Nursing, Psychotherapy and Community Health

Department of Further and Higher Education, Research, Innovation and Science

- Simon Harris, TD – Minister for Further and Higher Education, Research, Innovation and Science

[Transcript available here](#)

13 December 2022

Fiacre Ryan and Carmel Ryan

Irish Congress of Trade Unions

- David Joyce, Equality Officer/Developmental Officer/Global Solidarity Officer & Social Policy
- Deirdre O'Connor, Deputy General Secretary at the INTO
- Michelle Quinn, Chair of ICTU Disability Committee

Specialisterne Ireland

- Peter Brabazon, Chief Executive Officer
- Noreen Murphy, Operations Manager

[Transcript available here](#)

24 January 2023

Inclusion Ireland

- Derval McDonagh, Chief Executive Officer
- Angela Locke Reilly, Advocacy Project Worker
- Sarah Jane Lavin, Director and Self-Advocate

Atlantic Technological University

- Dr Áine Roddy, Assistant Lecturer in Health Informatics & eHealth, Department of Health & Nutritional Science at ATU Sligo

[Transcript available here](#)

31 January 2023

Science Foundation Ireland

- Dr Ciarán Seoighe, Deputy Director General
- Dr Lorna Lopez, Associate Professor at Maynooth University and Principal Investigator of the Family Genomics Research Group
- Dr Olive Healy, Associate Professor in Applied Behavioural Analysis in the School of Psychology, Trinity College Dublin

Middletown Centre for Autism

- Rosemary Steen, Chairperson
- Jim Lennon, Chief Executive Officer
- Dr Fiona McCaffrey, Head of Research and Development
- Jill McCanney, Head of Learning Support and Assessment

[Transcript available here](#)

14 February 2023

Irish Human Rights and Equality Commission

- Sinéad Gibney, Chief Commissioner
- Dr Frank Conaty, Commissioner
- Dr Rosaleen McDonagh, Commissioner

Office of the Ombudsman for Children

- Dr Niall Muldoon, Ombudsman for Children

- Karen McAuley, Head of Policy
- Áine Jackson, Policy Officer

Office of the Ombudsman

- Ger Deering, Ombudsman
- Ann-Marie O'Boyle, Investigator

[Transcript available here](#)

21 February 2023

Department of Social Protection

- Rónán Hession, Assistant Secretary, Working Age Income Supports
- Geraldine Hurley, Assistant Secretary, Employment Services
- Annette Conroy, Principal Officer, Employment Services Policy

[Transcript available here](#)

28 February 2023

Psychological Society of Ireland

- Dr Louise Higgins, Senior Clinical Psychologist

Irish Association of Speech and Language Therapists

- Áine Lawlor, Chairperson of IASLT Professional Standards Standing Committee

- Maria Gleeson-Cary, Speech and Language Therapy Manager

Association of Occupational Therapists of Ireland

- Odhrán Allen, Chief Executive Officer
- Rosalind Noël, Senior Occupational Therapist and Member of AOTI Management Team

[Transcript available here](#)

2 March 2023 – Meeting in the Seanad Chamber

Session A:

Linda Whitmarsh and Ronan Whitmarsh, Cavan Monaghan Parents Committee

Máire Bríd Ní Chonghaile and Richard Taylor, Galway Autism Partnership

Síle Parsons, Autism School Dublin 15

Margaret Lowndes, D12 Campaign 4 Autism Inclusion

Órla Egan, St. Joseph's National School, Longford

Josephine Feeney and Donna Leavy

Laura O'Mahony and Raymond O'Mahony

Elisha Sweeney and Colette Heaney, Mayo Autism Camp

Hilda Duignan and Clare Earley, Autism Parents Athlone

Fergal O'Malley and Rachel O'Malley

Mark Devereux, Mount Sion Primary School, Waterford

Leanne Adams and Louise O'Toole

Anne-Marie Ford and Dr Aoiveen Mathews, Tullydonnell Parents Association

Session B:

Mark Kenny and Ger Kenny

Deasún Kelly

Evie Nevin

Nicholas Foote

Amanda Fox, Cara Outreach Support Service, Waterford

Nem Kearns and Aoife Sheridan, Neuro Pride Ireland

Naomhán Mhaonaigh

Darragh Cullivan and Rosaleen Cullivan

Regina Lautwein

Adam Harris, AslAm

Amanda McGuinness

Zarah Doyle, AslAm and SparkAbility

[Transcript available here](#)

7 March 2023

National Disability Authority

- Dr Rosalyn Tamming, Head of Policy, Research and Public Affairs
- Dharragh Hunt, Senior Policy Officer and Public Affairs Advisor

Autistic Doctors International

- Dr Mary Doherty, Founder

[Transcript available here](#)

28 March 2023

University College Dublin

- Julie Tonge, Disability Officer in the Access and Lifelong Learning Centre

CentralReach

- Lisa Marie Clinton, Director of Strategy and Business Development in Adult Transition and Employment

[Transcript available here](#)

18 April 2023

Technological University of the Shannon

- Dr Frances O’Connell, Vice President of Student Education and Experience
- Dr Carolann Bargary, Head of Access and Disability Services
- Lisa Hanlon, Head of Disability Services

Irish Society for Autism

- Pat Matthews, Executive Director
- Tara Matthews, Deputy Executive Director

County and City Management Association

- Norma Purtill, Senior Staff Officer at Limerick City and County Council

Limerick City and County Council

- Damien Brady, County Librarian
- Patricia Cusack, Librarian at Watch House Cross Community Library

[Transcript available here](#)

25 April 2023

The Adult Autism Practice

- Davida Hartman, Clinical Director

Thriving Autistic

- Tara O'Donnell-Killen, Chief Executive Officer
- Jessica K Doyle, Co-Director

Neuro Pride Ireland

- Nem Kearns, Co-Founder
- Cír Doyle, Co-Founder

Blessing Dada, Mental Health Activist

[Transcript available here](#)

16 May 2023

AsIAM

- Adam Harris, Chief Executive Officer

Irish Planning Institute

- Brendan Allen FIPI, Honorary Treasurer
- Emma Flanagan MIPI, Convenor, Practice Committee
- Dr Seán O'Leary MIPI, Senior Planner

National Disability Authority

- Dr Gerald Craddock, Chief Officer, CEUD
- Mary Tallant, Senior Standards and Monitoring Officer

[Transcript available here](#)

23 May 2023

Department of Health

- Mary Butler TD, Minister of State with responsibility for Mental Health and Older People

Department of Education

- Norma Foley TD, Minister for Education

[Transcript available here](#)

30 May 2023

Family Carers Ireland

- Clare Duffy, Policy and Public Affairs Manager
- Catherine Cox, Head of Communications and Policy

Officials of the Mental Health Directorate of the Scottish Government

- Jacqueline Campbell, Head of Autism and Learning Disabilities Unit
- Suzanne Kinross, Policy Manager

[Transcript available here](#)

Appendix 2 – Sustainable Development Goals

In July and September of 2020 respectively, Dáil and Seanad Éireann adopted the following motion with regard to Oireachtas Committee oversight of the implementation of the UN Sustainable Development Goals:

“It shall be the instruction to each Select Committee appointed pursuant to Standing Order 95 that the work programme provided for in Standing Order 100(4) shall include the consideration of such aspects of-

(c) progress on the implementation of the Sustainable Development Goals set out in the United Nations 2030 Agenda for Sustainable Development,

As are within the scope of the Committee’s orders of reference as set out in Standing Orders.”

While this provision does not apply to the Joint Oireachtas Committee on Autism as a special committee, it was nevertheless agreed by the committee that it should outline those goals and sub-targets within the SDG framework as might bear on the issues affecting autistic people as presented to the committee in the course of their work.

The following are the Sustainable Development Goals and sub-targets which, in the view of the committee, are most directly relevant to autistic people in Ireland.

Goal 1 – No Poverty

End Poverty in all its forms everywhere

- By 2030, reduce at least by half the proportion of men, women and children of all ages living in poverty in all its dimensions according to national definitions
- Implement nationally appropriate social protection systems and measures for all, including floors, and by 2030 achieve substantial coverage of the poor and the vulnerable
- By 2030, ensure that all men and women, in particular the poor and the vulnerable, have equal rights to economic resources, as well as access to

basic services, ownership and control over land and other forms of property, inheritance, natural resources, appropriate new technology and financial services, including microfinance

Goal 3 – Good Health and Well-Being

Ensure healthy lives and promote well-being for all at all ages

- Achieve universal health coverage, including financial risk protection, access to quality essential health-care services and access to safe, effective, quality and affordable essential medicines and vaccines for all

Goal 4 – Quality Education

Ensure inclusive and equitable quality education and promote lifelong learning opportunities for all

- By 2030, ensure that all girls and boys complete free, equitable and quality primary and secondary education leading to relevant and effective learning outcomes
- By 2030, ensure that all girls and boys have access to quality early childhood development, care and pre-primary education so that they are ready for primary education
- By 2030, eliminate gender disparities in education and ensure equal access to all levels of education and vocational training for the vulnerable, including persons with disabilities, indigenous peoples and children in vulnerable situations
- Build and upgrade education facilities that are child, disability and gender sensitive and provide safe, non-violent, inclusive and effective learning environments for all

Goal 8 – Decent Work and Economic Growth

Promote sustained, inclusive and sustainable economic growth, full and productive employment and decent work for all

- By 2030, achieve full and productive employment and decent work for all women and men, including for young people and persons with disabilities, and equal pay for work of equal value

Goal 9 – Industry, Innovation and Infrastructure

Build resilient infrastructure, promote inclusive and sustainable industrialization and foster innovation

- Develop quality, reliable, sustainable and resilient infrastructure, including regional and transborder infrastructure, to support economic development and human well-being, with a focus on affordable and equitable access for all

Goal 10 – Reduced Inequalities

Reduce inequality within and among countries

- By 2030, empower and promote the social, economic and political inclusion of all, irrespective of age, sex, disability, race, ethnicity, origin, religion or economic or other status

Goal 11 – Sustainable Cities and Communities

Make cities and human settlements inclusive, safe, resilient and sustainable

- By 2030, provide access to safe, affordable, accessible and sustainable transport systems for all, improving road safety, notably by expanding public transport, with special attention to the needs of those in vulnerable situations, women, children, persons with disabilities and older persons
- By 2030, provide universal access to safe, inclusive and accessible, green and public spaces, in particular for women and children, older persons and persons with disabilities

Appendix 3 – Orders of Reference

Order of the Dáil

The following order was agreed by Dáil Éireann on 14 December 2021.

That, in accordance with the recommendation of the Committee on Standing Orders and Dáil Reform pursuant to Standing Order 118A(2)(b), a Special Committee on Autism is hereby established, with Orders of Reference as contained in the report of the Committee on Standing Orders and Dáil Reform entitled "Orders of Reference for Special Committee on Autism", a copy of which was laid before Dáil Éireann on 8th December, 2021.

[14 December 2021](#)

Order of the Seanad

The orders of reference were agreed by the Seanad on 9 February 2022.

[9 February 2022](#)

Dáil Orders of Reference for Special Committee on Autism

That, notwithstanding anything in Standing Orders—

- (1) a Special Committee consisting of 9 members of Dáil Éireann be appointed, to be joined with a Special Committee to be appointed by Seanad Éireann, to form the Joint Committee on Autism;
- (2) the Joint Committee shall consider matters relating to the services and supports provided by the State for autistic people and, in so doing, may have regard to the Resolutions of Dáil Éireann of 2 April 2019 and 29 April 2021 on these matters;
- (3) the Joint Committee shall make its final report to both Houses of the Oireachtas on the matters contained in paragraph (2) within nine months of the first public meeting of the Joint Committee, and shall, on the making of its final report, stand dissolved;⁷⁸⁷⁹

⁷⁸ 9th March, 2023

Dear Leo,

I write to inform you that the Committee on Parliamentary Privileges and Oversight has agreed to the Committee's request to extend the deadline for its final report to 1st June 2023.

The Motion changing the Orders of Reference to this effect was agreed by Seanad Éireann on 7th March 2023.

The Committee's agreement was incorporeal and noted by the Committee at its meeting of 8th March 2023.

Yours sincerely,

*Ivan Farmer
Clerk to the Committee on
Parliamentary Privileges and Oversight*

⁷⁹ Our Ref: D51/13

Leo Bollins, Clerk to the Joint Committee on Autism

Rith an Dáil an tOrdú seo istigh an 07 Márta, 2023 agus cuirtear faoi bhur mbráid é mar eolas daoibh mar is cuí.

The attached Order was passed by the Dáil on 7th March, 2023 and is forwarded to you for your information and attention as appropriate.

*Richard Drumm,
Journal Office
7th March, 2023*

That the Orders of Reference of the Special Committee on Autism, contained within the Report of the Committee on Standing Orders and Dáil Reform entitled "Orders of Reference for Special Committee on Autism", as agreed by Order of the Dáil of 14th December, 2021, be amended in paragraph (3), by the deletion of "within nine months of the first public meeting of the Joint Committee" and the substitution therefor of "on or before 1st June, 2023."

- (4) the quorum of the Joint Committee shall be four, at least one of whom shall be a member of Dáil Éireann, and one a member of Seanad Éireann;
- (5) members of either House, not being members of the Joint Committee, may attend and take part in proceedings of the Joint Committee, or any sub-Committee thereof, but without having a right to vote or to move motions or amendments, save where they attend, pursuant to Standing Orders, as a substitute for an absent member (or for a substitute not in attendance);
- (6) having nominated members to be members of the Joint Committee, the parties in Government shall nominate one of those members to be Cathaoirleach of the Joint Committee; and
- (7) the Joint Committee shall have the powers defined in paragraphs (1), (2), (3), (4), (5), (9) and (10) of Standing Order 96.

Seanad Orders of Reference for Special Committee on Autism

That, notwithstanding anything in Standing Orders—

- (1) a Special Committee consisting of 5 members of Seanad Éireann be appointed, to be joined with a Special Committee to be appointed by Dáil Éireann, to form the Joint Committee on Autism;
- (2) the Joint Committee shall consider matters relating to the services and supports provided by the State for autistic people and, in so doing, may have regard to the Resolutions of Dáil Éireann of 2 April 2019 and 29 April 2021 on these matters;
- (3) the Joint Committee shall make its final report to both Houses of the Oireachtas on the matters contained in paragraph (2) within nine months of the first public meeting of the Joint Committee, and shall, on the making of its final report, stand dissolved;
- (4) the quorum of the Joint Committee shall be four, at least one of whom shall be a member of Seanad Éireann, and one a member of Dáil Éireann;
- (5) members of either House, not being members of the Joint Committee, may attend and take part in proceedings of the Joint Committee, or any sub-Committee thereof, but without having a right to vote or to move motions or amendments, save where they attend, pursuant to Standing Orders, as a substitute for an absent member (or for a substitute not in attendance);
- (6) having nominated members to be members of the Joint Committee, the parties in Government shall nominate one of those members to be Chairperson of the Joint Committee; and
- (7) the Joint Committee shall have the powers defined in paragraphs (1), (2), (3), (4), (5), (9) and (10) of Standing Order 72.

Powers of Select Committees – Dáil Standing Order 96

96. Unless the Dáil shall otherwise order, a Committee appointed pursuant to these Standing Orders shall have the following powers:

- (1) power to invite and receive oral and written evidence and to print and publish from time to time—
 - (a) minutes of such evidence as was heard in public, and
 - (b) such evidence in writing as the Committee thinks fit;
- (2) power to appoint sub-Committees and to refer to such sub-Committees any matter comprehended by its orders of reference and to delegate any of its powers to such sub-Committees, including power to report directly to the Dáil;
- (3) power to draft recommendations for legislative change and for new legislation;
- (4) in relation to any statutory instrument, including those laid or laid in draft before either or both Houses of the Oireachtas, power to—
 - (a) require any Government Department or other instrument-making authority concerned to—
 - (i) submit a memorandum to the Select Committee explaining the statutory instrument, or
 - (ii) attend a meeting of the Select Committee to explain any such statutory instrument: Provided that the authority concerned may decline to attend for reasons given in writing to the Select Committee, which may report thereon to the Dáil, and
 - (b) recommend, where it considers that such action is warranted, that the instrument should be annulled or amended;

(5) power to require that a member of the Government or Minister of State shall attend before the Select Committee to discuss—

(a) policy, or

(b) proposed primary or secondary legislation (prior to such legislation being published),

for which he or she is officially responsible: Provided that a member of the Government or Minister of State may decline to attend for stated reasons given in writing to the Select Committee, which may report thereon to the Dáil: and provided further that a member of the Government or Minister of State may request to attend a meeting of the Select Committee to enable him or her to discuss such policy or proposed legislation;

(9) subject to any constraints otherwise prescribed by law, power to require that principal office-holders of a—

(a) State body within the responsibility of a Government Department, or

(b) non-State body which is partly funded by the State,

shall attend meetings of the Select Committee, as appropriate, to discuss issues for which they are officially responsible: Provided that such an office-holder may decline to attend for stated reasons given in writing to the Select Committee, which may report thereon to the Dáil; and

(10) power to –

(a) engage the services of persons with specialist or technical knowledge, to assist it or any of its sub-Committees in considering particular matters; and

(b) undertake travel;

Provided that the powers under this paragraph are subject to such recommendations as may be made by the Working Group of Committee Cathaoirligh under Standing Order 120(4)(a).

Other Orders of the Dáil and Seanad

Dáil Order re First Meeting

That—

- a) the Joint Committee on Autism, and
- b) the Joint Committee on International Surrogacy,

may meet, notwithstanding the fact that in advance of the first meetings of each Committee, the full membership of either has not yet been appointed.

[1 March, 2022](#)

Seanad Order re First Meeting

That—

- a) the Joint Committee on Autism, and
- b) the Joint Committee on International Surrogacy,

may meet, notwithstanding the fact that in advance of the first meetings of each Committee, the full membership of either has not yet been appointed.

[3 March 2022](#)

Appointment of Members

Senators were nominated by the Seanad Committee of Selection and appointed by Order of the Seanad on [24 February 2022](#).

Deputies were nominated by the Dáil Committee of Selection and appointed by Order of the Dáil on [1 March 2022](#).

Deputy Pat Buckley was nominated by the Dáil Committee of Selection and appointed by Order of the Dáil on [12 July 2022](#).

The current [list of members](#) is available below on the [Committee's Web site](#).

Nomination of Chairperson

Letter from the Clerk to the Government Whips

From: Leo Bollins

Sent: Tuesday 1 March 2022

To: All Government Whips:

Dáil Minister of State Deputy Jack Chambers, Government Chief Whip,
Fianna Fáil

Deputy Brendan Griffin, Fine Gael Whip

Deputy Marc Ó Cathasaigh, Green Party Whip

Seanad Senator Seán Kyne, Fine Gael Whip

Senator Robbie Gallagher, Fianna Fáil Whip

Senator Vincent P Martin, Green Party Whip

Subject: Nomination to be Chairman of the Joint Committee on Autism

Nomination to be Chairman

Following the appointment of members to the Joint Committee on Autism, I would like to request that the parties in Government would let me know of their nomination of one of the Members of the Committee to be Cathaoirleach / Chairperson in accordance with the orders of reference.

I have listed the membership below.

Orders of Reference

The orders of reference for the Joint Committee on Autism provide for the nomination of the Cathaoirleach / Chairperson as follows:

6) having nominated members to be members of the Joint Committee, the parties in Government shall nominate one of those members to be Cathaoirleach / Chairperson of the Joint Committee; ...

Leo Bollins

Cléireach don Choiste | Clerk to the Committee

An Comhchoiste um Uathachas | Joint Committee on Autism

Seirbhís Thithe an Oireachtais | Houses of the Oireachtas Service

Letter from the Government Whips to the Clerk

From: Jack Chambers

Sent: Thursday 10 March 2022

To: Leo Bollins

Subject: RE: Nomination to be Chairman of the Joint Committee on Autism

Dear Leo,

Senator Carrigy is the Government nominated chairperson of this committee.

Regards,

Jack

Houses of the Oireachtas

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Kildare Street

Dublin 2

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