

Speech: Autistic Adults Aligning Disability Services 4th Nov 2021

1. I am speaking today on behalf of a group of autistic adults who came together to highlight areas that we feel are crucial to improving the lives of autistic adults and children. We would like to add our experience to give a greater understanding of the current issues faced by the Autistic community within a human rights framework.
2. Our previous submission to the Disability Matters Committee highlighted a range of issues of concern to the autistic community in Ireland. This submission puts particular focus on three urgent human rights issues experienced by autistic people in Irish care and educational settings, highlighting how they can best be brought into alignment with the UNCRPD. These issues are behavioural interventionist therapies, such as Applied Behaviour Analysis (ABA); the use of isolation, restraint and seclusion, and the provision of Augmented Alternative Communication (AAC). Additionally, we would like to speak about the lack of diagnostic and post-diagnostic service provision for autistic adults in Ireland.
3. The use of behavioural interventionist therapies to ‘train’ autistic people to appear “indistinguishable from their peers” contravenes the autistic person's right to their own agency and identity, which we argue is in contravention of Articles 3(8)¹ and 17² of the UNCRPD. Compliance training in the form of ABA and related behavioural therapies undermine the safety and well-being of autistic young people and leave them vulnerable to abuse and significant mental health difficulties in later life, including a more than 85% increased risk of developing c-PTSD³. The goals of behavioural interventionist training are not determined by or with the disabled people they are used on, as is required

¹ UN Convention on the Rights of Persons with Disabilities, Article 3 - General Principles: <https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities/article-3-general-principles.html>

² UN Convention on the Rights of Persons with Disabilities, Article 17 - Protecting the Integrity of the Person: <https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities/article-17-protecting-the-integrity-of-the-person.html>:

³ *Evidence of increased PTSD symptoms in autistics exposed to applied behavior analysis*, H. Kupferstein, *Advances in Autism* 4 (January 2018):

by the UNCRPD⁴. The premise of ABA is similar to that of so-called 'gay conversion therapies' and historically has links to that project⁵.

4. A growing body of research has established that these interventions are ineffective in "extinguishing challenging behaviours" and are violating the rights of autistic young people, causing significant long-lasting damage to their mental health and quality of life while offering no long-term improvements^{6 7}. As autistic adults who are very aware of the huge toll taken by 'masking'⁸, which includes the likelihood of increased suicidal ideation⁹, we are very concerned about the rise in use of these interventions throughout Ireland and call for an urgent investigation into these practices from a human rights perspective. Parents and carers who are in need of support are turning to this multi-billion-euro business model in the hopes of helping their autistic loved ones, without being made aware of the inherent dangers of forcing people to hide their authentic autistic identities.

5. Isolation, seclusion and restraint of disabled people are employed by schools and care services across Ireland as standard practice and can cause extreme trauma and have long-term mental health impacts^{10 11}. These practices are

⁴Incl. UNCRPD Art. 7 and others:

<https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities/article-7-children-with-disabilities.html>

⁵*Disturbing Behaviours: Ole Ivar Lovaas and the Queer History of Autism Science*, M.F. Gibson & P. Douglas, Catalyst Feminism Theory Technoscience 4(2):1-28 (October 2018):

https://www.researchgate.net/publication/328400705_Disturbing_Behaviours_Ole_Ivar_Lovaas_and_the_Queer_History_of_Autism_Science

⁶*Early intensive behavioral intervention (EIBI) for increasing functional behaviors and skills in young children with autism spectrum disorders (ASD)*, B. Reichow, K. Hume, E.E. Barton & B.A.. Boyd, Cochrane Developmental, Psychosocial and Learning Problems Group (May 2018):

https://www.cochrane.org/CD009260/BEHAV_early-intensive-behavioral-intervention-eibi-increasing-functional-behaviors-and-skills-young

⁷*The Department of Defense Comprehensive Autism Care Demonstration Quarterly Report to Congress Second Quarter, Fiscal Year 2019*, U.S. Dept. of Defense (October 2019):

<https://www.altteaching.org/wp-content/uploads/2019/11/TRICARE-Autism-Report.pdf>

⁸*Autistic Masking: Why Mask and What is the Cost?*, G. Kearns, AutLoud (May 2021):

<https://autloud.ie/autistic-masking-why-mask-and-what-is-the-ultimate-price-you-pay/>

⁹*Is Camouflaging Autistic Traits Associated with Suicidal Thoughts and Behaviours? Expanding the Interpersonal Psychological Theory of Suicide in an Undergraduate Student Sample*, S.A. Cassidy et al, Journal of Autism and Developmental Disorders 50(1) (October 2020):

https://www.researchgate.net/publication/337632075_Is_Camouflaging_Autistic_Traits_Associated_with_Suicidal_Thoughts_and_Behaviours_Expanding_the_Interpersonal_Psychological_Theory_of_Suicide_in_an_Undergraduate_Student_Sample

¹⁰Shining a light on seclusion and restraint in schools in Ireland: The experience of children with disabilities and

their families', Inclusion Ireland (September 2018):

<https://inclusionireland.ie/wp-content/uploads/2020/11/shining-light-seclusion-and-restraint-schools-ireland.pdf>

¹¹'School is Not Supposed to Hurt: Investigative Report on Abusive Restraint and Seclusion in Schools', National Disability Rights Network (January 2009): <https://www.ndrn.org/wp-content/uploads/2019/03/SR-Report2009.pdf>

3

disproportionately used against intellectually disabled, neurodivergent and ethnic minority children - and pose a risk to their right to equal access to education as articulated under Article 24 of the UNCRPD¹². At present, we have no transparency on the prevalence of these practices in Ireland nor are the institutions using them under any obligation to report instances to an independent monitoring body.

6. It is our belief that these practices, when viewed in the context of the harm they cause and conscious of their disproportionate use on disabled people, are not compliant with UNCRPD Article 14¹³ and Article 15¹⁴. We urge the Committee to examine this issue and to encourage the Department of Education to introduce similar reporting and oversight on the use of isolation, seclusion and restraint in schools as that introduced for the use of reduced timetables in September of this year. We believe that the current lack of monitoring of these practices in schools and care settings could potentially constitute a failure to fully realise Article 16(3) of the UNCRPD.¹⁵

7. Regrettably, the expressed goal of most therapies offered to autistic people in Ireland is to make us "indistinguishable from [our] peers"¹⁶. This often leads to an emphasis on using verbal speech and discouragement of any communication which is viewed as not 'typical', denying autistic people agency. Acknowledging how fundamental communication is to our lives, in conjunction with the specific importance of non-verbal speech in Autistic culture, we contend that prioritisation of verbal speech over non-verbal speech is not in alignment with the Definitions and General Principles of the Convention, which specifically reference Augmentative and Alternative Communication modes.¹⁷

¹² UN Convention on the Rights of Persons with Disabilities, Article 24 - Education

¹³ UN Convention on the Rights of Persons with Disabilities, Article 14 - Liberty & Security of Person ¹⁴ UN Convention on the Rights of Persons with Disabilities, Article 15 - Freedom from torture or cruel, inhuman or degrading treatment or punishment

¹⁵ UN Convention on the Rights of Persons with Disabilities, Article 16 - Freedom from exploitation, violence and abuse

8. Finally, we would like to emphasize the need for a review to be conducted into diagnostic and post-diagnostic service provision for autistic adults. The majority of autistic adults have no access to autism diagnosis and post-diagnostic support. Autistic people may have been diagnosed with another condition, without knowing they are autistic, which may be the core issue. Therefore, we call for routine autism screening of adults with mental health or learning disabilities, as they would benefit from more tailored support. Also the lack, or very limited, public pathways to autistic diagnosis unfairly impacts those who can't afford to pay privately, disproportionately those from minority groupings.¹⁸

9. Autistic people have a higher incidence of mental health conditions, self-harm and suicidality¹⁹, which demonstrates that there is an urgent need for autism treatment pathways in mental health services. We request that autistic adults are granted access to post-diagnostic support and treatment from specialists, advisors and counselors with up-to-date knowledge on autism, autistic-informed approaches and on how to support mentally unwell autistics. Health services need to have consideration of conditions commonly co-occurring with autism, and provide appropriate screening, diagnosis and support. To bring Ireland in line with the UNCRPD, Personal Assistance Services need to be put on a statutory basis and to be made available based on need and not diagnosis²⁰, including to autistic adults. Article 6 of the UNCRPD recognises the multiple forms of discrimination experienced by disabled women and girls; in order for Article 6 to be upheld measures must be taken to ensure that women and girls have full and equal access to all rights, which includes equal access to correct diagnosis and support.

¹⁷ UN Convention on the Rights of Persons with Disabilities:

<https://www.un.org/disabilities/documents/convention/convoptprot-e.pdf>

¹⁸'*Extending the Minority Stress Model to Understand Mental Health Problems Experienced by the Autistic Population*', M. Botha & D. M. Frost (October 2018):

<https://journals.sagepub.com/doi/10.1177/2156869318804297>

10. In conclusion, we would like to emphasize that when planning and providing services to disabled people, it is essential to consider what we are trying to achieve and why, and whether there are any ethical implications²¹. It is crucial to work with autistic people and their representative organisations to develop ways to support autistic people that are positive and effective, which don't enforce neurotypicality or prioritise non-disabled views on the value of disabled lives and choices. Identifying and measuring targets that are meaningful and endorsed by the autistic community is essential, both to prevent harmful interventions which oppose self- and societal acceptance and to ensure that all therapies are aligned with the provisions, and the vision, of the UNCRPD.

¹⁹*'People like me don't get support': Autistic adults' experiences of support and treatment for mental health difficulties, self-injury and suicidality* - L. Camm-Crosbie, L. Bradley, R. Shaw, S. Baron-Cohen, S. Cassidy (2019): <https://journals.sagepub.com/doi/full/10.1177/1362361318816053>

²⁰ *'The Disability Framework Action Plan'*, Dept. of Health (July 2021):

<https://www.gov.uk/en/publication/f7943-the-disability-framework-action-plan-working-group/> ²¹*'So what exactly are autism interventions intervening with?'*, D. Milton, *Good Autism Practice*, 15 (2). pp. 6-14 (2014): <https://kar.kent.ac.uk/62631/>

Summary of key points

- This submission puts particular focus on three urgent human rights issues experienced by autistic people in Irish care and educational settings, highlighting how they can best be brought into alignment with the UNCRPD.
- These issues are behavioural interventionist therapies; the use of isolation, restraint and seclusion in educational, health and care settings, and the provision of Augmented Alternative Communication (AAC).
- The use of behavioural interventionist therapies to ‘train’ autistic people to appear “indistinguishable from their peers” contravenes the autistic person's right to their own agency and identity, which we argue is in contravention of Articles 3(8) and 17 of the UNCRPD.
- Compliance training in the form of ABA and related behavioural therapies undermine the safety and well-being of autistic young people and leave them vulnerable to abuse and significant mental health difficulties in later life. Also, the goals of behavioural interventionist training are not determined by or with the disabled people they are used on.
- A growing body of research has established that these interventions are ineffective in “extinguishing challenging behaviours” and are violating the rights of autistic young people, causing significant long-lasting damage to their mental health and quality of life while offering no long-term improvements.
- As autistic adults who are very aware of the huge toll taken by ‘masking’, which includes the likelihood of increased suicidal ideation - we are very concerned about the rise in use of these types of interventions throughout Ireland and call for an urgent investigation into these practices from a human rights perspective.
- Isolation, seclusion and restraint of disabled people are employed by schools and care services across Ireland as standard practice, and are disproportionately used against intellectually disabled, neurodivergent and ethnic minority children.

- The use of isolation, seclusion and restraint poses a risk to their right to equal access to education as articulated under Article 24 of the UNCRPD. ● At present, we have no transparency on the prevalence of these practices in Ireland nor are the institutions using them under any obligation to report instances to an independent monitoring body.
- It is our belief that these practices, when viewed in the context of the harm they cause and conscious of their disproportionate use on disabled people, are not compliant with UNCRPD Article 14 on Liberty and Security of the Person and Article 15 on Freedom from Torture or Cruel, Inhuman or Degrading Treatment or Punishment.
- We urge the Committee to examine this issue and to encourage the Department of Education to introduce similar reporting and oversight on the use of isolation, seclusion and restraint in schools.
- We believe that the current lack of monitoring of these practices in schools and care settings could potentially constitute a failure to fully realise Article 16(3) of the UNCRPD.
- We believe that monitoring must be viewed as an interim step in implementing the UNCRPD, with the long-term goal being the introduction of interventions which are person-centred and human rights compliant alongside the eradication of any practices which impinge on an individual's liberty, autonomy, dignity or right to be free from violence and cruel or degrading treatment.
- Regrettably, the expressed goal of most therapies offered to autistic people in Ireland is to make us "indistinguishable from [our] peers". This often leads to an emphasis on using verbal speech and active discouragement of any communication which is viewed as not 'typical', denying the autistic people agency.
- Acknowledging how fundamental communication is to our lives, in conjunction with the specific importance of non-verbal speech in Autistic culture, we contend that prioritisation of one method of communication (verbal speech) over others (such as Sign Language or AAC use) is not in alignment with the Definitions and General Principles of the Convention, which specifically reference Augmentative and Alternative Communication modes.

- In order for service provision to be in better alignment with the UNCRPD, knowledge of and access to AAC - and other necessary assistive technologies - must be embedded in all education, health and care settings.
- Training for all staff in these services must emphasise that discrimination against any form of communication in favour of verbal speech is in contravention of disabled people's rights
- AAC devices or reasonable accommodations should not be either offered as a means to elicit desired behaviour or be restricted or withheld as a punishment for 'challenging' behaviour. Access to them is an unconditional right of the disabled individual.
- A review is needed into diagnostic and post-diagnostic service provision for autistic adults, as the majority of autistic adults have no access to autism diagnosis and post-diagnostic support, with gender minorities and those from marginalised backgrounds being particularly affected.
- Many autistic adults in Ireland have been misdiagnosed with other conditions, and may not know they are autistic, which may be the core issue. ● One third of people in receipt of support for mental health or learning disabilities are autistic and, therefore, routine autism screening of adults with mental health or learning disabilities is required, to ensure they are receiving appropriate support.
- Autistic people have a higher incidence of mental health conditions, self-harm and suicidality, and there is an urgent need for autism treatment pathways in mental health services.
- We request that autistic adults are granted access to post-diagnostic support and treatment from specialists, advisors and counselors with up-to-date knowledge on autism, autistic-informed approaches and on how to support mentally unwell autistics.
- Health services need to have consideration of conditions commonly co-occurring with autism, and provide appropriate screening, diagnosis and support.
- To bring Ireland in line with the UNCRPD, personal assistance needs to be put on a statutory basis to be made available to autistic adults. ● Article 6 of the UNCRPD recognises the multiple forms of discrimination experienced by

Article 6 is upheld to ensure that women and girls have full and equal access to all rights, which would include equal access to correct diagnosis and support.

- We would like to emphasize that when planning and providing services to disabled people, it is essential to consider what we are trying to achieve and why, and whether there are any ethical implications.
- It is crucial to work with autistic people and their representative organisations to develop ways to support autistic people that are positive and effective, which don't enforce neurotypicality or prioritise non-disabled views on the value of disabled lives and choices.
- Autistic-informed interventions would help bridge the divide between parents desperate for post-diagnostic support and autistic people demanding respect and participation.
- Autistic people, including children, should be involved in all decisions that affect them.
- Identifying and measuring targets that are meaningful and endorsed by the autistic community is essential, both to prevent harmful interventions which oppose self- and societal acceptance and to ensure that all therapies are aligned with the provisions, and the vision, of the UNCRPD.

Further reading/resources

'LISTEN', CommunicationFIRST (February 2021) [LISTEN | CommunicationFIRST](#)

'*Augmentative and Alternative Communication (AAC)*', Saoirse (The Autistic Underground), Neuro Pride Ireland (August 2021): [Augmentative and Alternative Communication \(AAC\) by Saoirse, The Autistic Underground.](#)

How Much Compliance is Too Much Compliance: Is Long-Term ABA Therapy Abuse?, A.H. Sandoval-Norton & G. Shkedy, Cogent Psychology 6(1) (July 2019): [\(PDF\) How Much Compliance is Too Much Compliance: Is Long-Term ABA Therapy Abuse?](#)

10

The Therapist Neurodiversity Collective [Restraint and Seclusion](#)

Pearson, A. & Rose, K. (2021). A conceptual analysis of autistic masking: Understanding the narrative of stigma and the illusion of choice. *Autism in Adulthood*. [A Conceptual Analysis of Autistic Masking: Understanding the Narrative of Stigma and the Illusion of Choice | Autism in Adulthood](#)

Cassidy, S. A., Gould, K., Thompson, E., Pelton, M., Robertson, A. E., & Rogers, J. (2020). Is camouflaging autistic traits associated with suicidal thoughts and behaviours? Expanding the interpersonal psychological theory of suicide in an undergraduate student sample. *Journal of Autism and Developmental Disorders*, 50(10), 3638-3648. <https://doi.org/10.1007/s10803-019-04323-3>.

The Alliance Against Restraint and Seclusion [What are the alternatives to restraint and seclusion?](#)

Transcript of an interview with O. Ivar Lovass about ABA and it's

practices neurodiversity.com | o. ivar lovaas interview with paul chance
(1974)

Ethical Concerns with Applied Behavior Analysis for Autism Spectrum “Disorder”

Daniel A. Wilkenfeld, Allison M. McCarthy <https://muse.jhu.edu/article/753840/pdf?>