

Submission S054

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Family and Community Development Committee



## **Submission into the Victorian Government (Family and Community Development Committee) Inquiry into services for people with Autism Spectrum Disorder**

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## **1. Introduction**

Communication Rights Australia is a human rights information and advocacy organisation which works in partnership with people who have communication difficulties. People request our service when they experience discrimination, isolation or exclusion.

We represent a range of people on a continuum from severe speech and communication difficulties (such as Autism Spectrum Disorder, acquired brain injury), illness (such as Motor Neurone Disease, stroke, mental health, physical and sensory impairment, intellectual disability), through to children whose capacity to communicate impacts on correctly and consistently sending their message (such as Apraxia). People approach us when their ability to communicate their message is impacting on their ability to access their human rights.

Communication Rights uses the United Nations Convention on the Rights of People with Disabilities (“UNCRPD”), Victorian Charter of Human Rights and Responsibilities Act, disability discrimination legislation and government policies to ensure people can enjoy their rights. Our activities promote change and facilitate inclusion into community activities.

A large proportion of people with Autism Spectrum Disorder (“ASD”) have communication difficulties, so this is a group we have considerable experience with. Through that experience, many issues around service delivery to people with ASD have come to our attention. This submission seeks to highlight these issues, and in doing so addresses the following terms of reference of this inquiry:

- b.the availability and adequacy of services provided by the Commonwealth, State and local governments across health, education, disability, housing, sport and employment services;
- c.the adequacy of services to be provided under the National Disability Insurance Scheme (NDIS); and
- d.evidence of the social and economic cost of failing to provide adequate services.

## **2. Access to communication support affecting general access to services**

This section is relevant to both the second and fourth terms of reference. Access to communication supports goes to the heart of the question of accessibility and availability of services, and is therefore relevant to the second term of reference (b). Without access to such supports, the foreseeable and indeed documented results include higher rates of unemployment, homelessness, abuse and violence - which represent evidence of the social and economic costs of failing to provide adequate services (term of reference d).

With ASD affecting approximately 1 in 100 Victorians, and a communication disorder forming part of that diagnosis, it is estimated that there are over 40,000 Victorians living permanently with ASD-related communication difficulties.

The single greatest challenge for people with ASD is getting access to appropriate communication support. These supports may be simple tools (eg visual word cards), technologically sophisticated devices (eg speech generating device or iPads), the provision of a communication partner, or training in social skills to address pragmatic language disorders. Regardless of the type, these supports exist and are readily available across Victoria. Yet still too often we hear of people being denied the right to use such supports. The reasons these supports are not always accessible to people include:

- lack of awareness and/or understanding about their appropriateness/usefulness for a particular person;
- lack of resources preventing their acquisition; and/or
- lack of training for service providers.

Whether a person is taking part in an education setting, day program, health service, or interacting with the justice system or any other service covered by the second term of reference for this inquiry, it is vital that the individual has a functional method of communication so their rights, preferences and wishes can be respected and realised.

Without access to a functional method of communication, that person is effectively being denied full participation in and access to the service being provided. This may amount to discrimination against people with ASD on the basis of their communication disability, and constitute a breach of their right to freedom of expression. The further foreseeable results of being denied access to appropriate communication supports are people's wishes not being heard, people not being given the opportunity to achieve their potential, and, at worst, people being abused. The statistics are all too well known:

- people with disabilities, especially complex communication needs as is the case for many people with ASD, experience higher rates of being subject to violence and abuse than for people with no disability<sup>1</sup>;
- people with communication disabilities are subjected to restrictive practices at higher rates than people with no disability<sup>2</sup>;
- unemployment rates for individuals with ASD are around 65% compared with only about 6% for the whole population<sup>3</sup>; and

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<sup>1</sup> See, for example, the Victorian Equal Opportunity and Human Rights Commission ("VEOHRC"), *Beyond Doubt: The experiences of people with disabilities reporting crime - Summary Report*, July 2014.

<sup>2</sup> *ibid*, p45.

<sup>3</sup> Amaze Autism Victoria, [www.amaze.org.au](http://www.amaze.org.au).

- individuals with ASD are over-represented in the homeless population and in the justice system<sup>4</sup>.

The following sections discuss the particular barriers within the education and justice systems facing people with ASD/communication disabilities that lead to the sorts of outcomes listed above.

## 2.1 Education system

One quarter of Communication Rights Australia's advocacy cases for the 2014-15 year related to the education system. We received a far greater number of requests for advocacy in this area, however due to limited resources we were unable to take on all of those cases<sup>5</sup>. Despite our resource limitations, in the 2014-15 year, through our advocacy we were able to reinstate 21 students with communication or speech difficulties back into the school system. These 21 students are not the only Victorian students with ASD who face such barriers. There are a much larger number of students unable to fully exercise their right to education due to the considerable barriers to accessing education for people with communication difficulties.

The types of issues students with ASD/communication difficulties face in the education system include:

- schools not allowing children with ASD to be enrolled at all, or to attend full-time (VEOHRC's 2012 *Held Back* report found that students with disability are still refused enrolment in schools based on the schools alleged inability to accommodate for the students' needs); and
- schools not allowing students with ASD to participate fully (VEOHRC's 2012 *Held Back* report found that students with disability do not receive the necessary adjustments to participate fully in exams and assessments, and students with disability are denied equal access to attend excursions, school camps and other extracurricular activities).

These issues still exist in 2016 for students with ASD and arise due to a number of different barriers including:

### A. Lack of understanding around communication disabilities amongst school teaching and non-teaching staff

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<sup>4</sup> *ibid.*

<sup>5</sup> Inadequate resourcing for advocacy to people with disabilities is widely recognised. As noted by the Victorian Ombudsman, "[t]he department funds 24 advocacy services to assist people with disability in Victoria. However, the funding provided is extremely limited with only around 30 per cent going to individual advocacy. As a result many of these services do not have the resources to provide individual services to people with disability but instead focus on systemic advocacy" (Victorian Ombudsman, *Reporting and investigation of allegations of abuse in the disability sector, Phase 1 - the effectiveness of statutory oversight*, June 2015, p86).

For example, in regard to communication disabilities, Speech Pathology Australia has noted that “[p]rofessional staff in the classroom can form the view that if the student is inarticulate, the underlying problem is an intellectual disability. This is not the case as these children are cognitively intact but have severe language impairment”<sup>6</sup>. This may lead to such students:

- not being provided with learning activities/curriculum content at the appropriate level for their intellectual ability;
- having Individual Learning Plans that do not include goals and strategies set at the appropriate level; and/or
- not being provided with the appropriate communication tools.

#### B. Lack of awareness amongst school staff of legal rights and obligations regarding education

VEOHRC’s *Held Back* report found that 40 per cent of educators were unaware of the Disability Standards for Education 2005 and their obligation to comply with the Standards including the requirement to make reasonable adjustments<sup>7</sup>. There has been significant progress in this regard for students with physical disabilities, but not for those with communication disabilities. There are too many examples of schools responding reactively to students with communication disabilities, using disciplinary or punitive responses rather than proactively identifying effective teaching and engagement strategies. The Standards leave decision making about appropriate adjustments to educators, many of whom are not specifically or sufficiently trained with regard to the disability and/or individual needs in question. This gap raises the need for training as well as practice guidelines.

#### C. Inadequate access to resources and/or support services

This is both a funding issue and an organisational issue - if school staff are not adequately trained about disabilities and the supports that can assist those with such disabilities, or able to readily access this information, they cannot be expected to appropriately identify the necessary supports for students with communication difficulties. As noted in VEOHRC’s 2012 *Held Back* report, “there continues to be significant unmet need for support services for students with disabilities, including integration aides, occupational therapists, speech therapists, other specialist staff and assistive technology. If these are not provided when required, students with disabilities cannot participate effectively in education”<sup>8</sup>.

#### D. Inadequate requirements around provision of appropriate supports

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<sup>6</sup> VEOHRC *Held Back: The experiences of students with disabilities in Victorian schools*, September 2012, p43.

<sup>7</sup> *ibid*, p10 & p172.

<sup>8</sup> *ibid*, p60.

While the right to education is enshrined in international conventions which Australia has ratified (ie UNCRPD), as well as Australia's own commonwealth and state legislation (eg *Disability Discrimination Act 1992* (Cth), *Equal Opportunity Act 2010* (Vic)), and schools are legally obligated to make reasonable adjustments to enable students with disabilities to participate, these laws are framed in general terms and are subject to some limitations. For example, there is no specific legal requirement that schools ensure students have access to the communication tools they require should they have communication difficulties. So while a student with a disability may be attending school, if s/he is not provided with the supports necessary to enable him/her to communicate at school, that student is still effectively being denied the right to an education. It is frequently reported that students with communication disabilities face either no access to appropriate equipment, or their equipment is not consistently used.

#### E. Overly restrictive criteria for the Program for Students with Disabilities (PSD)

It is frequently reported by parents, educators and allied health professionals alike that the PSD is too limited and too many students are assessed as not meeting the criteria, and therefore not able to access the valuable supports it can provide. This has consequences for students in the short term - having to struggle unsupported day after day - and also for those students and society more broadly in the longer term. According to Speech Pathology Australia, empirical research clearly demonstrates that a deviation of only 1.5 standard deviations below the mean is the threshold beyond which there is high risk of long-term negative outcomes associated with not attaining a minimum level of educational achievement, and including the acquiring of psychiatric illness and experience of unemployment<sup>9</sup>. Despite this, the PSD criteria require a student to have results 3 or more standard deviations below the norm.

#### F. Inadequate practice/requirements around individual learning plans

There is no regulatory framework governing the development and implementation of individual learning plans (ILP). This results in a huge burden falling on the shoulders of often already stressed and overwhelmed parents or other care givers, or key teachers or support persons, to be proactive in ensuring an appropriate ILP is prepared and implemented by a school. Often, plans are not prepared, or if they are, they are not adequately drafted, and/or there is little real implementation or review. This represents a significant missed opportunity to support the best possible outcomes for students with ASD and communication disabilities.

#### G. Lack of independent complaints process

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<sup>9</sup> Speech Pathology Australia, 2014, *Submission to the Inquiry into the prevalence of different types of speech, language and communication disorders and speech pathology services in Australia*, p36.

The situation where all the above barriers exist is compounded by an inadequate complaints process. As noted by VEOHRC, “the current complaints process lacks independence as it allows the respondent to the complaint – the school – to be the primary decision maker about whether a complaint is substantiated”<sup>10</sup>.

## 2.2 Justice system

There are two important aspects to be considered in any discussion about the involvement of people with disabilities in the justice system. The first issue is the over-representation of people with disabilities in the justice system both as victims<sup>11</sup> and offenders<sup>12</sup>. This over-representation serves as a stark reminder of the cost to society of people with disabilities not being given full support in areas such as education, employment and housing. Dropping out of school, being unemployed and being homeless are risk factors for ending up in the justice system<sup>13</sup>.

The second issue is the barriers to access to justice that people with disabilities face once involved in the justice system. The result of these barriers is a justice system that does not ensure equitable access for people with communication disabilities. Not only can this amount to unlawful discrimination under Victorian and federal anti-discrimination laws, but it represents a cost to society in the form of offenders not being brought to justice and victims not being protected<sup>14</sup>.

The types of issues people with ASD and communication difficulties face in the justice system include:

- frequently experiencing prejudicial assessments of their competency to give evidence as a witness or victim to criminal proceedings, and
- being prevented from making reports to police.

These issues arise due to the following barriers:

### A. Failures of the legislative framework

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<sup>10</sup> VEOHRC, *Held Back: The experiences of students with disabilities in Victorian schools*, September 2012, p140.

<sup>11</sup> “National and international studies reveal that people with disabilities are more likely to be victims of crime than other groups in the general population” (VEOHRC, *Beyond Doubt: The experiences of people with disabilities reporting crime - Summary report*, July 2014, p18).

<sup>12</sup> Hughes N, *Neurodisability in the youth justice system: recognising and responding to the criminalisation of neurodevelopment impairment*, 2015, Table 1.

<sup>13</sup> Australian Institute of Criminology, *National Crime Prevention Framework*, para 6.1.3.

<sup>14</sup> “The perception that a person with disability lacks credibility as a witness to or victim of crime often leads to the decision not to prosecute alleged perpetrators. This heightens the vulnerability of people with disability to further harm because the perpetrator is aware that charges are less likely to be brought or prosecuted than if the victim were a person without disability” (Anti-Discrimination Commissioner (Tasmania), *Submission to ALRC inquiry (submission 71)* - quoted in ALRC, ‘Final report: Equality, Capacity and Disability in Commonwealth Laws’, Aug 2014 (ALRC Report 124), p224-5).

While evidence laws applicable in Victoria do allow evidence to be given “by any appropriate means”<sup>15</sup>, in reality this is not occurring sufficiently for people with complex communication needs to equitably access the justice system. As noted by VEOHRC, police officers themselves believe the *Evidence Act* “tied their hands and was not flexible enough to meet the requirements of people with disabilities, particularly those with communication disability”<sup>16</sup>. Police have reported “having to push hard to have briefs authorised [ie allowing matter to go to court] where behaviours that form part of a disability were seen to compromise the quality of evidence and, as a result, the likelihood of a conviction”<sup>17</sup>.

The problem is that the *Evidence Act* does not provide guidance about what the appropriate means are, and does not clearly specify that these apply to people with communication disabilities. As a result, the courts remain overly cautious about using alternative communication methods<sup>18</sup>.

#### B. Misperceptions by officers of the justice system of cognitive and credibility limitations of people with communication disabilities

In 2014 the Australian Human Rights Commission reported “that people with disabilities frequently experience prejudicial assessments of their competency to give evidence as a witness to criminal proceedings”<sup>19</sup>. The Australian Law Reform Commission and the Judicial Commission of NSW have similarly acknowledged this problem<sup>20</sup>. This situation persists despite research establishing that most people with disabilities are no different from the general population in their ability to give reliable evidence as long as communication techniques are used that are appropriate for the particular person<sup>21</sup>.

#### C. Police feeling ill equipped to deal with people with communication disabilities and not being aware of how to make the appropriate reasonable adjustments to processes to cater for people with communication disabilities

VEOHRC has reported that “[p]olice...say they feel poorly equipped to make the reasonable adjustments required to communicate with many people with disabil-

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<sup>15</sup> *Evidence Act* 2008 (Vic) s31.

<sup>16</sup> VEOHRC, *Beyond Doubt: The experiences of people with disabilities reporting crime - Summary report*, July 2014, Executive summary, p9.

<sup>17</sup> *ibid*, p36.

<sup>18</sup> *ibid*, pp38-9.

<sup>19</sup> Australian Human Rights Commission, *Equal Before the Law: Towards Disability Justice Strategies*, 2014, p21.

<sup>20</sup> ALRC, *Final report: Equality, Capacity and Disability in Commonwealth Laws*, Aug 2014, p225-6; Judicial Commission of NSW, *Equality before the Law Bench Book*, 2006, para 5.3.1.

<sup>21</sup> Judicial Commission of New South Wales, *Equality before the Law Bench Book*, 2006, para 5.3.1 - cited in ALRC, *Final report: Equality, Capacity and Disability in Commonwealth Laws*, Aug 2014, p225-6.

ities”<sup>22</sup>. In particular, during VEOHRC’s investigation police identified that knowing how to assist people with “complex communication needs, especially if the person is non-verbal” as one of the biggest challenges<sup>23</sup>. VEOHRC also noted that while some specialised parts of the police force had knowledge and equipment that supported effective communication<sup>24</sup>, “general duties police did not have the same knowledge or resources”, recognising that “[t]his creates a problem when they are the first point of contact”<sup>25</sup>.

#### D. No/inadequate communication supports provided to people with communication difficulties in order to enable them to communicate in police interviews or in court

As discussed above, there is a notable absence in the Victorian justice system’s legislative and regulatory framework of unambiguous guarantees for people with communication disabilities to be given access to the necessary communication supports. But even in the rare case where the need for such supports is recognised and efforts are made to ensure access to those supports, the process is problematic. This is because there is currently no formalised system in place to enable judicial and/or police officers to efficiently access those supports, and the organisations providing such supports are acutely under-resourced. This critical aspect was noted by the ALRC, which acknowledged that amendment of evidence laws to provide an entitlement to communication supports in itself “does nothing to ensure that support is actually available”, recognising that there is a need for resourcing to ensure the relevant supports are available, not simply a legislative entitlement to them.

### 3. National Disability Insurance Scheme (NDIS)

In relation to the third term of reference - the adequacy of services to be provided under the NDIS - the advocacy sector has great hopes for the NDIS but is concerned about continued uncertainty around key details about how it will operate and the actual provision of information to all who require it.

The main barriers for individuals with communication difficulties accessing information are difficulty expressing themselves in the manner of their choosing, being understood by communication partners, poor responsiveness of communication

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<sup>22</sup> VEOHRC, Beyond Doubt: The experiences of people with disabilities reporting crime - Summary report, July 2014, p51.

<sup>23</sup> *ibid* p29.

<sup>24</sup> For example, “Sexual Offence and Child Abuse Investigation Teams (SOCIT) members described using picture boards, tablets and other communication aids, drawing on training and having reasonable access to supports” (VEOHRC, Beyond Doubt: The experiences of people with disabilities reporting crime - Summary report, July 2014, p22).

<sup>25</sup> VEOHRC, Beyond Doubt: The experiences of people with disabilities reporting crime - Summary report, July 2014, p22.

partners and the lack of functional communication experienced by some. The impact of other impairments, such as dexterity, mobility impairments and cognitive impairments, also make it difficult to access information. Literacy difficulties and difficulties created by the complexity of government language and the way that information is formatted are also barriers. In addition, lack of access to technology such as Augmentative and Alternative Communication (AAC) devices makes requesting information very difficult. Additional barriers are created when communication partners have a poor understanding of AAC and of their role with AAC users.

Most significantly, our concerns relate to the below issues:

A. Education - Program for Students with Disabilities

It is currently unclear whether the PSD will be replaced by the NDIS or otherwise affected by the NDIS. As noted above, it has been repeatedly reported that the PSD is too restrictively applied and inadequately funded to provide sufficient support to all the students who have additional needs in the school setting due to their disability. If the NDIS were to apply to these children, they may be able to access supports that otherwise would not be available to them and consequently their outcomes could be significantly improved.

B. Communication support training

There is currently lack of clarity around whether a person's NDIS package will cover the cost of training their staff in appropriate communication skills and the liability of this cost when staff leave.

C. Over-dependence of the NDIA on the provision of information through online services, public forums and telephones

Online services, public forums and telephones are often inaccessible to people with communication disabilities. The NDIA website states that you can access information through phone contact, participants' portal or through a publication. If you do not have speech the phone is problematic. If you do not have internet access the website and Participant's Portal is inaccessible. If you are unaware of publications – how can you ask for them? The overemphasis by the NDIA to distribute information is not a viable solution for many of those with communication difficulties and lower income groups. Less than 40% of people with communication difficulties have internet access.

Time allocated to the provision of information is a barrier. Large forums are not conducive to people who use alternative forms of communication asking questions or participating. A person with a communication difficulty may take 10 times longer to ask a question than others and by this time most forums have moved on to other topics.

#### D. Lack of access to independent communication support people to assist individuals with their communication and planning

Assistive technology only considers people who already have functional communication. Consider those who do not, or who use a low technology device – such as an e-tran. They require the support of a skilled communication partner to assist them to obtain information, ask questions or tell people what they want in a plan. This role is not funded or recognised by governments as a tool for support for people who want to participate in activities of the NDIA on an equal basis as other members of the disability community do.

A safer and successful NDIS requires that every voice can be heard. While many people with disability can speak out for themselves and request access to information to protect their rights, many people with communication or speech difficulties rely on others who understand their method or means to communicate to support them to access that information.

It is concerning that there is uncertainty about these matters at a time when the NDIS has already begun being rolled out. Details about the application of the NDIS in relation to these areas needs to be considered, decided upon and provided to all relevant stakeholders urgently.

The recent 2015 Victorian Ombudsman Report on the Reporting and Investigations of Abuse in the Disability Sector highlighted the needs of people with communication and speech difficulties, noting specifically that “those who cannot [speak out for themselves] are especially vulnerable” (p9 Executive Summary) and that for people with limited communication, “the market driven model” of the NDIS “can present new barriers” and that this fact must be acknowledged and addressed through the NDIS.

#### **4. Recommendations**

In order to overcome the barriers facing people with ASD and complex communication needs in accessing the education system, we make the following recommendations:

- an effective monitoring system should be implemented to ensure schools are not discriminating against students with ASD in enrolments or participation in school curriculum or extracurricular activities;
- training and practice guidelines should developed and made widely available to teachers and other school staff around the Disability Standards;
- increased funding to close the gap of unmet need in terms of provision of specialist support and/or technologies should be immediately provided;
- amendments to legislation and the relevant regulatory frameworks should be made without further delay, guaranteeing access to communication supports where needed;

- the criteria for the PSD should be expanded so students with ASD are not excluded from accessing the supports they need at the high rate they currently are;
- a regulatory scheme for ILPs should be introduced, requiring monitoring to ensure that ILPs are prepared and regularly reviewed, and providing guidelines for best practice; and
- establishment of an independent complaints process should be considered.

In order to address the barriers identified above in relation to the justice system, the following should be immediately implemented:

- disability training for police members;
- guaranteed access to communication supports (whether devices, communication assistants, or other form) for people with communication disabilities who are involved in the justice system, whether as victims making a report or as witnesses in court proceedings; and
- establishment of a disability liaison unit within Victoria Police.

In relation to the NDIS, we make the following recommendations:

- information about the status of the PSD under the NDIS should be provided without further delay;
- confirmation that the scheme will cover the cost of training any carer/worker who works with a person with complex communication needs to learn how to use the person's communication device/system should be provided as a matter of urgency; and
- urgently establish a funded scheme for skilled communication partners to be provided to those in need, to assist with accessing information about the NDIS as well as with planning for their own packages.