



PEOPLE WITH DISABILITY
AUSTRALIA

A voice
of our
own

Barriers to people with autism
are barriers to us all
Submission to the Select Committee on
Autism

JULY 2020

About PWDA

People with Disability Australia (PWDA) is a leading disability rights, advocacy and representative organisation of and for all people with disability. We are the only national, cross-disability organisation - we represent the interests of people with all kinds of disability. We are a non-profit, non-government organisation.

PWDA's primary membership is made up of people with disability and organisations primarily constituted by people with disability. PWDA also has a large associate membership of other individuals and organisations committed to the disability rights movement.

We have a vision of a socially just, accessible and inclusive community, in which the human rights, belonging, contribution, potential and diversity of all people with disability are recognised, respected and celebrated with pride. PWDA was founded in 1981, the International Year of Disabled Persons, to provide people with disability with a voice of our own.

PWDA is a NSW and national peak organisation and founding member of Disabled People's Organisations Australia (DPO Australia) along with Women With Disabilities Australia, First Peoples Disability Network Australia, and National Ethnic Disability Alliance. Disabled Peoples Organisations (DPOs) are organisations that are led by, and constituted of, people with disability. The key purpose of DPO Australia is to promote, protect and advance the human rights and freedoms of people with disability in Australia by working collaboratively on areas of shared interests, purposes, strategic priorities and opportunities.

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Introduction

People with Disability Australia (PWDA) is pleased to make this submission to the *Select Committee on Autism's Inquiry into the Services, Support and Life Outcomes for People with autism in Australia and the associated need for a National Autism Strategy*.

PWDA welcomes the Committee's reference to the United Nations' *Convention on the Rights of Persons with Disabilities* (CPRD) and many of its principles in the Terms of Reference. As Australia has signed and ratified the CPRD, any strategy concerning people with autism must be based on its principles. The CPRD's principles are:

- Respect for inherent dignity and individual autonomy, including the freedom to make one's own choices, and independence of persons
- Non-discrimination
- Full and effective participation and inclusion in society
- Respect for difference and acceptance of persons with disabilities as part of human diversity and humanity
- Equality of opportunity
- Accessibility
- Equality between men and women
- Respect for the evolving capacities of children with disabilities and respect for the right of children with disabilities to preserve their identities.¹

The CPRD captures the 'social model' of disability, in which the social setting, communication and attitudinal environment around impairment are challenged.² Within this paradigm, a person's impairment does not need to be cured or normalised, but rather accepted as diversity, with support provided as needed. Further, it is the social, economic, cultural, and environmental settings that need to change and adapt to enable all people with disability to participate and contribute.

While we welcome efforts to improve the lives of people with a disability, we are concerned that the Inquiry focuses on one cohort of people with disability. Singling out a cohort of people with disability does not align with the social model of disability. A social model

¹ *Convention on the Rights of Persons with Disabilities*, opened for signature 13 December 2006, 2515 UNTS 3 (entered into force 3 May 2008) ('CPRD') art 3.

² People With Disability Australia, *Social Model of Disability* (Web Page, 2008) <<https://pwd.org.au/resources/social-model-of-disability/>>.

approach involves looking at barriers to disability in general, rather than focusing on one disability as a 'problem' that needs to be solved.

We also wish to highlight that many promising plans to improve the lives of those with disability have been undermined by a lack of funding for the National Disability Strategy. In light of the above, we make the following general recommendations:

Recommendation 1: The Committee ensures all recommendations are underpinned by the principles and obligations contained in the CPRD and other human rights treaties, including the Convention on the Rights of the Child (CRC).

Recommendation 2: The Australian Government directs its funding and efforts towards measures that promote the advancement of human rights for all people with disability, rather than any specific cohort.

Recommendation 3: The Australian Government increases funding to enable the effective implementation of the National Disability Strategy and National Disability Agreement.

Despite our concerns about the Inquiry's focus on one specific disability, we recognise that particular cohorts of people with disability may have specific support needs. In that regard, this submission primarily focuses on our concerns with the use of Early Intensive Behavioural Intervention (EIBI), which we consider a restrictive practice.³ The submission also provides high level comments about other areas, including women and girls with autism, education and employment.

Specifically, this submission responds to Terms of Reference (TORs) c, d and k and argues that:

- special measures must be taken to raise awareness of autism symptoms in girls and assist schools and services in recognising and responding to signs of abuse in this particularly vulnerable cohort (**TORs paragraph c: misdiagnosis and under representation of females in autism data, and gender bias in autism assessment and support services**)
- the Government should cease funding EIBI, redirect funding to interventions that comply with the CPRD and regulate privately-funded EIBI (**TORs paragraph d: international best practice with regards to diagnosis, support services and education, effectiveness, cost and required intensity**)

³ EIBI is an intensive behavioural therapy for children with autism, based on the principles of Applied Behaviour Analysis (ABA).

- Australia must transition from parallel 'special' and 'mainstream' education systems to one truly inclusive education system (**TORs paragraph d: international best practice with regards to diagnosis, support services and education, effectiveness, cost and required intensity**)
- the Government should create a National Jobs Plan to increase employment of people with disability in mainstream work and develop a national advertising campaign to encourage employers to hire people with disability (**TORs paragraph k: the social inclusion and participation of people with autism within the economy and community**)

Summary of recommendations

Recommendation 1: The Committee ensures all recommendations are underpinned by the principles and obligations contained in the CPRD and other human rights treaties, including the Convention on the Rights of the Child (CRC).

Recommendation 2: The Australian Government directs its funding and efforts towards measures that promote the advancement of human rights for all people with disability, rather than any specific cohort.

Recommendation 3: The Australian Government increases funding to enable the effective implementation of the National Disability Strategy and National Disability Agreement.

Recommendation 4: The Australian Government ensures all Government-issued and Government-sponsored information sources directed at parents, such as Raising Children Network, include information about the signs and symptoms of autism in girls.

Recommendation 5: Training be developed and disseminated to schools, health services and child protection services about the high risk of victimisation, especially sexual abuse, facing autistic girls and how to recognise and respond to signs of victimisation in this cohort.

Recommendation 6: Sexual violence services receive training on how to make their services accessible for autistic girls and women.

Recommendation 7: The Australian Government works with State and Territory governments to ensure that all Government-issued and Government-sponsored information sources, including Raising Children Network, include warnings about EIBI's potential to cause harm to children with autism.

Recommendation 8: The Australian Government must ensure that safeguards are put in place to identify and cease the use of privately-funded EIBI where it becomes apparent that it is causing trauma for the child.

Recommendation 9: The Australian Government establishes a national regulation scheme for privately-funded ABA practitioners, including a code of conduct, complaints mechanism and minimum education and continuing professional development requirements.

Recommendation 10: The Australian Government ceases to fund EIBI in all of its services, including the NDIS, Helping Children with Autism (HCWA), Medicare and the Childcare Benefit and Rebate.

Recommendation 11: The Australian Government works with State and Territory governments to cease State and Territory funding of EIBI in all of their programs.

Recommendation 12: If the NDIS continues to fund EIBI, NDIS planners and HCWA advisors should be required to provide parents with information about the risks of EIBI and information about alternative interventions to enable a truly informed choice.

Recommendation 13: The Australian Government works in consultation with the autistic community to identify appropriate interventions.

Recommendation 14: The Australian Government funds interventions that have been developed in partnership with or by people with autism themselves.

Recommendation 15: The Australian Government only funds interventions that comply with the CPRD, including interventions aimed at enhancing people with autism's coping skills and adapting their environments to accommodate their needs.

Recommendation 16: Establish a National Action Plan for Inclusive Education, including a plan to transition from parallel 'special' and 'mainstream' education systems to one inclusive education system in line with the CRPD definition of inclusive education.

Recommendation 17: Create a National Jobs Plan to increase employment of people with disability in mainstream work.

Recommendation 18: The Australian Government develops a national advertising campaign to tackle discrimination and attitudes toward people with disability at work and encourage employers to consider employing people with disability in newly flexible work environments.

Terms of reference

c. misdiagnosis and under representation of females in autism data, and gender bias in autism assessment and support services

Autistic females

Women and girls with autism are harder to identify and are often misdiagnosed, undiagnosed or receive an autism diagnosis later in life.⁴ This means that they may not receive the right support in a timely manner.⁵ Recent research suggests that underdiagnosis can occur because women and girls are better able to ‘mask’ their autism, having a stronger ability to blend in socially and better language and imitation skills.⁶

Article 26(1) of the CPRD requires States to take ‘effective and appropriate measures... to enable persons with disabilities to attain and maintain maximum independence, full physical, mental, social and vocational ability, and full inclusion and participation in all aspects of life.’⁷ Article 26(1)(a) states that services and programmes begin at the earliest possible stage.⁸ An autism diagnosis is often the ‘gateway’ to support systems, such as the NDIS, that are in place to uphold the rights contained in the CPRD. Where a woman or girl with autism misses out on a diagnosis, or is diagnosed late, they miss out on supports and thus their rights under the CPRD.

This lack of support is particularly concerning given that girls with autism are particularly vulnerable to abuse.⁹ Children with autism in general are at ‘considerable risk’ for experiencing multiple forms of victimisation in childhood, such as physical abuse, psychological or emotional abuse from an adult, bullying, sexual assault by peers and

⁴ Yellow Lady Bugs and the Department of Education and Training Victoria, *Spotlight on Girls with Autism* (Guide, 2008) 4.

⁵ *Ibid.*

⁶ *Ibid.*

⁷ CPRD (n 1) art 26(1).

⁸ *Ibid* art 26(1)(a).

⁹ Vide Ohlsson Gotby et al, ‘Childhood Neurodevelopmental Disorders and Risk of Coercive Sexual Victimization in Childhood and Adolescence – A Population-based Prospective Twin Study’ (2018) 59(9) *Journal of Child Psychology and Psychiatry* 957.

property crime compared to their non-autistic peers.¹⁰ Autistic girls in particular are at an almost threefold risk of sexual abuse.¹¹ Proactive prevention and intervention strategies are needed to decrease autistic girls' vulnerability to abuse.¹²

Early support may also prevent instances of family violence. Parents of children with autism experience many social, physical and psychological tensions and often have extensive care responsibilities.¹³ This may contribute to an increased risk of family violence. Receiving support services early on can help create a safe home for children with disability, including children with autism.¹⁴

We commend the recent Australian autism diagnosis and assessment guidelines, *A National Guideline for the Assessment and Diagnosis of Autism Spectrum Disorder* for providing information about how gender may affect the behaviour of people with autism.¹⁵ However, the Australian government must take further action to ensure greater awareness of how autism presents in girls and how to protect autistic girls from abuse. As such, we recommend that:

Recommendation 4: The Australian Government ensures all Government-issued and Government-sponsored information sources directed at parents, such as Raising Children Network, include information about the signs and symptoms of autism in girls.

Recommendation 5: Training be developed and disseminated to schools, health services and child protection services about the high risk of victimisation, especially sexual abuse, facing autistic girls and how to recognise and respond to signs of victimisation in this cohort.

Recommendation 6: Sexual violence services receive training on how to make their services accessible for autistic girls and women.

¹⁰ Jonathan A Weiss and Michelle A Fardella, 'Victimization and Perpetration Experiences of Adults with Autism' (2018) 9 *Frontiers in Psychiatry*.

¹¹ Vide Ohlsson Gotby et al (n 9).

¹² Jonathan A Weiss and Michelle A Fardella (n 10).

¹³ Fateme Mohammadi, 'Parents' Perspectives on Family Violence against Children with Autism' (2019) 22(9) *Archives of Iranian Medicine* 505, 506.

¹⁴ See, eg, Sally Robinson et al, *Violence Prevention and Early Intervention for Mothers and Children with Disability: Building Promising Practice* (Report, 2020).

¹⁵ Andrew Whitehouse, 'New Autism Guidelines Aim to Improve Diagnostics and Access to Services' (2018) *The Conversation*.

d. international best practice with regards to diagnosis, support services and education, effectiveness, cost and required intensity

Early intensive behavioural intervention

The Australian Government funds various therapies for people with autism, which vary in their objectives, methods and intensity. As a party to the CPRD and other international human rights treaties, Australia should only fund therapies that meet international human rights standards. In this context, PWDA is particularly concerned about the use of EIBI to treat children with autism.

In brief, we believe EIBI should not be funded because it breaches numerous provisions of the CPRD and CRC. We also believe it is a restrictive practice under the *National Framework for Reducing and Eliminating the Use of Restrictive Practices in the Disability Service Sector* (the National Framework for Restrictive Practices) and should not be funded because it is not the 'least restrictive' practice available.¹⁶

Where government funding ceases, EIBI may still be funded privately. As such, a number of our recommendations are aimed at regulating privately-funded EIBI and ensuring parents are aware of the risks of EIBI when assessing treatment options.

What is EIBI?

EIBI is an intensive behavioural therapy for children with autism, based on the principles of Applied Behaviour Analysis (ABA).¹⁷ ABA is based on behavioural psychology and was first used on children with autism in the United States in the 1960s by Ole Ivar Lovaas. Lovaas drew on earlier work by famed behaviourists such as Ivan Pavlov and B.F. Skinner, who aimed to condition animals, and work in the 1950s that had begun extending behavioural conditioning to humans.¹⁸ Lovaas and fellow behaviourists aimed to make children with

¹⁶ Department of Social Services, *National Framework for Reducing and Eliminating the Use of Restrictive Practices in the Disability Service Sector National Framework* (Framework, 2014).

¹⁷ Brian Reichow, 'Overview of Meta-Analyses on Early Intensive Behavioral Intervention for Young Children with Autism Spectrum Disorders' (2012) 42(4) *Journal of Autism and Developmental Disorders* 512.

¹⁸ For a summary of this history, see Patrick Kirkham, 'The Line Between Intervention and Abuse – Autism and Applied Behaviour Analysis' (2017) 30(2) *History of the Human Sciences* 107.

autism as ‘normal’ as possible, through practices such as discouraging repetitive behaviours used by children with autism to reduce energy and anxiety.¹⁹ These early forms of ABA used principles of punishment and reward,²⁰ and implemented them through aversive practices such as electric shock therapy and hitting.²¹ Treatment was considered successful if children with autism were ‘indistinguishable from their normal friends.’²²

While modern-day EIBI does not involve physical punishments, it still seeks to change behaviour through giving and withholding rewards.²³ In addition to changing behaviour, it aims to increase children with autism’s social and communication skills.²⁴ EIBI generally involves 20-40 hours per week of one-on-one therapy, delivered by ABA therapists and/or parents at home or in a centre.²⁵

EIBI can last for several years and initially involves an emphasis on the Discrete Trial Training (DTT) teaching technique.²⁶ DTT aims to teach behaviours and skills by breaking skills down into smaller steps.²⁷ Rewards are used to encourage desired behaviours and skills.²⁸ For example, the therapist might give the child a task and only reward the child if the task is performed without undesirable behaviour (eg without hand flapping or hitting the therapist).²⁹ If the child responds correctly, they will receive a reward, such as computer time or a break.³⁰ If the child responds incorrectly, the reward will be delayed and the therapist might model the correct response and start again.³¹

¹⁹ Elizabeth Devita-Raeburn and Spectrum, *Is the Most Common Therapy for Autism Cruel?* (Article, 11 August 2016) <<https://www.theatlantic.com/health/archive/2016/08/aba-autism-controversy/495272/>>.

²⁰ Child Mind Institute, *The controversy around ABA* (Article, 2020) <<https://childmind.org/article/controversy-around-applied-behavior-analysis/>>.

²¹ ‘Screams, Slaps and Love: A Surprising, Shocking Treatment Helps Far-gone Mental Cripples’, *Life Magazine* (1965) <http://neurodiversity.com/library_screams_1965.html>.

²² O Ivar Lovaas, ‘Behavioral Treatment and Normal Educational and Intellectual Functioning in Young Children with autism’ (1987) 55(1) *Journal of Consulting and Clinical Psychology* 3, 8.

²³ Raising Children Network, *Applied Behaviour Analysis* (Web Page, 29 June 2020) <<https://raisingchildren.net.au/autism/therapies-guide/aba>>; Raising Children Network, *Discrete Trial Training (DTT)* (Web Page, 29 June 2020) <<https://raisingchildren.net.au/autism/therapies-guide/discrete-trial-training>>.

²⁴ Raising Children Network, *Applied Behaviour Analysis* (Web Page, 29 June 2020) <<https://raisingchildren.net.au/autism/therapies-guide/aba>>.

²⁵ Brian Reichow, ‘Overview of Meta-Analyses on Early Intensive Behavioral Intervention for Young Children with Autism Spectrum Disorders’ (2012) 42(4) *Journal of Autism and Developmental Disorders* 512; Peggy Hailstone, *Parent Involvement in ABA/IBI* (Article) <<https://abia.net.au/web/wp-content/uploads/2016/07/ABIA-Jan-2014-Article-Parent-Involvement-in-ABA.pdf>> and Raising Children Network, *Applied Behaviour Analysis* (Web Page, 29 June 2020) <<https://raisingchildren.net.au/autism/therapies-guide/aba>>.

²⁶ Autism Partnership Australia, *Little Learners Autism Program* (Web Page, 2013) <<http://www.autismpartnership.com.au/LittleLearnersAutismProgram>>.

²⁷ Raising Children Network, *Discrete Trial Training (DTT)* (Web Page, 29 June 2020) <<https://raisingchildren.net.au/autism/therapies-guide/discrete-trial-training>>.

²⁸ Ibid.

²⁹ Henny Kupferstein, ‘Evidence of Increased PTSD Symptoms in Autistics Exposed to Applied Behavior Analysis’ (2018) 4(1) *Advances in Autism* 20.

³⁰ Ibid.

³¹ Ibid.

EIBI breaches Australia's international human rights obligations

EIBI is often cited as the 'golden standard' for autism treatment.³² However, PWDA is concerned that it breaches a number of Australia's international human rights obligations. The key features of EIBI that result in human rights breaches are:

- it aims to change people with autism instead of promoting inclusion and acceptance of autism
- it is extremely time intensive
- it can be abusive
- ABA therapists are unregulated.

Each of the above features and their corresponding human rights breaches will be addressed below.

EIBI aims to change the person instead of promoting inclusion and acceptance

EIBI aims to change the behaviour of people with autism to make them 'fit in' to society and therefore violates the CPRD's core principle of '[r]espect for difference and acceptance of persons with disabilities as part of human diversity and humanity'.³³ EIBI aims to reduce 'undesirable' behaviours such as arm flapping and promote 'desirable' behaviours such as sitting in a chair.³⁴ This is in contrast to approaches that accept diversity and adapt environments to accommodate people with autism. For example, promoting an inclusive society where people accept differences in behaviours, such as hand flapping and providing children with autism with therapy balls instead of seats at mainstream schools.³⁵

This point is highlighted by autistic self-advocate, Julia Bascom, who explains that her hand flapping is a form of communication and expression, but that it is forbidden in ABA:

I need to silence my most reliable way of gathering, processing, and expressing information, I need to put more effort into controlling and deadening and reducing and removing myself second-by-second than you could ever even conceive, I need to

³² Morton Ann Gernsbacher, 'Is One Style of Early Behavioral Treatment for Autism "Scientifically Proven"'? (2006) 7 *Journal of Developmental Processes* 19.

³³ CPRD (n 1) art 3(d).

³⁴ Raising Children Network (n 25).

³⁵ See, eg, Nader Matin Sadr et al, 'The Impact of Dynamic Seating on Classroom Behavior of Students with Autism Spectrum Disorder' (2017) 11(1) *Iranian Journal of Child Neurology* 29.

*have quiet hands, because until I move 97% of the way in your direction you can't even see that's there's a 3% for you to move towards me.*³⁶

EIBI is extremely time-intensive

In addition to trying to change people with autism, EIBI is problematic due to its enormous time commitment. Requiring children to participate in 20-40 hours per week of therapy is a clear breach of international human rights law.

The right to play, family life and inclusion

Article 31(1) of the CRC recognises the child's right to 'rest and leisure, to engage in play and recreational activities appropriate to the age of the child and to participate freely in cultural life and the arts.'³⁷ Being subject to 20-40 hours per week of EIBI severely limits the time available for children to enjoy rest, leisure, play and recreation. This is particularly so for children who attend a full week of school or kindergarten and are then subject to EIBI outside those hours.

Certain sources argue that EIBI is actually play, as teaching is often done through play-based exercises.³⁸ However, a distinction needs to be made between play-based therapy and unstructured play. 'Playing' 20-40 hours per week one-on-one with an adult who is constantly giving instructions is very different to unstructured, child-led play. Indeed, General Comment No.17 (2013) explains that:

Caregivers may contribute to the creation of environments in which play takes place, but play itself is non-compulsory, driven by intrinsic motivation and undertaken for its own sake, rather than as a means to an end.³⁹

General Comment No.17 (2013) specifically highlights that rehabilitative activities for children with disability which allow little or no time for self-directed activities infringe the rights contained in Article 31 of the CRC.⁴⁰ It states that '[n]arrowly focusing all of a child's leisure time into programmed or competitive activities can be damaging to his or her physical,

³⁶ Julia Bascom, *Quiet Hands* (Blog Post, 5 October 2011) <<https://juststimming.wordpress.com/2011/10/05/quiet-hands/>>.

³⁷ *Convention on the Rights of the Child*, opened for signature 20 November 1989, 1577 UNTS 3 (entered into force 2 September 1990) ('CRC') art 31(1).

³⁸ Autism Awareness Australia, *Behavioural Interventions* (Web Page, 2020) <<https://www.autismawareness.com.au/therapies/early-intervention/applied-behaviour-analysis-aba/>>.

³⁹ Committee on the Rights of the Child, *General Comment No.17 (2013) on the Right of the Child to Rest, Leisure, Play, Recreational Activities, Cultural Life and the Arts (Art. 31)*, UN Doc CRC/C/GC/17 (17 April 2013) ('*General Comment No.17*') [14(c)].

⁴⁰ *Ibid* [42].

emotional, cognitive and social well-being.⁴¹ EIBI is clearly a breach of Article 31(1) of the CRC.

The right to family life

EIBI also interferes with children with autism's family time. Article 23(3) of the CPRD requires States to ensure that children with disability have equal rights with respect to family life.⁴² The 20-40 hours a week a child spends in therapy is time that could have been spent with their parents and/or siblings.

Parent-led therapy is not a solution, but rather an aggravation of this problem. Our advocates have reported that when parents are required to perform extensive care duties, family relationships are negatively impacted. The line between parent and unpaid carer becomes unclear and resentment may grow towards the child with disability. In some cases this can place the child at risk of harm.

Our advocates also reported instances where non-autistic siblings were neglected due to the parent having to spend 20-40 hours per week delivering EIBI. The CRC states that the best interests of the child must be a primary consideration in all government actions concerning children.⁴³ States parties must ensure that children are provided with the care necessary for their well-being, 'taking into account the rights and duties' of their parents.⁴⁴ Funding parent-administered EIBI programs may therefore breach the CRC where parents are left with inadequate time to care for their other children.

Full and effective participation and inclusion in society

EIBI's time involvement leads to the breach of the CRPD's general principle of '[f]ull and effective participation and inclusion in society'.⁴⁵ While their peers are at playdates, at the park, going to the movies or attending dance classes, children with autism are undergoing intensive therapy. This is particularly concerning where EIBI is undertaken at a centre, as children are physically separated from both their families and mainstream society. For example, the Little Learners Autism Program involves children as young as one year old attending a segregated centre for four full days a week.⁴⁶ Segregation of children with disability in this context does not reflect legislated approaches to support young children's early learning and development through the National Quality Framework and early childhood

⁴¹ *General Comment No.17* (n 40) [42].

⁴² *CPRD* (n 1) art 23(3).

⁴³ *CRC* (n 38) art 3(1).

⁴⁴ *Ibid* art 3(2).

⁴⁵ *CPRD* (n 1) art 3(c).

⁴⁶ *Autism Partnership Australia* (n 27).

education curriculum within Australia's Early Years Learning Framework.⁴⁷ Children with autism cannot enjoy full participation and inclusion in society when they are effectively removed from it for 20-40 hours per week.

EIBI can be abusive

In addition to infringing on the child's right to play, family life and inclusion in society, in some circumstances EIBI can be a form of child abuse. Article 16 of the CRPD requires States to take all appropriate measures to protect people with disability from all forms of abuse.⁴⁸ Article 19 of the CRC similarly requires States to take all appropriate measures to protect children from abuse.⁴⁹

What is abuse?

The World Health Organization defines child abuse as:

*... all forms of physical and/or emotional ill-treatment, sexual abuse, neglect or negligent treatment or commercial or other exploitation, resulting in actual or potential harm to the child's health, survival, development or dignity in the context of a relationship of responsibility, trust or power.*⁵⁰

According to this definition, where EIBI is experienced as ill-treatment and harms or potentially harms a child's mental health, development or dignity, it is child abuse. EIBI always occurs in the context of a relationship of responsibility, trust and power as it is between an adult educator or parent and a child. It therefore has the potential to fit the definition of child abuse, due to its goal to change children's identity and behaviours as well as its intensity and duration of interventions.

EIBI can harm a child's mental health and dignity

Many people with autism have reported negative experiences of ABA, including EIBI, highlighting that they were forced to mimic neurotypical social behaviour, damaging their self-esteem and shaming them.⁵¹ Autistic self-advocates have highlighted that ABA's

⁴⁷ Australian Children's Education & Care Quality Authority, *National Quality Framework* (Web Page) <<https://www.acecqa.gov.au/national-quality-framework>>.

⁴⁸ *CRPD* (n 1) art 16(1).

⁴⁹ *CRC* (n 38) art 19(1).

⁵⁰ *Report of the Consultation on Child Abuse Prevention, 29–31 March 1999, WHO, Geneva*. Geneva, World Health Organization, 1999 (document WHO/HSC/PVI/99.1).

⁵¹ Office of Developmental Primary Care, *First-Hand Perspectives on Behavioral Interventions for People with autism and People with Other Developmental Disabilities* (Report, 2017) 1.

mechanism of behaviour correction feels like censure and criticism.⁵² From a very early age, people with autism receive the message that the way they behave and move is fundamentally wrong.⁵³ It is clear from these reports that EIBI can harm a child with autism's dignity.

In addition to those individual reports, one study showed that people with autism who were exposed to ABA were 86 per cent more likely to meet the Post Traumatic Stress Disorder (PTSD) criteria than people with autism who were not exposed to ABA.⁵⁴ Based on the alarming findings of the study, the researcher predicted that almost half of children with autism exposed to ABA will meet PTSD criteria four weeks after commencing intervention.⁵⁵ The author of the study explains that when a therapist forces a child with autism to suppress one of their self-stimulatory behaviours, this can be perceived by the person with autism as harmful or threatening:

[a]utistic people have a sensitivity to the way any situation is initially appraised, and a benign situation which was perceived as harmful or threatening to the individual can become a [potentially traumatic event] which could trigger [posttraumatic stress symptoms] due to their underlying vulnerability.⁵⁶

As such, it appears EIBI has the potential to harm a child's mental health and development as well as their dignity. EIBI meets the definition of child abuse in cases where it is experienced as emotional ill-treatment and harms or potentially harms the child's mental health and/or dignity. As such, Article 16 of the CPRD and Article 19 of the CRC require Australia to take all appropriate measures to protect children with autism from the potential for EIBI to be abusive.

In this regard, we recommend that:

Recommendation 7: The Australian Government works with State and Territory governments to ensure that all Government-issued and Government-sponsored information sources, including Raising Children Network, include warnings about EIBI's potential to cause harm to children with autism.

Recommendation 8: The Australian Government must ensure that safeguards are put in place to identify and cease the use of privately-funded EIBI where it becomes apparent that it is causing trauma for the child.

⁵² Office of Developmental Primary Care (n 52) 4.

⁵³ Child Mind Institute (n 21).

⁵⁴ Henny Kupferstein (n 29) 27.

⁵⁵ Ibid.

⁵⁶ Ibid 20.

EIBI is provided by therapists who are unregulated

A key step to protecting children with autism from EIBI as a form of abuse is to regulate the ABA therapist profession. In Australia, ABA practitioners are not required to hold formal qualifications in order to practice ABA techniques.⁵⁷ A practitioner may seek accreditation through international bodies, such as the *Behavior Analyst Certification Board (BACB)* and the *Association for Behavior Analysis International (ABAI)*.⁵⁸ However, Australia does not recognise these bodies as a national standard of accreditation.⁵⁹ Indeed, the Association for Behaviour Analysis Australia has itself highlighted that the lack of regulation is problematic.⁶⁰

Article 16(3) of the CPRD specifically requires States to ensure that all programs for people with disability are ‘effectively monitored by independent authorities’ to prevent exploitation, violence and abuse.⁶¹ As such, we recommend that:

Recommendation 9: The Australian Government establishes a national regulation scheme for privately-funded ABA practitioners, including a code of conduct, complaints mechanism and minimum education and continuing professional development requirements.

EIBI is a restrictive practice

In addition to breaching Australia’s human right’s obligations, EIBI should be considered a restrictive practice under the National Framework for Restrictive Practices. As such, it should not be used or funded because it is not the least restrictive practice available. It should be noted that PWDA believes that restrictive practices should generally be eliminated in compliance with Article 12 (equal recognition before the law) and Article 15 (freedom from torture or cruel, inhuman or degrading treatment or punishment) of the CPRD. However, in Australia, restrictive practices are currently regulated rather than prohibited.

The National Framework defines ‘restrictive practice’ as:

⁵⁷ Association for Behaviour Analysis Australia, *Frequently Asked Questions* (Web Page) < <https://auaba.com.au/faq>>.

⁵⁸ See, for example: Behavior Analyst Certification Board, *Board Certified Behavior Analyst* (Web Page) <<https://www.bacb.com/bcba/#BCBAEligibilityRequirements>> and Association for Behavior Analysis International, *Applying for Accreditation* (Web Page, 2020) < <https://www.bacb.com/bcba/#BCBAEligibilityRequirements>>.

⁵⁹ Raising Children Network (n 25).

⁶⁰ Association for Behaviour Analysis Australia, *ABA Australia Position Statement on National Regulation* (Web Page, 18 June 2020) <<https://auaba.com.au/PSR>>.

⁶¹ CPRD (n 1) art 16(3).

... any practice or intervention that has the effect of restricting the rights or freedom of movement of a person with disability, with the primary purpose of protecting the person or others from harm.⁶²

Restrictive practices can take a number of forms, one of which is environmental restraint, which involves 'restricting a person's free access to all parts of their environment.'⁶³ While the National Framework for Restrictive Practices does not provide further guidance on this definition, the *National Disability Insurance Scheme (Restrictive Practices and Behaviour Support) Rules 2018* (Cth) states that 'environment' includes 'items and activities.'⁶⁴ As discussed earlier, EIBI restricts children's access to many activities due to its intensive time requirement. EIBI's 20 to 40 hours per week of intervention means children have little time to engage in free play, extra-curricular activities and family time that other children enjoy. Children's access to activities is especially compromised where they attend a full school week and must then complete 20-40 hours of therapy after school hours. Therefore, EIBI is a restrictive practice.

EIBI is not the least restrictive practice

According to the National Framework for Restrictive Practices, restrictive practices should only be used as a last resort.⁶⁵ Where a restrictive practice is used, it must be the least restrictive practice available and only be used for the shortest possible period of time.⁶⁶ In addition, the National Framework for Restrictive Practices states that a restrictive practice should only be used where it is 'proportionate and justified in order to protect the rights or safety of the person or others.'⁶⁷

EIBI is not the least restrictive practice available, as there are many other less-intensive interventions available for children with autism.⁶⁸ The most desirable interventions will be discussed in the next section below. In addition, EIBI is not proportionate and justified to protect children with autism's rights or the rights of others. Any improvement in behaviour is outweighed by the multiple breaches of child's rights, as outlined in the above section.

Promoters of EIBI may argue that EIBI is proportionate and justified to protect children with autism's rights, by modifying their behaviour to help them 'fit in' to society. This argument assumes that to participate in society children with autism must change, rather than having society change. However, all children with autism's rights in the CPRD must be interpreted in line with the CPRD's core principle of '[r]espect for difference and acceptance of persons

⁶² Department of Social Services (n 17) 4.

⁶³ Ibid 5.

⁶⁴ *National Disability Insurance Scheme (Restrictive Practices and Behaviour Support) Rules 2018* (Cth) r 6(e).

⁶⁵ Department of Social Services (n 17) 6.

⁶⁶ Ibid.

⁶⁷ Ibid.

⁶⁸ Raising Children Network (n 25).

with disabilities as part of human diversity and humanity'.⁶⁹ EIBI goes against this principle by seeking to change children with autism. As such, EIBI is not protecting children with autism's rights and is not a permissible restrictive practice.

Given that the National Framework for Restrictive Practices and Australia's international human rights obligations prohibit EIBI, we recommend that:

Recommendation 10: The Australian Government ceases to fund EIBI in all of its services, including the NDIS, Helping Children with Autism (HCWA), Medicare and the Childcare Benefit and Rebate.

Recommendation 11: The Australian Government works with State and Territory governments to cease State and Territory funding of EIBI in all of their programs.

Recommendation 12: If the NDIS continues to fund EIBI, NDIS planners and HCWA advisors should be required to provide parents with information about the risks of EIBI and information about alternative interventions to enable a truly informed choice.

Appropriate Interventions

Given the failings of EIBI, Australia should cease all forms of its funding and only support interventions that comply with the CPRD. That is, interventions that do not try to change people with autism to make them appear more 'normal', but rather aim to enhance enjoyment of their rights.

In developing approaches to appropriate supports and therapies, the Australian Government must consult with and take into the account the views of people with autism. Autistic self-advocates have expressed a preference for treatments that help them understand their autism and cope with sensory overload, rather than train them to appear superficially 'neurotypical'.⁷⁰ Such therapies might include children's social skills groups, occupational therapy for sensory integration, play therapy and mindfulness to help with anxiety.⁷¹

⁶⁹ CPRD (n 1) art 3(d).

⁷⁰ Office of Developmental Primary Care (n 52).

⁷¹ Daniel A Wilkenfeld and Allison M McCarthy, 'Ethical Concerns with Applied Behavior Analysis for Autism Spectrum "Disorder"' (2020) 30(1) *Kennedy Institute of Ethics Journal* 31, 59 and Office of Developmental Primary Care, *First-Hand Perspectives on Behavioral Interventions for People with autism and People with Other Developmental Disabilities* (Report, 2017) 1.

We also support interventions that have been developed in partnership with or by people with autism themselves. We believe that those interventions will have taken into account the well-being of people with autism. One example is Reframing Autism, which provides support and education to people with autism and their families and seeks to celebrate, not change people with autism.⁷²

In addition, environments, such as kindergartens and schools, should be adapted to create more structure and routine for children with autism. There are a range of measures that can be useful, for example, providing visual supports, creating 'quiet' and 'loud' play areas, using environmental cues (for example, using placemats to signal where children sit at lunch time) and reducing bright lights.⁷³ More information about adapting environments for people with autism is available at: <https://www.autism.org.uk/about/family-life/in-the-home/environment.aspx>.

Accordingly, we recommend that:

Recommendation 13: The Australian Government works in consultation with the autistic community to identify appropriate interventions.

Recommendation 14: The Australian Government funds interventions that have been developed in partnership with or by people with autism themselves.

Recommendation 15: The Australian Government only funds interventions that comply with the CPRD, including interventions aimed at enhancing people with autism's coping skills and adapting their environments to accommodate their needs.

⁷² Reframing Autism, *Visions and Values* (Web Page, 2020) <<https://www.reframingautism.com.au/visions-and-values/>>.

⁷³ Amaze, *Autism and Inclusion at Kindergarten* (Booklet, 2019) <https://www.amaze.org.au/wp-content/uploads/2019/06/Amaze-Autism_Inclusion_at_Kindergarten_booklet_2019.pdf>.

Education

PWDA is concerned about the reduction in inclusive education for students with disability. Inclusive education involves students with disability participating in mainstream educational institutions that have undergone the necessary changes and modifications needed to overcome barriers commonly experienced by these students.⁷⁴ It does not involve education in separate schools or separate classrooms within mainstream schools.⁷⁵

Alarming, rather than moving towards a mainstream education system, Australia is moving towards a segregated education system. For example, while the NSW Department of Education is developing a Disability Strategy for all its schools across NSW, this strategy is not founded on an Inclusive Education policy based on the principles of General Comment 4 of the CRPD (see below).

The proportion of autistic students placed in mainstream classes reduced by 82.4% between 2009 and 2015.⁷⁶ During that period, segregated setting placements rose, with special class placements increasing by 5% and special school placements increasing by 41%.⁷⁷ This may be partially due to a lack of understanding about what inclusive education actually means. The term may be misconstrued as meaning that people with disability are 'included' by providing any means of education, particularly segregated education.

The benefits of inclusive education

Moving towards inclusive education will greatly benefit people with disability and communities. Research shows that when students with disability are educated in a mainstream setting, they enjoy 'enhanced educational attainment, increased post-secondary education, and are more likely to be engaged in competitive employment.'⁷⁸ Research has also shown that inclusive education provides benefits to students without disability, including 'enhanced learning opportunities and experiences; education that is more sensitive to differing student needs; growth in interpersonal skills and greater acceptance and understanding of human diversity; and increased flexibility and adaptability.'⁷⁹

⁷⁴ Committee on the Rights of Persons with Disabilities, *General Comment No.4 (2016) on the Right to Inclusive Education*, UN Doc CPRD/C/GC/4 (25 November 2016) [11].

⁷⁵ Ibid.

⁷⁶ Kate de Bruin 'The Impact of Inclusive Education Reforms on Students with Disability: An International Comparison' (2019) 23 (7-8) *International Journal of Inclusive Education* 811, 816.

⁷⁷ Ibid.

⁷⁸ Dr Kathy Cologon, *Towards Inclusive Education: A Necessary Process of Transformation* (Report, 2019) 10.

⁷⁹ Ibid 8.

While some parents may view special schools as necessary for their children, this is because there is currently no real choice between special schools and mainstream inclusive education. PWDA supports the recently released road map from the Coalition of Inclusive Education ...

Investing in making mainstream schools truly inclusive is just as wise economically as it is socially. Under-education leads to poor prospects of employment later in life.⁸⁰ Indeed, only 38% of working-age people with autism and 53.4% of all working age people with disability are part of the labour force, compared to 84.1% of people without disability.⁸¹ By failing to adequately invest in inclusive education, the costs are incurred later on through social support payments.

International obligations

Not only does inclusive education make social and economic sense, ensuring access to inclusive education is a requirement under the CPRD.⁸² The Committee on the Rights of Persons with Disabilities has raised concern about the 'significant increase in students with disabilities experiencing a segregated education, seclusion, isolation and a lack of age-appropriate settings, and about insufficient funding for inclusive education in mainstream schools' in Australia.⁸³ While the obligation to ensure access to inclusive education is progressive in nature, *General Comment No.4* explicitly states that 'sustaining two systems of education: a mainstream education system and a special/segregated education system' is unacceptable.⁸⁴ As such, Australia must act with urgency to transition from parallel 'special' and 'mainstream' education systems to one truly inclusive education system.

Recommendation 16: Establish a National Action Plan for Inclusive Education, including a plan to transition from parallel 'special' and 'mainstream' education systems to one inclusive education system in line with the CRPD definition of inclusive education.

⁸⁰ Education and Employment References Committee, The Senate, Commonwealth of Australia, *Access to Real Learning: the Impact of Policy, Funding and Culture on Students with Disability* (Report, 2016) 4.

⁸¹ Australian Bureau of Statistics, *Autism in Australia* (Report, 2018)
<<https://www.abs.gov.au/AUSSTATS/abs@.nsf/Lookup/4430.0Main+Features102018>>.

⁸² CPRD (n 1) art 24.

⁸³ Committee on the Rights of Persons with Disabilities, *Concluding Observations on the Combined Second and Third Periodic Reports of Australia*, UN Doc CPRD/C/AUS/CO/2-3 (15 October 2019) [45].

⁸⁴ *General Comment No.4* (n 75) [39].

k. the social inclusion and participation of people with autism within the economy and community

Employment

People with disability, including people with autism, face common barriers to employment. These include attitudinal, physical, communication, information, financial and structural barriers.⁸⁵ As such, any efforts towards increasing employment of people with autism should form part of a broader strategy to increase the employment of all people with disability.

In our *Federal Pre-Budget Submission 2020*, we called for a National Jobs Plan to increase employment of people with disability in mainstream work.⁸⁶ As outlined in our submission, the National Jobs Plan must implement recommendations from the Australian Human Rights Commission's 2016 *Willing to Work Inquiry into Employment Discrimination Against Older Australians and Australians with Disability*, including the following priority initiatives:

1. introduce specific targets for employment, beginning with a minimum quota of 15% for employment of people with disability in the public sector, with the NDIA minimum quota to be set at 51%
2. set specific targets, performance indicators and timeframes for increasing the workforce participation for people with disability across all sectors, including the private sector
3. address intersectional barriers that make it harder for many of us to find and keep work, such as gender and cultural discrimination and rural and remoteness
4. strengthen the transition of young people with disability from the school education system into tertiary education and into open/mainstream employment
5. build capacity within the social security system to support those of us with episodic disability who may move in and out of employment
6. have a monitoring and evaluation framework, with key milestones, and specified dates for public reporting on progress.
7. transition all workers with disability in Australian Disability Enterprises into mainstream employment.⁸⁷

⁸⁵ Australian Human Rights Commission, *9 Barriers to Employment* (Web Page) <<https://humanrights.gov.au/our-work/9-barriers-employment>>.

⁸⁶ People With Disability Australia, *Federal Pre-Budget Submission* (Submission, 2020) <<https://pwd.org.au/wp-content/uploads/2020/02/SB-20200131-PWDA-Treasury-Pre-Budget-Submission-1.pdf>>.

⁸⁷ Australian Human Rights Commission, *Willing to work: National Inquiry into Employment Discrimination Against Older Australians and Australians with Disability* (Report, 2016).

We continue to support this recommendation and believe it will improve employment outcomes for people with autism as well as other people with disability.

Recommendation 17: Create a National Jobs Plan to increase employment of people with disability in mainstream work.

We also wish to highlight that the current pandemic provides an opportunity to leverage new flexible-work arrangements to increase employment of people with disability. Without a proactive approach through a National Jobs Plan for all people with disability, it is likely that people with disability will face even more barriers to employment during the economic downturn due to the COVID-19 pandemic. As such we recommend that:

Recommendation 18: The Australian Government develops a national advertising campaign to tackle discrimination and attitudes toward people with disability at work and encourage employers to consider employing people with disability in newly flexible work environments.



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our own**