

Submission on the Education of Persons with Special Educational Needs (EPSEN) Act 2004

Disabled Women Ireland

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Introduction

Disabled Women Ireland (DWI) welcomes the opportunity to provide a submission on the Education of Persons with Special Educational Needs (EPSEN) Act 2004. DWI is committed to the realisation of the UN Convention on the Rights of Persons with Disabilities (UN CRPD), wherein disabled people are entitled to an education under Article 24, along with Article 42 of the Irish Constitution.

In this submission, we will outline the aspects of EPSEN that support disabled children to realise their right to an education, as well as highlight the issues and barriers which inhibit children from accessing an inclusive education system as they are entitled to under Article 24 UNCRPD. In addition to outlining these challenges, we will also provide suggestions on how EPSEN should be amended to ensure a human-rights compliant, inclusive educational framework for disabled children/ children with special educational needs with concomitant required policy and practise changes.

About Disabled Women Ireland

DWI is Ireland's only national cross-impairment Disabled Persons' Organisation (DPO)¹ representing disabled women, girls and non-binary people. DWI is an unfunded, entirely voluntary all-island organisation led and directed by our members who are located across 25 counties North and South, living in both urban and rural areas. Our members self-identify as disabled and we understand disability as a broad concept which includes physical, sensory, mental and intellectual impairments and which is in keeping with the conceptualisation of disability described in the UN Convention on the Rights of Persons with Disabilities (UN CRPD)².

Originally established in 2018, DWI advocates for measures which enable disabled people to participate meaningfully, equally and fully in all aspects of society in line with human rights obligations, with specific insight into the interaction of gender and disability. We adhere to a human-rights and equity-based view of disability justice which aligns with the Social, rather than Medical, model of disability.

A note on language:

In keeping with the Social Model of disability, which understands disability as an interaction between an individual's impairments or differences and societal and structural barriers, we will mainly use identity-first-language, or 'disabled people', throughout this submission. However, we alternate between the person first language used in the UN CRPD ("persons with disabilities") and identity-first language in recognition of the multiple ways in which disabled people may choose to identify.

¹ A DPO is an organisation whose primary focus is advocating for the rights of disabled people where a clear majority at all decision-making levels are disabled people themselves, as defined under General Comment No. 7 (2018) of the UN CRPD: <http://docstore.ohchr.org/SelfServices/FilesHandler.ashx?enc=6QkG1d%2FPPRiCAqhKb7yhsnbHatvuFkZ%2Bt93Y3D%2Baa2pjFYzWLBuOvA%2BBBr7QovZhbuyqzIDN0plweYI46WXrJJ6aB3Mx4y%2FspT%2BQrY5K2mKse5zjo%2BfvBDVu%2B42R9iK1p>

² Article 1, UN Convention on the Rights of Persons with Disabilities (Dec. 2006): <https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities/article-1-purpose.html>

Furthermore, while we recognise and support the capacity and autonomy of young people who fall within the scope of the ESPEN Act, for clarity we will follow the Convention on the Rights of the Child's lead in using 'child' to refer to all individuals under the age of 18 and/or in primary or secondary education for the purposes of this submission.

Language Use in the Act

DWI first wish highlight our concern with the ongoing use of the term "special educational needs" and the description of disabled children as having "special needs". Such language, aside from being antiquated and patronising, is incompatible with a human rights-based understanding of disability and the UN CRPD. The needs of children with disabilities are exactly the same as their non-disabled peers, but disabled children can require extra support to ensure those needs are met. Framing the needs of disabled children as "special" implies that these needs are somehow additional, and therefore are non-essential.

Following consultation with our members, Disabled Women Ireland instead suggest the use of the term "**individualised educational requirements**" as we feel that this language better reflects a human rights understanding of disability. It frames those with individualised educational requirements as rights holders and frames the supports needed to enable children to fulfil these rights as being essential and non-negotiable. We also feel that the use of the term "individual" focuses attention on the individual themselves and emphasises the importance of an individualised approach, one that is centered on the child themselves.

"[The] Language needs to be challenged. It's supports that are necessary to make sure that those needs are met that are missed. Not special needs, the same needs"

- **DWI Consultation Participant**

Recommendations:

- Amend the language used within the EPSEN Act in line with a human-rights based understanding of disability which centres the individual needs of the disabled child.

EPSEN, the UN CRPD and Inclusive Education

Under Article 41 of the Irish Constitution and Article 28 of the UN Convention on the Rights of the Child (UN CRC), children living in Ireland have the right to an education. This right is reaffirmed in Article 24 of the UN CRPD, which states that all disabled people, including children, have the right to an education on an equal basis with others³. Article 24 also requires States to create an "*inclusive educational system at all levels*", and must ensure that disabled children are not "*excluded from the general educational system on the basis of disability*"⁴.

³ Article 24: Education; UN Convention on the Rights of Persons with Disabilities.

⁴ *ibid.*

While the EPSEN Act supports the concept of an inclusive education system, it contains a number of caveats which permit a separate, segregated education system for disabled children. The EPSEN act says that inclusive education shall be created "*wherever possible*" and can be overruled in circumstances where providing for inclusive education would be considered to be "*inconsistent with the best interests of the child*" or "*the effective provision of education for children with whom the child is to be educated.*"⁵

Including these caveats in the EPSEN Act is deeply problematic for two reasons. First, these stipulations place the EPSEN Act in direct contravention of the UN CRPD. Reflecting this, in their Joint Statement on the rights of children with disabilities, the CRC and CRPD Committees state that:

*"The Committees emphasize that high-quality inclusive education requires the education of all children on equal terms in the same general education system, adapting the educational system to the diverse educational requirements, abilities, potentials and preferences of each child. The Committees also reaffirm that the right to quality inclusive education is not compatible with sustaining two systems of education: a mainstream education system and a special/segregated education system."*⁶

Following its recent review under the UN CRC the Committee reasserted their position by recommending in their Concluding Observations that the Irish State must "*ensure inclusive education in early childhood education and mainstream schools for all children with disabilities.*"⁷

Secondly, there is little evidence to support the notion that inclusive educational systems are not in the best interests of either disabled children, or the non-disabled children with whom the child is educated. A 2016 report found that after reviewing 280 articles across 25 countries, inclusive educational systems were beneficial to **both** disabled students **and** their non-disabled peers.⁸ There is a danger that the use of language in the Act suggesting that inclusive education could be inconsistent with non-disabled children's educational interests may lend undue legitimacy to prejudiced views that the presence of disabled children in mainstream schools and classes detracts from the classroom environment for other children.

Increases in segregated education

That the EPSEN Act continues to permit the existence of a segregated, separate education system for disabled children is particularly egregious given the deeply concerning increase in

⁵ Section 1 of the Education of Persons with Special Educational Needs, 2004.

⁶ Committee on the Rights of the Child and Committee on the Rights of Persons with Disabilities, 'Joint Statement: The rights of children with disabilities' (2022)

⁷ Committee on the Rights of the Child, 'Concluding Observations on the Combined Fifth and Sixth Periodic Reports of Ireland' (2016) UN DocCRC/C/IRL/CO/5-6, para 37(c)

⁸ Hehir *et al*, A Summary of the Evidence for Inclusive Education (2016). Available at: <https://files.eric.ed.gov/fulltext/ED596134.pdf>

the numbers of children being educated in separate environments, namely in "special schools" and in "special classes" within mainstream schools. As of 2022, there are 2,535 such classrooms in schools across Ireland and 383 new special classes opened this year alone⁹. As of 2021, 8,018 children are educated in so-called "special schools"¹⁰. Also concerning is the fact that many children with disabilities are on waiting lists for places in such schools or travel long distances to attend such schools because their needs cannot be met elsewhere. While an education system which comprises a segregated education system for disabled children is not compatible with an inclusive education model and contravenes the Committee's recommendation, the popularity of such classes and schools arises from a fear that children attending mainstream education will not receive the supports that they require to participate fully in education.

As highlighted by the Ombudsman for Children's 2022 Report '*Plan for Places*', the State's reliance on creating more special classrooms to address the current increases in demands is particularly concerning as "*if the Department continues to generate solutions that contain some element of separation, then it will become increasingly difficult to unwind them in the future.*"¹¹

Recommendations:

- Amend the EPSEN Act to ensure the adoption of an inclusive education system, informed by the principles of Universal Design for Learning, across all educational settings as required by the State's obligations under the UN Convention on the Rights of Persons with Disabilities.
- Ensure that all educational establishments are made fully accessible, including for those with sensory impairments and/or sensory processing differences.
- The Departments of Education and of Children, Equality, Disability, Integration and Youth should co-create a dedicated National Strategy or appropriate and actionable policy framework, with measurable timeframes and targets to prioritise transition from the current segregated educational system to an inclusive UNCRPD-compliant system. Goals and targets of this strategy should be identified in close consultation with disabled people through their CRPD identified representative organisations, with a particular focus on prioritising the input of disabled children and young people. We further recommend that the relevant Ministers provide an annual update on implementation of the strategy to the Dail and to relevant CRPD monitoring bodies, such as IHREC.

⁹ Minister of State for Education, Norma Foley TD., Joint Committee on Disability Matters debate, Discussion, Education and the UNCRPD, 20 September 2022 [35423/22]

¹⁰ Department of Education, Education Indicators for Ireland. December 2021

¹¹ Ombudsman for Children, Plan for Places, June 2022.

Facilitating Inclusive Education: Access to Resources and Supports

A key step in creating an inclusive education system is ensuring that school communities have access to the resources needed to create inclusive educational settings. Indeed, in our consultation, many of our members highlighted examples of good practice and excellent support by schools, teachers and other members of the school community. For example, one member spoke about additional supports that were provided in their child's classroom, but were accessible to all students in the class:

“They have a reading corner in the mid in their corner of their room, any stage during the day a child can...go over and sit down. They have fidget toys, they have ear defenders, they have all these different things that if a child just needs a break at any stage they can go. They don't need to ask permission. They don't need the [individualised plans], or anything like that, and not only does that help those children who are disabled it helps normalize it because it's not just something that only disabled kids have permission to do. Anybody regardless of [disability]. People just sometimes need a break from things. “If classroom itself is still too stressed, they have sandboxes and water boxes in the hallways of the classrooms that teach this support. [The] teacher can take this child outside...and these are just the normal part of their everyday school experiences, regardless of their disabilities.”

Others spoke about additional teachers in classrooms who give individualised support when and where it is needed most:

“In my child's school they have a support teacher – not for any particular student – but as a support for the teacher and it works really well.”

While there is still a need for training and awareness raising around inclusive education, the feedback provided to us from our members suggest that when resources are made available to schools, many are using those in effective ways to the advantage of both the disabled and non-disabled children in those schools.

However, our members also spoke at length to the reality that many schools do not have access to the resources required to ensure an inclusive education system. In the absence of appropriate resources to facilitate inclusive education schools, we are seeing (as discussed above) an increase in the number of special classrooms and segregated units being created within mainstream education and children being left without a school place. The result of this is that children are not being able to access their right to education as guaranteed under the UNCRPD and the State is failing in its responsibilities to disabled children.

Our members, along with other disabled persons organisations such as ASIAm and schools themselves, have raised concerns that the number of SNAs overall continues to be insufficient.¹² The result of this is that many students are left without the support needed to

¹² Majority of principals lack confidence in special education council - Conor Capplis, Irish Independent (5 December 2022): <https://www.irishexaminer.com/news/arid-41022065.html>

participate in education. Moreover, since the start of the COVID-19 pandemic, the number of SNAs in mainstream education remains unchanged leading to an increase in unmet need.¹³ This is despite the fact that the number of SNAs in special schools continues to increase, with 1,100 more SNAs allocated for 2022/23. Further, recent difficulties in sourcing substitute teachers, due to the rising cost of living and limited housing provision, has resulted in many SNAs being reassigned to fulfil teaching roles.¹⁴

Specific cohorts of disabled children are disproportionately affected by the lack of support and a lack of understanding of what is required for inclusive education. These include children with intellectual disabilities, Autistic and otherwise neurodivergent children, d/Deaf children, non-speaking children and/or children who communicate using Augmentative and Alternative Communication (AAC). For example, reports suggest a lack of understanding, training and resources for staff to support children who use Augmentative and Alternative Communication (AAC).¹⁵ Few children using AAC are facilitated in mainstream classrooms and until 2019 no AAC user had completed the Leaving Certificate in Ireland. We call for improvise guidelines to better recognise, respect and increase access to all forms of AAC.

Placing children with disabilities on reduced timetables is a common practice in Irish schools. A report by Inclusion Ireland found that approximately one in four children with an intellectual or developmental disability had been placed on reduced timetables and this lasted for more than 20 days for half of these children.¹⁶ This is despite guidelines from the Department of Education specifying that it should only occur in circumstances where it may be "*part of a transition or reintegration intervention, based on the needs of the individual students*" and should not be used "*as a behavioural management tool in the form of a sanction*". In most cases, the justification given for placing a child on reduced timetables is that they are displaying 'challenging behaviour'. This is stigmatising for disabled children and does not recognise that what is often deemed 'challenging behaviour' is most often a response to environmental factors, lack of accessibility and lack of support. It also denies children their right to education.

Insufficient access to resources is of particular concern to DWI, given that not all children with individual educational requirements will be recognised as having such requirements, particularly those from minority groups. For example, many groups including girls, non-binary people, members of the Traveller community and those from other ethnic minority or migrant backgrounds have historically not been recognised as being disabled or as having educational needs; for example there are stark disparities in access to Autism diagnosis for

¹³ Department of Education, Special Needs Assistant Allocation 2022, Circular No 0035/2022, May 2022

¹⁴ Principals warn of 'devastating' impact of teacher shortage - Emma O Kelly, Education Correspondent, RTÉ (28 October 2022): <https://www.rte.ie/news/education/2022/1028/1331821-teacher-shortage/>

¹⁵ An autism class opens. What happens then? - Irish Examiner (12 September 2022): <https://www.irishexaminer.com/news/spotlight/arid-40948382.html>

¹⁶ Education, Behaviour and Exclusion The Experience and Impact of Short School Days on Children with Disabilities and their Families in the Republic of Ireland - Inclusion Ireland, September 2019.

girls¹⁷ and ethnic minority children ¹⁸ and in diagnosis and support for ADHD for girls¹⁹ and ethnic minority children.²⁰ While it is no replacement for recognising and providing individualised supports to individuals in these groups, inclusive educational systems will create fewer educational barriers and stressors for these ‘missed’ students, for children living with unstable home environments (due to abuse in the home or other factors) and for the student body as a whole.²¹

Recommendations:

- Ensure that adequate resources are allocated by the Department of Education to facilitate the creation and maintenance of inclusive educational systems.
- Provide unconscious bias, equity and Disability Equality Training to teachers, principals, SNAs and other educational staff. This training should be created and delivered by, or in partnership with, Disabled Persons’ Organisations (DPOs).

Implementation Failures

A key challenge to ensuring an inclusive educational system, even within the framework of the EPSEN Act is, that despite being signed into law 19 years ago, significant portions of the Act remain unimplemented. These include provisions which confer statutory rights to educational assessment, individualised educational plans (and their regular review) and services to support the implementation of these plans and provisions which create an independent appeals board.

These provisions are the core of the EPSEN Act and are among the most essential in ensuring that disabled children have their rights under Article 24 UN CRPD upheld. The failure of the State to implement these sections of the Act constitutes a failure on the State’s part to uphold the rights of disabled children under both the UN CRC and the UN CRPD and must be rectified as a matter of urgency.

We are aware that many schools are already implementing individualised educational plans (IEPs), and while in many cases these plans are effective, the lack of a statutory entitlement to IEPs has resulted in unequal access to such supports. Concurrently, the delay in the operationalisation of the Special Educational Appeals Board means that disabled children

¹⁷ Barriers to Autism Spectrum Disorder Diagnosis for Young Women and Girls: a Systematic Review - G. Lockwood Estrin et al., *Review Journal of Autism and Developmental Disorders* Volume 8, pp. 454–470 (2021).

¹⁸ Racial, Ethnic, and Sociodemographic Disparities in Diagnosis of Children with Autism Spectrum Disorder - B. S. Aylward et al., *Journal of Developmental & Behavioural Pediatrics*. 2021 Oct-Nov; 42(8): pp. 682–689.

¹⁹ Females with ADHD: An expert consensus statement taking a lifespan approach providing guidance for the identification and treatment of attention-deficit/ hyperactivity disorder in girls and women - S. Young et al., *BMC Psychiatry* Volume 20, Article number: 404 (2020).

²⁰ Racial and Ethnic Disparities in ADHD Diagnosis and Treatment - Dr. T. R. Coker et al., *Pediatrics*. 2016 Sep; 138(3): e20160407.

²¹ How Inclusive Interactive Learning Environments Benefit Students Without Special Needs - S. Molina Roldán et al., *Frontiers in Psychology*, Sec. Educational Psychology Volume 12 (2021).

and their families have no means of challenging or seeking legal redress when supports and services are not provided to them.

We also wish to note that we are deeply concerned that the review of the EPSEN Act, while essential in the process of creating an inclusive education system, will essentially amount to a further delay in the implementation of the statutory rights to education assessments, individualised education plans, support provision and an appeals mechanism.

Recommendations:

- Implement the EPSEN Act in its entirety, ensuring that disabled children have statutory rights to individualised educational assessments, educational plans and related supports, alongside an independent appeals process for those who feel their rights under the EPSEN Act have not been realised.
- Resource and operationalise the Special Education Appeals Board as a priority, and raise awareness amongst children falling under the remit of the Act, their parents, guardians and/or their appropriate representatives (for example, of children in care) of how to access the appeals process. It is essential that this process is fully accessible, and that adequate support to progress an appeal is given to those who need it.

Provisions absent from the Current Legislation

Prohibition of Seclusion and Restraint

In Irish educational settings the continued use of seclusion and restraint in response to so-called 'challenging behaviour' or as a disciplinary measure represents a serious breach of the rights enshrined under Article 24 UN CRPD. Although there is strict regulation of these practices in prisons and mental health settings, schools and other educational settings have no obligation to record or report instances and there is no statutory oversight body responsible for monitoring them. This means that data relating to the prevalence of such practices in Ireland is not available, but community evidence and research reports indicate that such practices are widespread. These practices commonly include: disabled pupils being locked in a room in solitary confinement and physically prevented from leaving, being forcibly removed from classrooms and other spaces, or held face-down on the floor by one or more adults as part of many schools routine behavioural management approaches and are disproportionately used against intellectually disabled, neurodivergent and ethnic minority children, as highlighted by Inclusion Ireland's 2018 Report.²²

Restraint and seclusion practices cause physical injury,²³ are traumatic and have long-term negative effects on the students they're used on, which can include PTSD, anxiety, feelings

²² Shining a light on seclusion and restraint in schools in Ireland: The experience of children with disabilities and their families - Inclusion Ireland (Sept. 2018)

²³ 22 NI families claim their special needs children were restrained and injured in school - Jilly Beattie, Belfast Telegraph (5 May 2021): <https://www.belfastlive.co.uk/news/belfast-news/22-ni-families-claim-special-19910126>

of degradation, lowered perceptions of safety and self-worth²⁴ and increased suicidal ideation.²⁵ Internationally, dozens of children have died and hundreds have been permanently maimed due to being restrained in schools, using similar or identical techniques to those used in Ireland, frequently by trained professionals.²⁶ The prone restraint techniques used in our schools are the same as those used fatally on George Floyd and many others. There is no safe way to use these practices, there is always risk.²⁷

“Young people showing challenging behaviour in school are more likely to have experienced past traumas. If they are subjected to seclusion, restraint or exclusion, that experience can mirror the traumatic events that happened to them. This increases the likelihood of further challenging behaviour and an escalation of the cycle.”

- Centre for Mental Health UK²⁸

"Any restraint [in schools] in any position can cause death when carried out using methods that compromise breathing, exceeds cardiac capacity, or has the potential to inflict severe injury to the head, neck, or torso."

- 2021 Report into deaths in school due to use of restraint²⁹

As stated by Amnesty International in their observations on Article 24, the use of restraint, seclusion and aversive interventions undermines efforts to the realisation of the rights enshrined under Article 24 and is not compatible with an inclusive educational system.³⁰ Indeed Article 28 of the UN CRC explicitly states that *"School discipline should be administered in a manner consistent with the child's human dignity"*³¹ and Article 24 of the UN CRPD states that:

*“States parties must prohibit all forms of corporal punishment and cruel, inhuman and degrading treatment of children, in all settings, and ensure appropriate measures are taken to enforce this ban.”*³²

Article 37 of the Convention on the Rights of the Child also *“No child shall be subjected to torture or other cruel, inhuman or degrading treatment or punishment.”* In their recent Concluding Observations to Ireland, the Committee on the Rights of the Child recommended

²⁴ Restraints and Seclusion: Schools - National Alliance on Mental Illness (NAMI): <https://www.nami.org/Advocacy/Policy-Priorities/Stopping-Harmful-Practices/Restraints-and-Seclusion-Schools>

²⁵ Schoolboy with autism 'wanted to die after teachers restrained him and secluded him' - Shauna Corr, Belfast Telegraph (31 May 2021): <https://www.belfastlive.co.uk/news/belfast-news/schoolboy-autism-wanted-die-after-20693855>

²⁶ 'He didn't deserve that': Remembering young people who've died from restraint and seclusion - T. Johnston et al., CTInsider (October 2022)

²⁷ Approved restraint techniques can kill children, MoJ found

²⁸ Trauma, challenging behaviour and restrictive interventions in schools Briefing Note - Centre for Mental Health UK (Jan. 2020).

²⁹ A 26-Year Study of Restraint Fatalities Among Children and Adolescents in the United States - M. A. Nunno et al., Child & Youth Care Forum, Cornell University (August 2021).

³⁰ Amnesty International. UN Committee on the rights of persons with disabilities: Observations on the Draft General Comment No. 4 on Article 24 of the UN Convention on the Rights of Persons with Disabilities, 2016.

³¹ Article 28, UN Convention on the Rights of the Child.

³² Article 24, UN Convention on the Rights of Persons with Disabilities.

that the State "*Explicitly prohibit the use of restraint and seclusion in educational settings*".³³

In addition to denying disabled children their rights under Article 24, the use of seclusion and restraint directly violates disabled children's right to bodily integrity, liberty and security and non-discrimination, as enshrined under Articles 5, 14, 15, 16 and 17 of the UN CRPD.

As such DWI strongly recommends that the use of seclusion and restraint in educational settings is prohibited under legislation as part of the review of the ESPEN Act. To address historic and ongoing use of such damaging behavioural management techniques as punishment, an explicit reaffirmation of the State's commitment to respecting and upholding the equal rights of children who fall within the scope of the Act would be welcomed. Where behavioural issues arise, the focus should be on proven de-escalation techniques in cases of physical outbursts (with strict regulation and guidelines indicating any exceptional cases where physical intervention may be used as a last resort to prevent immediate and serious harm to the child) and, in cases of non-violent behavioural issues, there must be an obligation to first ensure that individual student support needs are being met and, where discipline is appropriate, only academic discipline techniques may be used. In addition, staff in all educational settings should be trained in a human rights-based approach to disability and appropriate complaints and review mechanisms put in place.

Recommendations:

- Explicit prohibition of the use of restraint and seclusion in all educational settings as a matter of urgency.
- Abolish the use of isolation rooms.
- An explicit ban on the use of shortened days or reduced timetables as a punishment or behavioural management technique. Oversight to ensure that reduced timetables are only used when it is demonstrably in the best interests of the individual child, with an appeals process to address disputed cases.
- Immediate introduction of mandatory recording and reporting of the use of restraint, seclusion and/or exclusion to guardians and/or appropriate primary caregivers (e.g.: for children in care) and to the Department of Education.
- Systematically and regularly collect and publish disaggregated data on the use of restraint and other restrictive interventions on children in order to monitor the appropriateness of discipline and behaviour management for children in all educational settings. Ensure such data is made available to organisations with a role in monitoring State implementation of the UN CRPD and UN CRC.
- Development and delivery of training on human-rights based discipline and de-escalation techniques to all relevant educational staff, including SNAs.

³³ Committee on the Rights of the Child, 'Concluding Observations on the Combined Fifth and Sixth Periodic Reports of Ireland' (2016) UN DocCRC/C/IRL/CO/5-6, para 37(h)

Use of non-rights compliant behaviourist techniques in educational settings

The use of behavioural interventionist techniques on disabled children has become increasingly widespread, with these practices being incorporated into mainstream school management and intensively used on a growing number of disabled children. This includes, but is not limited to, Autistic children and/or those with ADHD, d/Deaf children and children with intellectual disabilities. In the interest of brevity, we will discuss these techniques in the context of Autistic children due to the fact that the practices were first developed for use on Autistic children and they remain by far the most likely to be exposed to these techniques. However the concerns and indications of harm we will discuss extend to all children no matter their neurotype, sensory/communication differences or impairment.

Behavioural interventionist practices or ‘therapies’ were first developed by Ole Ivar Lovaas for use on Autistic children and homosexual boys.³⁴ These therapies are based on early 20th century psychological theory known as Behaviourism, which rapidly fell out of favour and was abandoned by mainstream psychology due to its foundational position that internal experiences such as emotions, motivations and life experiences are irrelevant in the study of human psychology, with only outward behaviour holding any scientific interest or value.³⁵ Behaviourist ideas were developed, through the Feminine Boy Project, into Gay Conversion Therapy while Lovaas went on to further develop Applied Behavioral Analysis (ABA) for use on Autistic children.

“You see, you start pretty much from scratch when you work with an autistic child. You have a person in the physical sense – they have hair, a nose and a mouth – but they are not people in the psychological sense. One way to look at the job of helping autistic kids is to see it as a matter of constructing a person. You have the raw materials, but you have to build the person.”

- Ivar Lovaas³⁶

Although the methods and techniques of ABA and the other which developed from it have changed in their use of rewards and aversives over the intervening years, and electrical shocks are not used as punishments in Ireland,³⁷ the foundational approach of seeking to modify Autistic children’s behaviour to ‘normalise’ them remains, with little or no focus on understanding and accommodating the neurological, sensory and communication differences of children of minority neurotypes nor investigation or measurement of the psychological impacts of the therapy. Practitioners using these techniques do not need any qualifications relating to autism or education in order to work with disabled children, and evidence of their long-term effectiveness is very poor³⁸ with habitual lack of control groups

³⁴ Disturbing Behaviours: Ole Ivar Lovaas and the Queer History of Autism Science - M. F. Gibson & P. Douglas (Oct 2018)

³⁵ Behaviorism - Stanford Encyclopedia of Philosophy (Jan. 2023): <https://plato.stanford.edu/entries/behaviorism/>

³⁶ Ivar Lovaas interview with Psychology Today, January 1974.

³⁷ 'It's torture': critics step up bid to stop US school using electric shocks on children - Ed Pilkington, The Guardian (18 Nov. 2018): <https://www.theguardian.com/us-news/2018/nov/16/judge-rotenberg-center-massachusetts-electric-shocks>

³⁸ TRI CARE Comprehensive Autism Care Demonstration - The U.S. Department of Defense Quarterly Report to Congress (Q2 2019) (“76% ...had little to no change in symptom presentation over the course of 12 months of Applied Behavior Analysis (ABA) services, with an additional 9% demonstrating worsening symptoms”).

and other scientific standards, and pervasive conflicts of interest discovered in supporting research.³⁹

Of much more urgent concern, however, is the significant and mounting evidence that behaviourist intervention practices increase children's vulnerability to sexual abuse and interpersonal violence, create learned helplessness and greatly increase risks of developing long-term mental health conditions and dying by suicide.⁴⁰ Autistic children subjected to behaviourist intervention therapies are 86% more likely to develop c-PTSD than those who were not.⁴¹ Behaviourist interventions are also poorly equipped to understand and support sensory differences common to autistic people which can cause real physical pain and overwhelm, if they recognise these differences at all. ABA's stated goal is to make Autistic children "indistinguishable from their [non-Autistic] peers" through task repetition and enforced compliance with therapists demands; an approach necessarily at odds with a human-rights view of Autistic differences which centres accommodation of differences and adaptation of inaccessible environments in line with the Social Model of disability and CRPD obligations.⁴²

While some behavioural therapies based on ABA, such as Positive Behavioural Support (PBS), recognise - to a limited extent - the role sensory processing differences play in Autistic children's reactions to their environment, issues surrounding compliance, erasure of children's autonomy and sense of self remain, as do heightened risks for vulnerability to abuse and a range of lasting mental health conditions.⁴³

Below are direct quotations given by Autistic adults reflecting on their experience of being subjected to behavioural interventionist therapies as school-age children:⁴⁴

"This is traumatic, it created internalised ableism, self-loathing."

"I was physically restrained, kept from using the toilet, force-fed."

"The focus on compliance made it harder for me to say no to people who hurt me later."

"I still feel ashamed of who I am. Rationally I know that being Autistic isn't wrong, it's just a different way of thinking, but it's hard to shake all those years of people trying to force me to be someone different."

"Stop trying to fix us. Short-term 'success' isn't worth the long-term PTSD."

³⁹ Pervasive Undisclosed Conflicts of Interest in Applied Behavior Analysis Autism Literature - K. Bottema-Beutel & S. Crowley, *Frontiers in Psychology*, Volume 12, Sec. Developmental Psychology (May 2021).

⁴⁰ For Whose Benefit?: Evidence, Ethics, and Effectiveness of Autism Interventions - The Autistic Self Advocacy Network (ASAN) & The International Council on Development and Learning (2020).

⁴¹ Evidence of increased PTSD symptoms in Autistics exposed to Applied Behavior Analysis - H. Kupferstein, *Advances in Autism* 4(3):00-00 (January 2018)

⁴² How much compliance is too much compliance: Is long-term ABA therapy abuse? - A. H. Sandoval-Norton & G. Shkedy, *Cogent Psychology* Volume 6, Issue 1 (2019).

⁴³ Why not Positive Behavior Support (PBS), Positive Behavioral Interventions and Supports (PBIS), or Positive Reinforcement? - Therapist Neurodiversity Collective (Accessed February 2023).

⁴⁴ "Recalling hidden harms": Autistic experiences of childhood Applied Behavioural Analysis (ABA) - O. McGill & A. Robinson, *Advances In Autism Journal* Vol. 7, No. 4 (2021).

These practices, unlike supportive therapies led by qualified professionals such as Speech & Language Therapy and Occupational Therapy, do not take the views, aims, distress or preferences of the disabled child into account when deciding desired therapeutic goals, and are therefore incapable of upholding the child's right to freedom from coercive treatment established under both the UN CRPD and the UN CRC. As one survivor of behavioural interventionist therapy put it, these therapies are by nature *"entirely coercive. [The practitioner] controlled all aspects of reinforcers and aversives completely. I had no choice."*⁴⁵

The Joint Oireachtas Committee on Disability Matters' recently published report highlights that:

*"...behavioural interventionist therapies such as PBS and ABA are medicalised and differ crucially from the principles underlying Speech and Language Therapy (SLT), and Occupational Therapy (OT). Behavioural interventionist therapies are ultimately founded on modifying disabled people's behaviour to meet goals decided by others; often to conform more closely with neurotypical communication, behaviour and/or norms and therefore the Committee believe cannot uphold the UNCRPD principles of autonomy, dignity, right to identity and freedom from non-consensual or degrading treatment."*⁴⁶

The Committee further called on the Government *"to undertake a review and provide a timeline for alignment of all relevant legislation with the UNCRPD"* and to *"establish a monitoring mechanism to ensure that persons with disabilities are not subjected to forced treatment"*.⁴⁷

While increased risk of c-PTSD and trauma have not been reported for the mainstreaming of behaviourist techniques across educational settings, such as in behavioural codes enforcing "active listening" and behavioural reward charts, there is growing evidence that these techniques are similarly increasing anxiety, demotivation and feelings of low self-worth in both disabled and non-disabled children.⁴⁸

While these practices do not fall under the remit of this act, we believe that it is important to raise our concerns about the potential unforeseen harms of these approaches and to highlight how wider educational practices and behavioural expectations are often discriminatory in effect against disabled children (for example, consistent eye contact is not a sign of attention for many neurodivergent children, Blind and visually impaired children and others) and to caution that current inflexible limits on attendance place unnecessary stress and fear on many disabled students with ongoing health concerns and/or frequent healthcare appointments and their families and would bear revision with this in mind.

⁴⁵ Ibid. Section 3.1, p. 276

⁴⁶ Aligning Disability Services with the United Nations Convention on the Rights of Persons with Disabilities - Joint Committee on Disability Matters, Item 60, p.24 (February 2023)

⁴⁷ Ibid.

⁴⁸ Punished by Rewards: The Trouble with Gold Stars, Incentive Plans, Praise, and Other Bribes - Alfie Kohn, HarperOne (August 2018). ISBN-13 978-1328450524

Recommendations:

- Review and regulation of all educational practices and therapies to ensure they are not harmful, reflect best practices and are in full alignment with the UN CRPD.
- Review of behaviourist techniques used in educational settings, whether or not they are part of a specific behavioural interventionist therapy, to ensure that they fully comply with human rights obligations relating to disabled children and that they are not associated with long-term negative outcomes.
- Banning the use of behavioural interventionist therapies on disabled children/children with special educational needs.
- Fully enacting legislative provisions for Individualised Educational Plans for each student who needs or requests one and ensuring that evidence is provided that each student was fully supported in deciding the goals and methods decided upon in their IEP, in line with the UNCRPD

Meaningful participation of disabled children

Both the UN CRPD and the UN CRC affirm the right of a child to have their views heard on all matters affecting them, and stipulate that these views should be given due weight in accordance with the child's age and maturity (Articles 7.3 and 12 respectively). More recently, in their Concluding Observations the CRC Committee also recommended that the State *“Ensure the right of children with disabilities to be heard in all decisions that affect them”* (29 d).

While the EPSEN Act contains specific provisions which ensure that parents have adequate opportunity to express their opinions about their child's education, there is little emphasis placed on hearing the views of the child themselves or on their participation in the process. Indeed, only if an educational plan is being prepared by the National Council for Special Education, shall the child be involved if it is considered appropriate by the special educational needs organiser *“having regard to the age of the child and the nature and extent of the child's special educational needs.”* There is no comparable provision where educational plans are prepared within the school, nor are there comparable provisions for children to be actively involved in assessments of educational needs, in the reviews of educational plans, or in appeals to the Special Educational Appeals Board.⁴⁹

Speaking from both the perspective of the parents of disabled children, and as former disabled children themselves, our members stressed the importance of ensuring that disabled children are involved in all aspects of their education - from educational assessment, to the creation of individualised plans and their review. Our members spoke of

⁴⁹ Mind The Gap: Research on barriers to the realisation of rights of children with disabilities in Ireland. - Ombudsman for Children in conjunction with the Centre for Disability Law & Policy, NUIG (March 2021).

their experiences in education of situations where their opinions went unheard and explained the long last impact that that had on them. From their experiences, they concluded that disabled children understand their needs best and their views must take priority - both as rights holders and as experts in their own experiences.

This is particularly relevant in the context of developing individualised educational plans (IEPs) where there is potential for a mismatch between the views of the parents and the views of the child. It is possible, and indeed likely that educational goals of parents, teachers or school principals are not the educational goals of the child themselves. For example, many of our members have had the experience of being prevented from taking certain subjects in school – either to facilitate their participation in additional learning support classes, or because subjects were deemed to be “too difficult” for the student (e.g. a physically disabled student was prevented from taking woodworking, or a dyslexic student was granted an exemption from Irish that they did not want).

Mismatches between the educational goals of the child and the parents also often happens in situations where the child is autistic or has ADHD, wherein the goals chosen by the parents can reflect a behavioral interventionist approach to the child’s behaviour and can cause further harm to the child. To address these pitfalls in the creation of IEPs, the child’s view on their educational goals should take priority, and children should be able to access the necessary supports to facilitate their view being heard.

Our members also highlighted that including the child in the development of IEPs is essential to ensure that IEPs are sufficiently flexible and adaptable to the support requirements of the child.

“I think, including the child's voice, would be a very important thing. That sort of individualized educational plans are great, but they need to be flexible.”

- **DWI Consultation Participant**

“True accessibility has to be adaptable. What's gonna work for me one day is not gonna work for me on another day.”

- **DWI Consultation Participant**

“Nobody understands or can grasp the individual nuances of how your impairments affect you particularly when they're learning based impairments”

- **DWI Consultation Participant**

Involvement of disabled people in the NCSE

The EPSEN Act also establishes the National Council for Special Education (NCSE). In its current form, there is very little participation of disabled people and disabled children with the NCSE and its Board. Given the cross-cutting requirement for State parties to prioritise consultation with disabled people and Disabled Persons’ Organisations (DPOs) in all aspects of legislation and policy relating to disabled people stipulated under Articles 4.3 and 33.3 of the UN CPRD, we propose the following changes to the NCSE under the EPSEN Act:

Recommendations:

- Amend the EPSEN Act to ensure that disabled children are involved in all aspects having their individual educational requirements met, including educational assessments, the creation of individualised educational plans and reviews.
- Ensure access to a wide variety of communication methods and supported communication is embedded across law and policy related to EPSEN to facilitate children and young disabled people to express their views.
- Amend §21 of the EPSEN Act so as to create a duty that Council members uphold the principles and requirements of the UN Convention on the Rights of Persons with Disabilities and the UN Convention on the Rights of the Child, and that the Council operate within a human-rights framework.
- Amend §21(2) of the EPSEN Act to require the Minister to give particular consideration to the appointment of members who are currently, or were formerly, students with educational needs wherever possible.
- Amend §21(3) of the EPSEN Act to create a requirement for the Minister to prioritise consultation with d) DPOs and e) student representative groups (prioritising disabled student representatives) before making appointments to the Council.
- Amend §21(4) of the EPSEN Act so as to create a mechanism whereby national DPOs may directly nominate candidates for appointment to the Council and which stipulates that a minimum of 2 members nominated by DPOs must be appointed to the Council.
- Create policy provisions which mandate all members of the NCSE board to be given Disability Equality and Unconscious Bias Training, to be developed and delivered in partnership with DPOs.
- Make provision that the Board of the NCSE regularly consult with organisations and bodies tasked with upholding children's rights, such as the Children's Rights Alliance and the Irish Human Rights and Equality Commission (IHREC).

Data Collection

A key challenge for DWI in preparing this submission (and previous submissions) is our inability to access data relating to the education of disabled children. In an ideal context, we would use such data to provide a robust evidence base to support the perspectives and opinions of our membership and to influence the recommendations that we provide.

Article 31 of the UN CRPD states:

1. States Parties undertake to collect appropriate information, including statistical and research data, to enable them to formulate and implement

policies to give effect to the present Convention. The process of collecting and maintaining this information shall:

a) Comply with legally established safeguards, including legislation on data protection, to ensure confidentiality and respect for the privacy of persons with disabilities;

b) Comply with internationally accepted norms to protect human rights and fundamental freedoms and ethical principles in the collection and use of statistics.

2. The information collected in accordance with this article shall be disaggregated, as appropriate, and used to help assess the implementation of States Parties' obligations under the present Convention and to identify and address the barriers faced by persons with disabilities in exercising their rights.

3. States Parties shall assume responsibility for the dissemination of these statistics and ensure their accessibility to persons with disabilities and others.⁵⁰

We therefore call on the State to ensure the collection of disaggregated data in relation to the education of disabled children and make such data available to Disabled Persons' Organisations in accessible formats. We also wish to highlight the importance of collecting and holding data in relation disabled people in a way that protects the individual's right to privacy, as mandated under Article 33 UN CRPD.

Recommendations:

- Collect disaggregated data in relation to disabled children in education and ensure that it is sent to Disabled Persons' Organisations (DPOs) in accessible, transparent formats.

Access issues with the consultation process

In addition to raising our concerns about the EPSEN Act, we also wish to highlight ongoing access issues with the current consultation process. While the Department's willingness to accept submissions in formats other than the online survey via email is welcomed, it is important to note that no postal address was given for submissions to be sent in hard copy. Additionally, information about the consultation process itself was not provided in Plain English, Easy-to-Read or Irish Sign Language, limiting the ability of many disabled and d/Deaf people to participate in this process. Our members also highlighted that the vagueness of the survey questions was also inaccessible and when we tried to ask questions about the consultation process by emailing the provided email address, we received no reply. All of which limit the ability of DPOs and other organisations to participate in this consultation process.

⁵⁰ Article 31, UN CRPD. Article

It is also important to note that under the UN CRPD the State has a responsibility to **actively** consult with disabled people through their representative organisations (Article 4.3) which, to our knowledge, has not happened. In addition to ensuring that the views of disabled people contribute to the review itself, active consultation with DPOs is essential to support DPOs, which are chronically under-resourced and underfunded, to contribute meaningfully to this process. DPOs can also support and advise government departments in ensuring that consultations are conducted in an accessible manner.

We are also concerned about the involvement of disabled children in this consultation process. While there are currently no DPOs for children in operation in Ireland, it is absolutely essential that the views of disabled children are actively sought out and prioritised in this process and that appropriate supports are provided to facilitate their involvement.

Recommendations:

- Ensure that future consultations are fully accessible to disabled people, through engaging with DPOs
- Adopt a systematic approach to providing alternative, accessible formats of all documents (policy and legislation) to ensure children and young people can participate in consultation processes and express their views on an equal basis with others.