

Driving Change:

Submission

Parliamentary Inquiry into service's for
people with autism spectrum disorder

April 2016

amaze

DRIVING CHANGE
FOR A BETTER VICTORIA
FOR PEOPLE ON
THE AUTISM SPECTRUM

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Introduction

Amaze welcomes the opportunity to provide a submission to the *Parliamentary Inquiry into the services for people with autism spectrum disorder*.¹ As the peak body for people on the autism spectrum and their families in Victoria, the Inquiry poses an important opportunity for Amaze to highlight the current issues within the Victorian autism community, provide pragmatic policy and programmatic solutions to these issues, with the overall objective of increasing independence, achieving the full potential and increasing the social, economic and community participation and opportunities of all Victorians on the autism spectrum.

The large gap in outcomes for people on the autism spectrum and those without disability is stark across Australia. The gap is across the lifespan and supported by current available data – be it in education, employment, wellbeing, community participation and recent international research indicating a gap in average lifespan of 16 years. There is a clear need for a specific and targeted response to address this disparity, that will not only directly benefit people on the autism spectrum, their families and carers, but all Victorians through resulting economic gains.

The Terms of Reference of the Inquiry are wide ranging, allowing reference and investigation into all facets of services that should be available for Victorians on the autism spectrum. An important fundamental principle to note upfront is that, whilst specialist supports and services are needed to facilitate greater participation for people on the autism spectrum, there is also a key imperative for the broader community and mainstream services and facilities to be available and fully accessible to people on the autism spectrum – and the Inquiry has a responsibility to ensure that those mainstream services are responding to the needs of people on the autism spectrum.

In order to create a society where people on the autism spectrum are valued and supported to reach their full potential, we need to look beyond the provision of services where a concerted effort is required to address the underlying ableism that is present within our society. People on the autism spectrum face discrimination and stigma every day – directly, indirectly and structurally. We have come a long way in recent years in creating a more inclusive society for people with disability, but there is much more to be done. In order to address this discrimination and stigma, there needs to be an effort to increase awareness and understanding of autism in Victoria alongside improvements with services provided to people on the autism spectrum. One effort without the other will not drive the societal and attitudinal change required to achieve a truly inclusive Victoria.

“Let’s move beyond shallow autism awareness and appreciate autistic people in fullness of their humanity.”

Steve Silberman, Address to the UN on World Autism Awareness Day 2016

Amaze works to ensure that the voice of people on the autism spectrum, their families and carers are central in all our work. In preparing this submission Amaze sought the experience, stories, input and ideas of the Victorian autism community, and their voices can be heard through these pages.

Amaze has a commitment to influence positive change for people on the autism spectrum and their supporters in Victoria. Every person on the autism spectrum should have the opportunity to exercise their own choice to participate meaningfully in and make a valued contribution to our society.

¹ The term autism spectrum disorder is used interchangeably with autism through this submission

About this submission

Amaze has provided information, resources and independent advice to the Victorian autism community for 48 years.

The trust and high regard that Victorian people on the autism spectrum and their families and supporters hold for Amaze is our organisation's greatest asset.

Without the support of our community, Amaze wouldn't exist. Therefore our responsibility is to represent the voices and views of our community accurately and provide solutions that are grounded in evidence to ultimately improve the quality of life for people on the autism spectrum.

This is the most extensive submission developed by Amaze in its history.

Its creation has followed the basic elements of policy development – community consultation, identification of the issues, evidence based solutions and pragmatic recommendations.

The extensive consultation process undertaken is described along with a summary list of 54 recommendations.

The submission is structured into a number of sections that respond directly to the Terms of Reference of the Inquiry:

Introduction

Summary of Recommendations

Part 1: Background and Environmental Context

Part 2: Response to the Inquiry Terms of Reference for Services for People with ASD

2.1 Diagnosis

2.2 Early Intervention

2.3 Education

2.4 Employment

2.5 National Disability Insurance Scheme

2.6 Restrictive Interventions

2.7 The Economic Cost of Autism

Amaze looks forward to the outcomes of the Inquiry and its influence in making Victoria a better place for people on the autism spectrum.

Consultation with the Victorian Autism Community

The direct lived experience from people on the autism spectrum, their families and carers is central to this submission. Amaze undertook an extensive consultation process in preparation of this submission, to capture the direct experience of the Victorian autism community and hear directly about the issues they are facing and how they would like them to be addressed.

To ensure that we captured as many participants as possible, Amaze designed a consultation strategy that was multi-modal, provided a number of options for participation and offered an opportunity for participants to contribute their experience and suggestions across many topics.

Amaze developed a detailed survey asking participants a number of questions relating to diagnosis, education, employment, support services, the National Disability Insurance Scheme and an open ended section to share anything further. We had a significant response to the survey with just over 500 responses, coming from a mix of people on the autism spectrum, family members of a person/s on the autism spectrum; carers of a person/s on the autism spectrum; educators, service providers, employers; and members of community organisations.

A mix of qualitative and quantitative data was obtained through the survey and with over 500 participants there was a substantial volume of qualitative information provided to Amaze, which is shared in the submission.

Amaze invested in an online platform to facilitate a number of online discussion forums to promote discussion and sharing of issues and ideas on a number of topics. These forums achieved an encouraging level of participation and engagement.

Amaze also attended a community forum hosted by Suzanna Sheed MP in Shepparton during the consultation period, and discussed a number of Amaze's priorities for the Inquiry along with issues facing people on the autism spectrum living in regional centers. The forum was very well attended with over 100 people attending, who asked a number of questions about the Inquiry and shared their personal experiences.

Amaze also leveraged its existing networks and day-to-day operations to increase the level of engagement in the consultation process – from sharing the consultation website on our social media, providing it to autism support groups statewide and emailing contacts a number of times to encourage participation.

Amaze is proud to have successfully engaged the Victorian autism community to such an extent in the development of this submission, as it aims to give voice to the views, opinions and experience of people on the autism spectrum and their supporters. Such was the potency and richness of the comments by the Victorian autism community, many have been include verbatim in this submission.

Summary of Recommendations

Recommendation 1: Any changes, amendments or new developments in the provision of services, programs and supports affecting or impacting people on the autism spectrum, should engage and consult with people on the autism spectrum.

Recommendation 2: The consultation and engagement outcomes from the development of the Victorian Autism Plan are made available to the Committee for the purpose of this Inquiry.

Recommendation 3: Collection of nationally consistent data on the occurrence and prevalence of autism.

The early years

Recommendation 4: The development and resourcing of a comprehensive access to diagnosis strategy to ensure that the diagnostic process is simpler and more supportive for young children, their families and older people seeking a diagnosis and with the outcome being a more rapid and responsive diagnosis, including:

- Greater provision of clear and concise information through the diagnosis process;
- Formal support through the diagnosis process, including peer to peer support for families;
- Greater level of understanding of autism and its early signs within the primary healthcare system and early childhood educators (GPs, MCN, etc) to provide timely referrals;
- Roll out developmental surveillance across the Maternal and Child Health (MCH) service state-wide;
- Strengthened referral pathways for families between the following players NDIS ECEI approach, NDIS, MCH/GP's, other children's services and diagnosticians;
- Establishment a number of early diagnosis centres across Victoria to reduce waiting times and lower the average age of diagnosis;
- Increase the capacity within the public health system to allow faster diagnosis of autism, with the objective of eliminating waiting lists;
- Greater understanding of girls on the autism spectrum and associated traits and presentations;
- Greater understanding of adult diagnosis of autism and associated traits and presentations
- Greater contemporary understanding of the evidence base supporting early diagnosis amongst paediatricians and paediatric psychiatrists;
- Public funding available for adults seeking a diagnosis; and
- Increase access to diagnosticians in regional Victoria.

Recommendation 5: A commitment to ensuring noone waits longer than three months to access a diagnosis in Victoria.

Recommendation 6: Ongoing funding for Autism Advisors to provide support and independent, evidence based information to families following diagnosis of autism.

Recommendation 7: Review the role of Autism Advisors within the context of the NDIS, with the view of providing a greater level of support to families in preparing to access the NDIS.

Recommendation 8: Expand the role of Autism Advisors to be accessible for all newly diagnosed people on the autism spectrum, regardless of age.

Recommendation 9: Ongoing funding from the NDIA for Early Days workshops following the full roll out of the NDIS.

Recommendation 10: Development of resources and information to assist people on the autism spectrum who have received a late diagnosis as teenagers or adults.

Recommendation 11: The establishment of peer support groups for people on the autism spectrum who have received a late diagnosis as teenagers or adults.

Recommendation 12: Early intervention therapies that are eligible for Government funding, including in an NDIS plan, have a sound evidence base as outlined in the efficacy systemic reports outlined.

Recommendation 13: Autism specific early interventions are delivered in a manner that is in adherence with Autism spectrum disorder: Evidence-based/evidence-informed good practice for supports provided to preschool children, their families and carers ². J. Roberts and K Williams, 2016.

Recommendation 14: All early intervention providers must comply with the National Guidelines, Best Practice in Early Childhood Intervention, Early Childhood Intervention Australia, 2016 ³.

Recommendation 15: Early intervention providers wishing to provide services to children on the autism spectrum must demonstrate autism specific experience in order to offer services, either Government funded or privately funded.

Recommendation 16: Single source of broadly accessible independent, reliable and evidenced based information for families outlining all their options regarding funding streams, evidence based early intervention programs, supplementary mainstream services, support services, peer-to-peer supports, etc.

Recommendation 17: Information presented in accessible formats for all.

Recommendation 18: Information to be strengths based not deficit, not overly medicalised and including personal experiences from both people on the autism spectrum and families.

Recommendation 19: The development of a skilled workforce development strategy to increase the supply of skilled early intervention practitioners to meet the anticipated demand of early intervention services within full scheme NDIS – this could be facilitated by the Productivity Commission given their prior experience with the NDIS.

Education

Recommendation 20: Greater awareness and training to be provided to all staff within the education system on the Disability Standards for Education 2005.

Recommendation 21: Greater information provided to all parents and families on the Disability Standards for Education 2005.

Recommendation 22: The establishment of an independent Schools Commissioner, to receive and investigate complaints from parents and students. The Commissioner should also consider the need to capture an increasing level of data relating to attendance, incidence of suspension and expulsions, educational outcomes and incidents investigated regarding students with disability, which are published annually.

Recommendation 23: The Government work closely with Amaze and other key stakeholder groups in implementing the recommendations of the Review of the Program for Students with Disabilities.

Recommendation 24: The Government ensure that the Inclusive School Index, once developed, is mandatory for all schools and the results are publicly available.

Recommendation 25: Funding to develop autism specific professional development material and courses to build the capacity of educators across Victoria.

Recommendation 26: Implementation all 25 recommendations from the Review of the Program for Students with Disabilities, specifically those relating to the development of a new funding model based on functional needs.

² Autism spectrum disorder: Evidence-based/evidence-informed good practice for supports provided to preschool children, their families and carers. J. Roberts and K Williams, 2016

³ National guidelines: best practice in early childhood intervention, Early Childhood Intervention Australia, 2016 <http://www.eciavic.org.au/documents/item/1118>

Recommendation 27: Implementation of all recommendations from the “Greater returns on investment in Education: Government Schools Funding Review”, specifically those relating to updating the Student Resource Package to better meet the needs of students with disability.

Recommendation 28: The current eligibility review for PSD funding is moved to Year 8 from Year 6, to allow time for the student to adjust to his/her new school environment and his/her teachers have sufficient time to observe the student’s needs.

Recommendation 29: Consideration of the best method of reviewing additional funding eligibility in the development of a new funding model, in conjunction with prior recommendation.

Recommendation 30: Development, implementation and funding for a Post-School Transitions Policy for students on the autism spectrum, to include: best practice transition planning guidelines, work experience opportunities, individual career planning, and ongoing support following school and focusing on achieving the person on the autism spectrum’s full potential.

Recommendation 31: Identify and investigate current best practice Transition To Work programs around Australia to support the previous recommendation.

Employment

Recommendation 32: The Federal Government expands its current trial of greater support to young people with mental illness program to young people on the autism spectrum.

Recommendation 33: An education campaign be developed and funded to dispel the myths about employing people on the spectrum, showcasing their strengths as employees and what reasonable adjustments can be made to accommodate them.

Recommendation 34: The development of capacity building training for employers on how to best support employees on the autism spectrum, including the development of an accessible resources to support the training.

Recommendation 35: Well-coordinated and accessible information regarding rights, responsibilities and services and supports is available for employers and employees.

Recommendation 36: Leadership from the Victorian Government is demonstrated through the employment of people on the autism spectrum and developing policies to support positive workplace cultures.

Recommendation 37: The investigation of the efficacy of wage subsidies for employers of people on the autism spectrum.

Recommendation 38: Government to facilitate and incentivise additional volunteering opportunities for people on the autism spectrum as pathways to employment – and to increase the capacity of employers to cater for people on the autism spectrum.

Recommendation 39: The Disability Employment Framework engages with people on the autism spectrum to provide lived experience of specific needs of people on the autism spectrum relating to employment.

The National Disability Insurance Scheme

Recommendation 40: Development and distribution of accurate, detailed and accessible information on the NDIS, specifically in relation to autism. These resources should be developed for a number of different audiences including people on the autism spectrum, families and carers and disaggregated into the different life stages. The development of such resources should occur through co-design with people on the autism spectrum and include partnerships with the Victorian Government and NDIA to ensure accuracy of information.

Recommendation 41: Regular review of the resources developed following recommendation 40, should occur to ensure accuracy of information given the fast changing environment of the NDIS.

Recommendation 42: The ECEI Access Partners have autism specific expertise relating to identification of early autism signs, diagnosis of autism, all evidence based clinical and therapeutic autism specific interventions and supporting families before and after diagnosis.

Recommendation 43: The ECEI Access Partners should not be registered providers of supports in the NDIS to mitigate perceived and real conflicts of interest.

Recommendation 44: LAC providers have planners and staff with experience in autism, and they are required to increase their capacity in relation to autism.

Recommendation 45: NDIA planners and frontline staff have experience in autism, and they are required to increase their capacity in relation to autism.

Recommendation 46: Pre-planning for people on the autism spectrum, their families and carers incorporates support from people who have been through the NDIS planning process.

Recommendation 47: Victorian Government and the NDIA investigate alternate funding methods, such as an element of block funding for services in regional areas, to mitigate potential market failure in regional and remote locations – with focus on developing a higher skilled workforce to deliver early intervention services.

Recommendation 48: The Victorian Government with the NDIA further investigate the potential of innovative service delivery methods such as utilising a telehealth model.

Recommendation 49: The development and open accessibility of autism specific training and capacity building is available to registered providers of supports.

Recommendation 50: The requirement of all staff delivering disability services to be required to undergo pre-employment checks to ensure they are of fit and proper character.

Recommendation 51: All staff delivering disability services be required to undergo initial and ongoing training relating to the prevention of abuse, neglect and violence towards people with disability.

Recommendation 52: The Victorian Government work with the NDIA to define the interface between the NDIS and other service systems (health, mental health, early childhood, school education, higher education and vocational education and training, employment, housing, transport, justice and aged care), recognising that not all people on the autism spectrum will be participating in the NDIS.

Restrictive Interventions

Recommendation 53: Amaze supports the recommendations of the Australian Law Reform Commissions enquiry into Equality, Capacity and Disability in Commonwealth Laws and the National Mental Health Commission's position paper in calling for a nationally consistent framework governing restrictive practice across all services systems.

Recommendation 54: The framework should be facilitated by the Council of Australian Governments and be binding in nature. Such a national framework would build on current practice and include:

- A national approach to the regulation and use of restrictive practices across all Government and Non-Government service systems, including, but not limited to, the National Disability Insurance Scheme, disability services, education, health, mental health and prisons;
- A national approach to the reduction and elimination of restrictive practices in Australia, guided by current evidence;
- Consistent definitions for seclusion, physical restraint, mechanical restraint, social restraint, chemical restraint, environmental restraint, psycho-social restraint, and consequence driven strategies; and
- A reporting and accountability framework that collects nationally consistent data to provide an accurate measure of instances of use of restrictive practices.

And to support the governing framework, appropriate government investment should be made in:

- Development of standards and guidelines to support national consistency in approach to reducing the use of restrictive practices;
- Capacity building and education within service systems to operationalise the framework and guidelines;
- National independent monitoring and reporting across services; and
- Awareness raising of issues relating to restrictive practices amongst key stakeholders, including people with disability, their families and carers.

PART 1: BACKGROUND AND ENVIRONMENTAL CONTEXT

Who is Amaze?

Amaze is the peak body in Victoria for people on the autism spectrum and their supporters. Amaze is a member-based not-for-profit organisation established in 1967 that represents around 55,000 Victorians living on the autism spectrum.

In 2015, Amaze launched its Strategic Directions to 2040 – a 25 year plan to achieve social impact where society respects every person on the autism spectrum and they have real opportunities to participate and contribute. To achieve this, our three main goals are to:

- Increase community awareness and understanding of autism;
- Improve attitudes and behaviours towards people on the autism spectrum;
- Create more opportunities for people on the autism spectrum to participate and contribute to society in meaningful ways.

Amaze operates under a number of principles that guide our work and underpin our decision making. They are:

1. **Person-centered** – We ensure that the voices of people on the autism spectrum, and those that support them, are central to our decision making processes.
2. **Evidence based** – We seek data and evidence to underpin decision making and we measure the outcomes of our work wherever possible.
3. **Courage** – We do not condone, commit or remain silent about discrimination, stigmatising language or policies used to disadvantage or invalidate the life experience of people on the autism spectrum and we actively work to improve or change negative attitudes and behaviours.
4. **Collaboration** – We recognise that we cannot do this work alone so we actively seek people and organisations with whom we collaborate and partner.
5. **Acknowledging and celebrating uniqueness and achievement** – We actively seek ways to celebrate and recognise the unique contribution and participation of all people on the autism spectrum.
6. **Excellence and Professionalism** – We are committed to delivering superior performance through the highest possible standards of skill, professionalism and integrity and a culture of disciplined people, thought and action. We recognise that organisational sustainability is essential to achieve our purpose.
7. **Independence** – We are committed to representing the needs of people on the autism spectrum and their families/supporters in an unbiased, non-aligned manner.

Human Rights and Legislative Framework

Within Australia there is a comprehensive human rights framework, legislative and policy framework that supports our nation's commitment to the fundamental rights and entitlements of people with disability, including those on the autism spectrum.

The United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) is the first binding international human rights instrument to explicitly address disability. The UNCRPD and its Optional Protocol opened for signature on 30 March 2007 and Australia became one of the original signatories. Australia ratified the UNCRPD in July 2008 and the Optional Protocol in 2009. The CRPD entered into force for Australia on 16 August 2008, and the Optional Protocol in 2009.

The purpose of the UNCRPD is to 'promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity'. The UNCRPD consolidates existing international human rights obligations and clarifies their application to people with disabilities, rather than creating 'new' rights.

By ratifying the UNCRPD, Australia accepted the obligation to recognise that all people with disability enjoy the same rights, opportunities and access to services on an equal basis with those without disability.

The World Health Organization has adopted several resolutions urging Member States (including Australia) to better address the needs of individuals on the autism spectrum. Most recently, on 24 May 2014, the World Health Assembly adopted a resolution titled 'Autism'. This resolution highlights the importance of advocacy and policy development across sectors. In particular, it urges Member States to recognize the needs of individuals on the autism spectrum in policies and programs related to early childhood and adolescent health. It also urges Member States to enhance policies, legislation and multi-sectoral plans to address issues related to autism, as part of a comprehensive approach to implementing the WHO's broader resolutions that aim to support all persons living with mental health issues or disabilities.

Australia has also implemented domestic legislation and policy aimed at upholding the human rights of people with disability, including those on the autism spectrum. The Disability Discrimination Act 1992 (DDA) is the primary legislative mechanism for eliminating discrimination on the basis of disability. It covers a range of areas, including education, employment and access to premises. Further state and territory legislation exists with similar objectives.

A key policy framework regarding people with disability is the National Disability Strategy 2010-2020, endorsed by the Council of Australian Governments (COAG) in 2011. The Strategy sets a 10 year reform plan for 2010-2020 for all Australian governments to address the barriers faced by Australians with disability. It aims to ensure that mainstream services and programs including healthcare, housing, transport and education are accessible and address the needs of people with disability. The Strategy has an important role to play in ensuring that the principles of the UNCRPD are integral to the policies and programs which affect people with disability in Australia.

Within Victoria, the Charter of Human Rights and Responsibilities Act 2006 outlines the basic human rights of all Victorians, including those on the autism spectrum. This is also a number of additional Victorian legislative instruments that support the implementation of these frameworks.

"Nothing about us without us."

Recommendation 1: Any changes, amendments or new developments in the provision of services, programs and supports affecting or impacting people on the autism spectrum, should engage and consult with people on the autism spectrum.

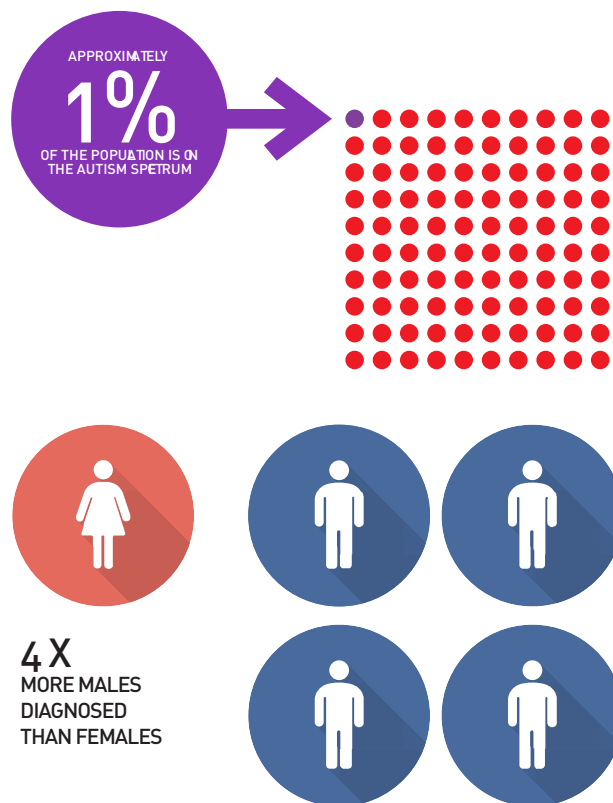
What is Autism?

“If you’ve only met one person with autism, you’ve only met one person with autism”.

Dr Stephen Shore

Autism Spectrum Disorder (or ASD) is a neurodevelopmental condition with symptoms that appear early in life. Amaze uses the terms “the autism spectrum” and “autism” to refer to this group of conditions. The term “spectrum” is used to describe the range of characteristics and abilities found in people with autism, as well as developmental changes, such as improvement in language ability, which might occur over time in a person with autism.

Autism is not a disease. People are born on the autism spectrum. It is a lifelong condition and there is no cure, but the way it affects people may change over time as a person grows and matures. Approximately 1% of the population is on the autism spectrum. Currently, four times as many males are diagnosed than females, but the number of females on the autism spectrum is increasing.



Every individual on the autism spectrum is different, but these features are present in some form:

Challenges in communicating and interacting with other people:

- Sharing interests and emotions. This can range from a lack of interaction to wanting to interact, but not knowing how to do it in an appropriate way.
- Using and understanding non-verbal communication, such as body language, eye contact or facial expressions.
- Making friends, maintaining friendships and adjusting behaviour to different social situations.

Repetitive routines in behaviour interests or activities:

- Repetitive speech, movements or use of objects.
- Routines, rituals or resistance to change.
- Interests that are very intense or narrow in focus.
- Being either over- or under-sensitive to sounds, smells, tastes, textures or visual stimuli. Often the same person will be over-sensitive to some things and under-sensitive to others.

Autism may be present with other conditions and it is important to understand the implications of this for each person. For example people on the autism spectrum may also be diagnosed with an intellectual disability, language delay, epilepsy, Attention Deficit Hyperactivity Disorder, anxiety and/or depression. Furthermore, no two people on the autism spectrum are alike. In practical terms this translates into each person having diverse needs for support in different areas of daily life to enable them to participate and contribute meaningfully to their community.

There are a number of other factors that can increase the likelihood of autism including:

- Studies have shown that among identical twins, if one child has autism, then the other will be affected about 36-95% of the time. In non-identical twins, if one child has autism, then the other is affected about 0-31% of the time.
- Parents who have a child with autism have a 2%-18% chance of having a second child who is also affected.
- Autism tends to occur more often in people who have certain genetic or chromosomal conditions. About 10% of children with autism are also identified as having Down syndrome, fragile X syndrome, tuberous sclerosis, or other genetic and chromosomal disorders.
- Almost half (about 44%) of children identified with autism have average to above average intellectual ability.
- Children born to older parents are at a higher risk for having autism.
- A small percentage of children who are born prematurely or with low birth weight are at greater risk for having autism.
- Autism commonly co-occurs with other developmental, psychiatric, neurologic, chromosomal, and genetic diagnoses. The co-occurrence of one or more non-autism developmental diagnoses is 83%. The co-occurrence of one or more psychiatric diagnoses is 10%.

The Victorian Autism State Plan

In the 2006 pre-election policy, "Addressing Disadvantage", the Victorian State Government committed to developing the Autism State Plan in partnership with Autism Victoria (now Amaze), with the aim to build new and better approaches for meeting the complex and growing needs of people on the autism spectrum.

After an extensive consultation and engagement process with the Victorian autism community, the Victorian Labor Government released an Autism State Plan (the Plan) in May 2009. This Plan was developed in recognition that "ASDs are becoming more prevalent and demand on services and support is growing" as well as in acknowledgment that "ASDs have particular features that distinguish them from other conditions".

The Plan identified six priority areas for the next ten years:

1. Make it easier to get support
2. Strengthen the ASD expertise of the workforce
3. Extend and link key services and supports especially during transition
4. Enhance and provide appropriate educational opportunities
5. Facilitate successful participation in the community
6. Develop a robust evidence base about ASD.

The 2009/10 State Budget provided an initial allocation of \$8.3 million over four years towards the Plan. This included over \$4 million to provide greater access to mental health services to increase the number of children with complex presentations of autism being assessed,

diagnosed and treated; and over \$4 million to improve regional coordination in education and to support teachers to complete postgraduate study in autism.

In April 2011, the new Minister for Disability Services said that the Coalition Government was committed to the Autism State Plan. However, it remains unclear as to the status of the State Plan after this point, but it may have been superseded by the new State Disability Plan, which was released in December 2012. Outcome 11 in the State Disability Plan is “better targeted and integrated services” and one strategy to achieve this outcome is to “provide better support for people with autism spectrum disorder”.

Actions for 2013-2014 in relation to this strategy include:

- Provide support to children, adults, families and carers who are dealing with autism spectrum disorder in a more coordinated and complementary approach across government
- Provide training and advice to disability support professionals over two years to better equip them to meet the needs of people with autism, their families and carers
- Use the Department of Education and Early Childhood Development’s regional autism spectrum disorder annual implementation plans to support an integrated early years and school approach through identifying regional priority areas such as professional learning and transition support
- Release operational guidelines for child-adolescent mental health services to help improve the assessment and treatment of children, young people and adults with complex presentations of autism spectrum disorder
- Implement and evaluate a new behaviour support service to test an approach that provides more effective and early support for young people with autism who display behaviours of concern, and their families and carers
- Provide training sessions to mental health clinicians across child, youth and adult mental health services that help to increase their knowledge and skills in assessment, diagnosis and early intervention for autism spectrum disorder and mental illness.

The disappearance of the Plan has been questioned by the Victorian autism community - especially given the extensive consultation process that was part of its development. This, in addition to the release of the Plan led to a significant amount of expectation within the community with the Plan not to be seen through and outcomes measured or achieved. Amaze is of the strong view that the records and outcomes of consultation process from the State Plan should be made available to the Committee for the purpose of this Inquiry. Many people shared their personal experiences through the consultation and the work of this Inquiry should build upon that foundation, instead of starting a fresh.

Recommendation 2: The consultation and engagement outcomes from the development of the Victorian Autism Plan are made available to the Committee for the purpose of this Inquiry.

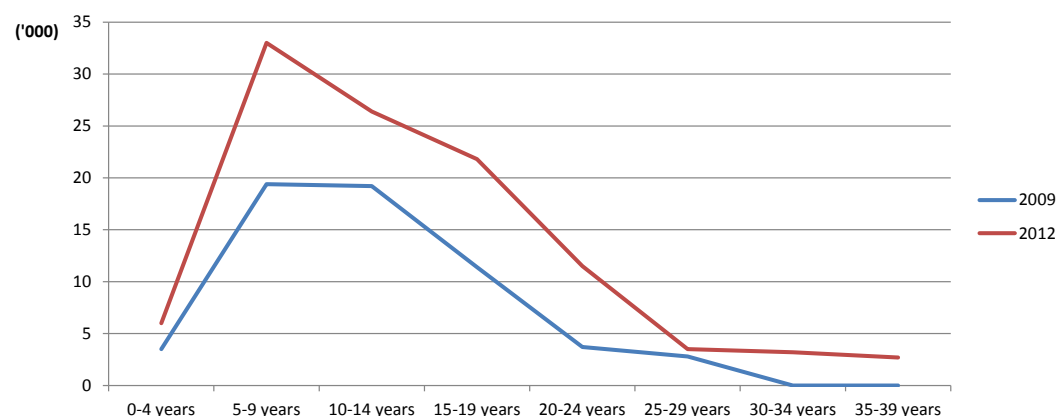
Prevalence of autism in Victoria

Globally there have been a number of prevalence studies over a number of decades that have all shown an increase in the incidence of autism. The first was in the 1960’s and produced a prevalence estimate of one in every 2,500 people (or 0.04% of the population) had autism. In the last decade, studies have continued to show a rise in prevalence ranging from 1 in 160 (or 0.62% of the population) through to a recent South Korean study that found a very high rate of 1 in 38 people (or 2.6% of the population).

The Centre for Disease Control in the United States has published all recent population based prevalence studies and states that “studies in Asia, Europe, Australia and North America have identified individuals with ASD with an average prevalence of between 1% and 2%”.

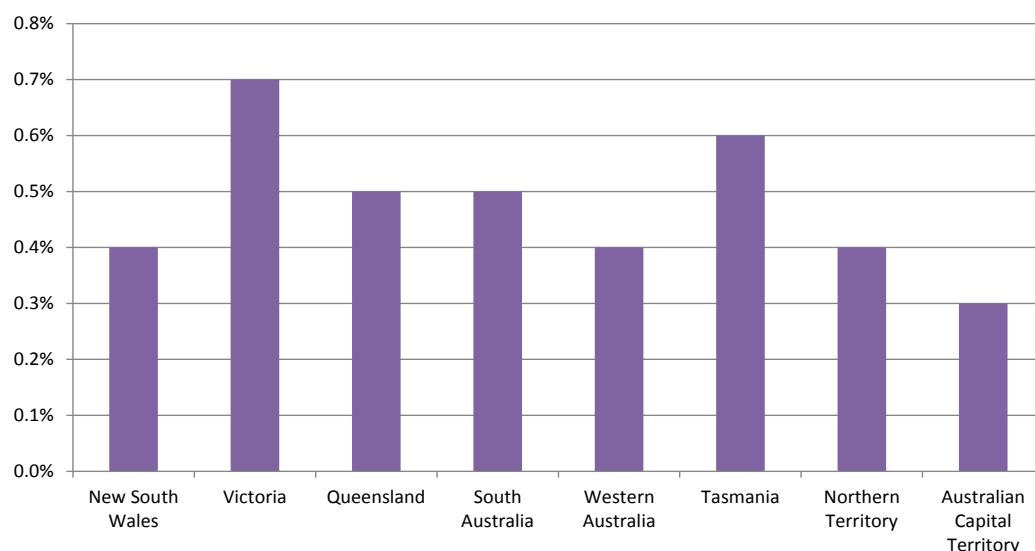
There is limited data on the age and incidence of autism diagnosis across Australia – at both a national and State or Territory level. The most recent Australian population based prevalence data was derived from the 2012 Survey of Disability, Ageing and Carers (SDAC). It is noted that the nature of the survey meant that “the data may underestimate the overall prevalence of autism spectrum disorders”. The 2012 SDAC showed an estimated 115,400 Australians (0.5%) had autism. This was a 79% increase on the 64,400 people estimated to have autism in 2009. Furthermore, autism was more commonly found in males than females, at a ratio of 4:1. The data also observed a considerable variation in the prevalence of autism across age groups, with a marked drop off in prevalence after peaking in the 5 to 9 years age group – this was consistent with the data from the 2009 SDAC, see below.

ALL PERSONS WITH AUTISM AGED 0-39 YERS, by Age-2009,2012



Source ABS Survey of Disability, Ageing and Carers, 2009 and 2012

The prevalence of autism by state or territory of usual residence varied slightly, ranging from 0.30% in the Australian Capital Territory to 0.72% in Victoria.



PROPORTION OF PEOPLE WITH AUTISM BY STATE OR TERRITORY OF USUAL RESIDENCE - 2012

Source ABS Survey of Disability, Ageing and Carers, 2012

It is clear that prevalence of autism in Australia and overseas appears to have increased significantly in recent decades. There are a number of factors that have been attributed to the increase in prevalence, including:

- An expansion in the diagnostic criteria;
- Changes in the methods used to measure prevalence rates;
- Increases in awareness and understanding;
- Lessening in stigma;
- Availability of government assistance specific to children with autism.

A higher level of detail expanding on these factors is available, and a recent article by Professor Andrew Whitehouse from the Telethon Institute for Child Health Research, University of Western Australia articulates these factors in greater depth - <https://theconversation.com/do-more-children-have-autism-now-than-before-4497>. Professor Whitehouse further states "It's quite possible the true prevalence of autism is increasing, and we just haven't yet identified the cause".

Recommendation 3: Collection of nationally consistent data on the incidence and prevalence of autism be established.

PART 2: RESPONSE TO THE INQUIRY TERMS OF REFERENCE FOR SERVICES FOR PEOPLE WITH ASD

2.1 Accessing a diagnosis of autism

If a child is suspected of having autism, an assessment is made by a team of professionals experienced in autism. The team will be made up of a paediatrician (or child and adolescent psychiatrist), a psychologist and a speech pathologist. Between them they will carry out a wide-ranging series of tests over several appointments, with the members of the multi-disciplinary assessment team. Once the assessment has been completed, the team will determine if the child meets the criteria for a diagnosis of autism and a diagnosis will be made.

There is evidence that children with autism can be reliably diagnosed by the age of 2 years, and general agreement that they can demonstrate recognisable symptoms in their first year of life. However, the average age of diagnosis in Australia is currently 49 months for children receiving the Helping Children with Autism (HCWA) program - with the most frequently reported age being 71 months.

Given that research suggests a reliable and accurate diagnosis is possible for many children with autism at 24 months, this finding represents a possible average delay of 2 years and with common delays of up to 4 years – this has also been supported by the experience shared by the community through Amaze's consultation.

Within the current disability services system, a diagnosis of autism is required to gain access to services, such as early intervention and additional supports in education.

There is significant evidence suggesting that the earlier age at which interventions begin for children on the autism spectrum, has been associated with improved outcomes with younger children showing greater gains from intensive early intervention.

Knowing that putting earlier interventions in place sooner provides greater opportunity to increase developmental outcomes for children on the autism spectrum, there is an imperative for these supports to be put in place as soon as signs of autism, or developmental delay are evident. Therefore having timely access to diagnostic services is critical in ensuring that interventions can be put in place.

Accessing diagnostic services within Victoria in a timely manner can be fraught for a number of reasons that have been shared with Amaze or identified through analysis:

- Lack of understanding of autism and its presentations by primary healthcare professionals such as local GPs or community nurses;
- Early signs of autism are not identified by family members but by other professionals such as a day care worker, a preschool teacher or another person closely involved in the care of children;
- Having to eliminate other possible causes of the developmental delay before reaching a hypothesis of autism;
- Lack of understanding of presentation of girls on the autism spectrum;
- A reluctance of paediatricians and paediatric psychiatrists to diagnosis autism under the age of three;
- Waiting lists for accessing diagnosis through the public health care systems;

- Limited access to diagnosticians in regional areas;
- Financial constraints for those seeking diagnosis through private diagnosticians, generally not wanting to wait for the public system;
- Lack of clear and concise information and support for family in navigating the diagnosis pathway;
- Parents and families have to fight the system to get a diagnosis, and getting confirmation of what they already suspect requires a great deal of persistence; and
- Parents having conflicting views of potential developmental delays.

The following comments from the Victorian autism community further illustrate this experience:

We had to wait 6 months to see the specialist for diagnosis. Once we saw him he had confirmed diagnosis within a week. 6 months on a new patient list is a long time when you need help.

Our initial meeting with the kindergarten field officer who voiced the concerns of the kindergarten was a very confronting experience for me as the parent and something I shall never forget.

No one could tell me how to go about getting diagnosis, it was by chance and pure luck we ended up getting in to see someone who was able to diagnose without too much difficulty after spending months trying to work through OT's and having other assessments done first.

There seems to be low awareness of how ASD presents in girls, preventing early diagnosis and meaning that girls miss out on funding.

Many girls will see a general psychologist who may treat anxiety, depression, eating disorder etc. and not look any deeper. General practitioners need to be educated.

I was initially frustrated with our first paediatrician due to her mentioning autism but not being willing to diagnose due to her age. It wasn't until we were lucky enough to get into our 2nd paediatrician that we got the diagnosis she needed.

The public waitlist was 9 months so we paid privately over \$1000 so we didn't miss out on early intervention. It was difficult to watch other people wait who couldn't afford it.

It was expensive. I would have been happy to pay for it. My husband was not. He took a lot of convincing. People are priced out of private services. Often both parents have differing perspectives on diagnosis. I found that resistance to seeking a diagnosis by my husband and extended family was emotionally and mentally difficult to pursue. Anything that makes the process easier would prevent people just giving up on the process because of the many barriers.

(Diagnosis) just took too long and too many misdiagnoses along the way.

The waiting list for the public system is too long! It should be done within weeks of a referral not months and months! Waiting times for appointments are far too long! For one appointment I had to wait 4 hours to be seen!!!!

We had to travel to Melbourne (from Bendigo) to get assessments done - otherwise we would have waited 2-3 years or longer.

Using inexperienced and unsupervised paediatric fellows as the first line of enquiry through the public system is hit and miss. You really need experts to assess kids.

Waiting lists to access professionals can be lengthy. We went through the private system to circumnavigate this. Even within the private system our first choice for the psychological assessment had a 3 month waiting list, so we decided to enlist the services of an alternative psychologist to expedite the process.

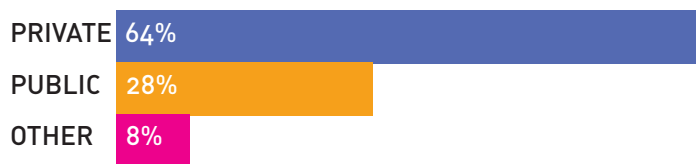
As an educator, I have witnessed many families' frustrations throughout this lengthy, stressful & emotional process.

Difficult experience due to brick walls, inconsistencies, lack of available affordable resources, lack of transparent information.

Diagnosis is important as it gives the child or young person a vehicle to reach their potential and independence. Parents are not listened to enough!

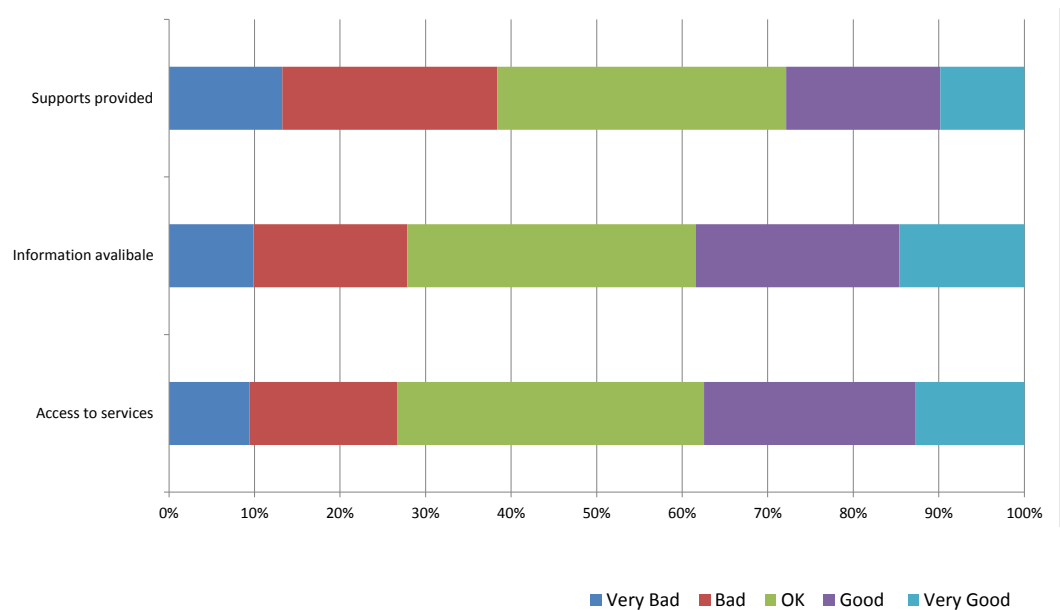
Fortunately I was able to afford it (private diagnosis), so it led to an early diagnosis. So now I have really seen the benefit of early diagnosis and early intervention = early improvements

Amaze also asked the community how they accessed their diagnosis:



We also asked respondents to rate a number of aspects of the diagnostic process from very good through to very bad:

HOW WOULD YOU RATE THE LEVEL OF THE FOLLOWING THROUGHOUT THE DIAGNOSIS PROCESS



There have been a number of projects that have been undertaken recently with the objective of identifying children at younger ages.

Childhood surveillance, early detection and early diagnosis - The University of Latrobe Olga Tennison Autism Research Centre (OTARC) case study.

We now understand that the onset of autism symptoms is variable during the first two years of life, with signs evident in some children from birth, while others may appear to be developing typically but then fail to progress, and yet others who may lose some of the skills already developed. This apparent slowing and/or regression in development is usually seen in the second year of life between 15 to 24 months of age. The variable pattern of onset means that one-off screening for signs of autism at a given age is not a suitable approach to identification, and has typically resulted in poor sensitivity (Barbaro & Dissanayake, 2009). Rather, a developmental surveillance approach is advocated during the second year of life on the basis of promising results from the Social Attention and Communication Study (SACS; Barbaro & Dissanayake, 2010).

Developmental surveillance

The developmental surveillance approach was adopted in the SACS, which was designed to prospectively identify infants who have an ASD through the universal Victorian Maternal and Child Health (MCH) service via their routine assessments during the first two years of life. The early phenotype of autism is marked by an absence of key behaviours important in children's social communicative development. Two hundred and forty one MCH nurses were trained to monitor infants' development on these key items (the absence of which is indicative of an ASD) during their routine check-ups at 8, 12, 18 and 24 months. Over 20,000 children seen by the MCH nurses were monitored for social attention and communication behaviours such as pointing, waving, imitation, eye contact, response to name and social smiles. Importantly, the behaviours monitored at each age differed, taking into account the development of these key skills

The training of nurses was undertaken at each of 17 Local Government Areas during a 2.5 hour session where nurses were trained on the early autism phenotype and the coupling of the first signs that are indicative of ASD development at each age. This training was well received with evaluations at the time of training, six months after and at the conclusion of the study showing excellent results (Barbaro, Dissanayake & Ridgway, 2011). The success of the SACS in prospectively identifying infants with an ASD via their MCH checkups promotes the utility of the training undertaken by the MCH nurses.

From 12 months onwards, infants who showed an absence of the key behaviours were referred by their MCH nurse to the team at La Trobe University for a thorough developmental assessment, and then followed up at 6-monthly intervals until 24 months of age, at which time they received a standardised assessment for autism. Eighty-one per cent of the children referred by the nurses met criteria for an ASD, with only one typically developing child being incorrectly referred. The remaining children had either a developmental and/or language delay. A follow-up study of all referred children at preschool age indicated high diagnostic stability (86%; Barbaro & Dissanayake, 2012).

Early Diagnostic Clinic for ASD

The success of the SACS in prospectively identifying infants and toddlers via routine developmental surveillance within a universal service, and the accuracy of early clinical diagnoses of ASDs at 24 months, led to the establishment of Australia's first Early Diagnostic Clinic (EDC) for Autism Spectrum Disorders, which focuses on children under the age of three years. Funded by the RE Ross Trust, the EDC was established in July 2011, and is an initiative of the Olga Tennison Autism Research Centre at La Trobe University. This clinic was a 'one stop shop' multidisciplinary diagnostic approach with children being able to access the number of diagnosticians on the same day under the same roof, minimising the amount of time waiting for families to get a diagnosis.

⁴ The trouble with autism: Delays in early identification and diagnosis, Dissanayake, C. InPsych 2012

A number of respondents to Amaze's consultation spoke highly of their experience of the OTARC model:

My daughters diagnosis at the Olga Tennison autism research centre at Latrobe was fantastic. We got an appointment at the early diagnosis clinic within 2 months, paid \$400 total and came out with a diagnosis that day. Quick and easy. They complete opposite of getting our son diagnosed!! I do wish they could diagnosis older kids too & that it was more widely known you can go there. Parents save so much time, stress & money doing it this way.

I really wish we had of known about the Olga Tennison ASD centre at Latrobe for getting a diagnosis for our first child! The cost and wait times for doing a multidisciplinary diagnosis was SO expensive and took such a long time, but we were desperate to start helping our son who was struggling immensely with life, that we just had to pay out of our own pockets.

The process was great because an OT, psych and paediatrician were in the one room.

We were lucky to have a great maternal health nurse that picked it up when my son was 2 years old. We then accessed a study at Latrobe University and from there then went to a paediatrician for formal diagnosis.

Amaze also sought suggestions as to how the diagnosis process could be made easier, some of the responses included:

Having a clear pathway to diagnosis outlined by someone, anyone!

A clear documented explanation of the steps to diagnosis without having to wait for appointments or return phone calls.

Earlier diagnosis, family support and education. Better communication between professionals.

Having access to closer services (from a regional participant).

Easier access to an authoritative governing body (eg Amaze) that could've guided me through the process from initial suspicions to diagnosis and beyond. More services and specialists across all areas of Melbourne (waiting lists were ridiculous)

Faster access to specialists once concerns were raised. Access to more support / support groups for parents.

GPs need to know more about diagnosis process and available services. Also public services are seriously lacking in regional areas.

A more centralised process of information and diagnosis. Many people went through different ways and there doesn't seem to be any consistency in approach.

Better teaching. Empathy. Understanding. Practical help.

A better public system. Knowing something is wrong with your child and being told it will be a 12-18+ month wait for services leaves you no choice but to go privately. Especially when early intervention is the key to good outcomes.

General practitioner to have had information on links to diagnosis.

Not having to pay private fees, average person wouldn't be able to afford, even with Medicare rebates.

Being believed (by medical professionals) 3 years earlier that my son was autistic.

Amaze do a good job in pulling together the disparate information from government services (state and federal).

Older diagnosis

Diagnosis of autism may not occur until adolescence although there may have been indications much earlier. Some people's autism may not be diagnosed until adulthood and may have experienced many years of anxiety and social and relationship difficulties before the diagnosis is confirmed. For adults this is complicated by a lack of professionals skilled in adult autism diagnosis. People diagnosed as adults have reported the negative impact of their condition on their relationships, problems looking after themselves on their own and difficulties getting and keeping a job.

There are currently no publicly funded adult autism assessment clinics in Victoria. For adults seeking an assessment, they are required to consult a psychologist and/or psychiatrist with experienced in the assessment and diagnosis of autism. Experiences shared with Amaze included:

Despite seeing a psychiatrist for 10 years for depression and social anxiety, Autism was never mentioned. It wasn't until my mum and I saw a counsellor for relationship issues that she asked if I had ever been assessed for Aspergers Syndrome. When I mentioned this to my Psychiatrist he bluntly stated that he didn't believe in Aspergers and that it was just the flavour of the month. Therefore I found another psychologist for the assessment.

I saw a few psychologists and psychiatrists over the years due to mental health issues and when I asked them if they thought I had ASD none of them thought it likely. It was only after my son was diagnosed with ASD, that I read widely about the condition and realised that I had many traits. I then sought out a psychologist who specialised in adults with ASD who did the assessment and diagnosis. I had to pay to see her privately as far as I am aware there are no public services for adults. It would have saved a lot of heartache if those psychologists that I saw earlier had a better understanding of how ASD presents in women, so I could have been diagnosed much earlier. There should also be funding for adults to get diagnosis, currently it is very expensive.

My GP, who had known me since childhood, was so uninformed about ASDs that she didn't believe I needed a referral for the diagnosis when I first approached her about it and needed much convincing. It seems absurd that a person who is in a situation of discovering that they are Autistic at the age of 42 - a highly stressful event in itself - should also be forced to inform their GP about it and beg for a referral. So more education for GPs about ASDs, especially in adults and adult women, is needed. Also, the diagnosis was extremely expensive (as I'm unemployed and am not on any benefits) and was not fully covered by Medicare. It should be either fully covered or be less expensive.

As an adult, it is so (sic) expensive for me to get an official diagnosis. There was no additional support for my son in the school system after getting his diagnosis.

It was quite a process to find someone locally who diagnosed adults at a price that was affordable. Once I found someone in my local area who diagnosed adults it only took about a month for an appointment.

One diagnosis leading to another

Another trend that Amaze has identified, both through our daily engagement with the Victorian autism community and through our consultation for this submission is an ever growing number of parents of children on the autism spectrum, who following their child's diagnosis are subsequently being diagnosed with autism. Some experiences and circumstances include:

My son was assessed at 8 years of age as having Aspergers. From this assessment process and further research on my part I realised how much this existed in my family especially my older brother, and then myself as well. I did adult assessment 2 years ago to confirm my suspicion of Aspergers as well.

I am sixty-six years old and recently completed a scale with a psychologist specialising in ASD. I am married and we have four children. My eldest grandson has been diagnosed as ASD and has a teachers aid to assist him at school. His father, my son is also a likely candidate for an ASD diagnosis although no formal evaluation has been scheduled.

I am the spouse of a person on the spectrum (currently undergoing the formal diagnostic process) and mother of autistic child.

We're not your average home with 2 adults and 3 children (ages 6, 8 and 14) all with both feet firmly planted on the spectrum.

The Autism Cooperative Research Centre (ACRC) has recently reported on the need for minimum national standards for autism diagnosis across Australia to enable more consistent diagnostic practices across States and Territories.

Role of diagnosis within the National Disability Insurance Scheme (NDIS)

It is important to note that with fundamental reform occurring in the disability service system, impacting on services and programs that are provided to people on the autism spectrum, there is a need to be cognisant of the implications these changes may have. As foreshadowed above, a diagnosis of autism has previously been required to access support services such as early intervention, educational supports, etc. However within the context of the NDIS, eligibility is based on functional impairment instead of diagnostic criteria therefore removing the immediacy of requiring a diagnosis to allow for interventions and services to be accessed.

This recent release of the National Disability Insurance Agency (NDIA) Early Childhood Early Intervention (ECEI) approach outlines that if a child demonstrates developmental delay they will be able to gain access to supports and services through the NDIS through an 'Access partner'. This is also in clear alignment of the social insurance principles that underpin the NDIS. We will provide greater analysis and recommendations on the ECEI and role of access partners further in the submission.

Amaze is of the view that a diagnosis should not be delayed once a clear presentation of autism is identified. Given the diversity in how autism presents, this may occur after a child is referred to the ECEI with developmental delay, or autism being clearly identified prior to coming into contact with the ECEI.

⁵ Autism Spectrum Disorder Diagnosis in Australia: Are we meeting Best Practice Standards?, Autism Co-operative Research Centre, Brisbane, Taylor, L., Brown, P., Eapen, V., Midford, S., Paynter, J., Quarmby, L., Smith, T., Maybery, M., Williams, K. and Whitehouse, A. 2016

Recommendation 4: The development and resourcing of a comprehensive access to diagnosis strategy to ensure that the diagnostic process is simpler and more supportive for young children, their families and adults seeking a diagnosis and with the outcome being a more rapid and responsive diagnosis, including:

- Greater provision of clear and concise information through the diagnosis process;
- Formal support through the diagnosis process, including peer to peer support for families;
- Greater level of understanding of autism and its early signs within the primary healthcare system and early childhood educators (GPs, MCN, etc) to provide timely referrals;
- Roll out developmental surveillance across the Maternal and Child Health (MCH) service state-wide;
- Strengthened referral pathways for families between the following players NDIS ECEI approach, NDIS, MCH/GP's, other children's services and diagnosticians;
- Establishment a number of early diagnosis centres across Victoria to reduce waiting times a lower the average age of diagnosis;
- Increase the capacity within the public health system to allow faster diagnosis of autism, with the objective of eliminating waiting lists;
- Greater understanding of girls on the autism spectrum and associated traits and presentations;
- Greater understanding of adult diagnosis of autism and associated traits and presentations
- Greater contemporary understanding of the evidence base supporting early diagnosis amongst paediatricians and paediatric psychiatrists;
- Public funding available for adults seeking a diagnosis; and
- Increase access to diagnosticians in regional Victoria.

Recommendation 5: A commitment to ensuring no-one waits longer than three months to access a diagnosis of autism in Victoria.

Post diagnosis support

The impact of receiving a diagnosis of autism in the early years can have significant impact on parents, broader family members, siblings and others. It may mean families have to reshape their expectations for their child and make sense of what a diagnosis means, both of which can cause a high level of stress and anxiety.

In 2010 the then Department of Families, Housing, Community Services and Indigenous Affairs published a report on post-diagnosis support for children with autism⁶. The report contained a literature review as well as interviewing a number of parents of children with autism and service providers. The findings included:

- A large amount of information on autism is available, but parents value personalised, specific information about their own child. Clinicians, service providers and families agreed that personalised information was the best way to assist families in moving from diagnosis through to therapy;
- Parents were typically provided with names of and contact details for early intervention and allied health services at diagnosis. Some parents found this useful, while others reported that this forced them to make choices for which they are ill-equipped;
- Although parents want information about the history and implications of autism, especially the long-term prospects of their child's health and happiness, the priority for most parents is information about appropriate and available therapeutic interventions. However, there was a lot of frustration with service providers not willing to recommend one therapy over another, and thus leaving it to the parent to make a decision on therapy; and
- Families obtained information and support from formal services and other family members. Formal support, in the form of support groups facilitated by peak bodies, is an important source of information; and formal support services offered respite as well as improving the behavioural skills of the child. In areas where there were no formal networks, some parents were getting together to create their own.

⁶ Post-diagnosis support for children with Autism Spectrum Disorder, their families and carers, K Valentine et al, Occasional Paper No. 35, Department of Families, Housing, Community Services and Indigenous Affairs, 2010

The following comments from families illustrate these issues:

After the initial diagnosis of ASD from (the) team at Travancore, it would have been good to have a follow up session to ask any questions. Even though I suspected ASD, everything that was said after Autism was a blur. I was confident enough to call back but many parents would not be.

The diagnostic process was smooth, however post the diagnosis there was a long wait for early intervention support and we had to source info and support privately in the interim. So much information was available but it was so much to take it all in.

The process was extremely emotional. You are caught in an avalanche of important information and specialist appointments at the same time you are mourning the loss of what you thought your child might be. We are 100% understanding and accepting of our gorgeous boy's ASD and wouldn't change anything about who he is but it has taken our family 2 years to come out of the cyclone of his diagnosis and be at peace with our new normal, emotionally and financially.

Things have improved since 2001 however I continue to hear stories of parents being told "your child has autism" over the phone and then left to their own devices.

Diagnosis was relatively easy, but everything since has been a series of doors slammed in our face.

Was so hard to get any information about what the diagnosis meant. It was good to get the diagnosis but there was no additional information about what to expect or where to get help. Following diagnosis we were just left in the lurch. No recommendations of what to do next. I had no idea where to turn next and it took months for me to find any kind of help (via an article in The Age) about a woman and her Aspergers son's journey! I contacted her and went to a conference to find out about our journey. Terrible lack of any support following diagnosis!

Got the diagnosis but then had no idea what to do. Every kid on the spectrum is different and has different needs so everyone ends up navigating a pathway to early intervention and support solo. I still haven't found any adequate support for my son.

There was absolutely no support or suggestions for us as to what we could do to support our son. The clinician quite openly said he didn't know what to suggest.

Receiving a diagnosis was one thing but understanding all the paper work and figures is another thing. As a result of the emotion that hits you when receiving a diagnosis (even if its expected) any other info becomes overwhelming. More time could be spent after diagnosis to educating families on understanding the results (eg the figures) on the reports.

It's a very stressful time for a parent and for young families. Sometimes the bluntness of service providers lacks empathy. Ironic.

Amaze also sought suggestions from respondents how they could have been better supported through the process:

Clearer information on what services are available after diagnosis.

More assistance with selecting the appropriate therapies. It was completely left to us and in those early days I actually would have appreciated someone to 'hold our hands' a little more.

Information about options to therapy, not being given false hope for my son's diagnosis, counselling, perhaps support group.

Access to a support group with parents that had walked the same path earlier in the diagnosis process. Amaze only kicks in once you have funding. You need it when you get the first appointment, not after all the testing is complete. I am now a member of First Steps ASD

Support and I envy those who find us and get the information of what to do and how to do it, easier than I did. I felt like I reinvented the wheel.

Informed of all services that could be provided, have found I have always had to look myself for most information or word of mouth from other mothers.

Maybe an information centre where parents can go and seek advice. It is such a hard time. Clear and concise information on support services available and follow up.

Access to good support as soon as diagnosis was obtained instead of waiting for months.

I would have liked to have someone to talk to myself, to help talk through my feelings about the diagnosis. There were supports in place for my daughter, but nobody there to help me through it all. It is an overwhelming experience, and a complicated process to arrange for assessment and then funding. Having a child on the spectrum is life changing and providing parents with almost no support is potentially dangerous. Who is caring for the carers?

Anything, everything. We were left floundering on our own even with the diagnosis.

Not just more information, but having all that information in one place. Basically, once we were given the diagnosis, because my son was over 6 years old, we were left hanging in the breeze, with no idea where to go, or what services we could access, grants we could apply for to help. Most information was piecemeal and gleaned from other people who were already in the system.

After assessment of ASD we didn't know how to access support & funding for our school. Having an ASD expert talk to our school and lease (sic) about the support our son needed would have been enormous help.

There needs to be positive and hopeful information provided to parents, letting them know it will be ok!

Autism Advisors

Amaze is funded through the Commonwealth Governments 'Helping Children with Autism' program to deliver the 'Autism Advisor' service, which provides post diagnosis support to families following diagnosis and administer their access to the 'Helping Children with Autism' Early Intervention funding. We provide this service to all families who have a child diagnosed under seven. Amaze has been running this service since 2008 and to date has supported over 12,000 families in Victoria. Since 2008, diagnosticians have increasingly been providing details of Amaze to newly diagnosed families as their next point of contact.

As outlined above, this can be a traumatic and confusing time for families and Amaze provides a 'safe and soft place to land' for these families. The Autism Advisors take the time to explain what the diagnosis means, for them and their child, what the next steps are for supports and services, provide independent and evidence based information and answer questions – whilst also arranging access to the Early Intervention funding available. This process may take a number of hours over a number of phone calls. A 2010 evaluation of the 'Helping Children with Autism' program found a 90% satisfaction rate with the service provided by the Autism Advisors.

A number of respondents also reflected on the assistance the Autism Advisors provided to them:

Having an autism advisor was invaluable in providing information about ASD and ASD specific supports and services.

Every person I spoke to in the process, especially at Amaze (Jaron was my key initial person), were amazing. I cried, more than once, but they were very understanding and comforting. They just got it. And helped me.

There is so much information available that it is quite overwhelming. Also, all children of the spectrum are quite unique, making it difficult to access individualised info. Amaze were very supportive and informative, it would be great however if Amaze was resourced to provide more individualised support.

It is a confusing process, not understanding all the therapies, governing body to begin with. It is only that we had Amaze to guide us and did a lot of research ourselves to understand what was needed for our son. Also having a paediatrician that understands autism, is also a huge benefit, but again a lot of research to find one that does!

Amaze is currently funded until the end of 2015/16 to provide the Autism Advisor service, however it is anticipated that the Commonwealth Government will renew the funding, but for how long is currently unknown.

With the transition to the NDIS and the cessation of the 'Helping Children with Autism' program, the role of the Autism Advisors in the long term is unknown. Amaze is of the view that the Autism Advisor program is hugely valuable in assisting families following diagnosis and needs to continue once the NDIS is rolled out.

The role of Autism Advisors has also now organically grown to provide information regarding the NDIS to families as they have initial contact and also from families who may not have been in contact with an Advisor for many years.

Recommendation 6: Ongoing funding for Autism Advisors to provide support and independent information to families following diagnosis of autism.

Recommendation 7: Review the role of Autism Advisors within the context of the NDIS, with the view of providing a greater level of support to families in preparing to access the NDIS.

Recommendation 8: Expand the role of Autism Advisors to be accessible for all newly diagnosed people on the autism spectrum, regard less of age.

Early Days Workshops

Another facet of the Helping Children with Autism package is the provision of "Early Days Workshops", which Amaze receives funding to provide. The Early Days Workshops are available to parents of children of children under seven who have a diagnosis or who are undergoing a diagnosis. Amaze delivers a number of different workshops including:

- Autism Introductory Workshop
- Understanding Behavior
- Encouraging Early Interactions
- Tips for Everyday Skills
- Progression to School
- Play and Social Learning
- Helping my Child Cope with Change

Between 2011 and March 2015 Amaze delivered 307 Early Day's workshops to 2977 attendants in Victoria. The workshops are well received by attendants.

Funding for these workshops has been secured until 2018, however Amaze would like to see funding for these workshops into the long-term as it is an important resource and capacity building tool.

A number of respondents spoke about the value of the Early Days Workshops:

I think a simplified map of what to do when your child is diagnosed would have been extremely helpful. I found Early Days courses through Amaze very helpful and very informative.

Information. Not one ever mentioned about the govt early intervention service. I discovered it at an Amaze early days workshop. There's a real lack of guidance for parents.

The Raising Children govt website was an excellent source of information in learning and making decisions on therapy. The Amaze videos were likewise very helpful, on what different therapists do. I got a lot out of the free 'Early Days' workshop.

There was a lot of information available such as the Early Day workshops but as we didn't have any family support it was difficult to get to sessions that were available. With an incredibly difficult 4yo and a toddler it was not as though we could find a suitable baby sitter for a couple of hours to get to these things. The fallout from having a different carer / change of routine would be too difficult to manage when you were all ready (sic) exhausted. I found most of my information on line once I got onto some reliable websites.

Recommendation 9: Ongoing funding from the NDIA for Early Day workshops following the full roll out of the NDIS.

Following older diagnosis

For those who diagnosis does not occur until later in life, there is little relevant information and few services and supports currently available to them. This is complicated by a lack of awareness, understanding and skill from the community and professionals.

A number of respondents described their experience finding support following late diagnosis:

More help with older late diagnosis kids. Financially but also support with information and specialist recommendations. The lady psych told us to medicate her.

It is very generous of the government to provide the funding for early intervention. But many children with Asperger's, and girls with ASD, are diagnosed after the age of 7. This means they get no funding, which is a shame.

Having some services available. Late diagnosis closes all options.

Recommendation 10: Development of resources and information to assist people on the autism spectrum who have received a late diagnosis as a teenager or adult.

Recommendation 11: The establishment of peer support groups for people on the autism spectrum who have received a late diagnosis as a teenager or adult.

2.2 Early Intervention

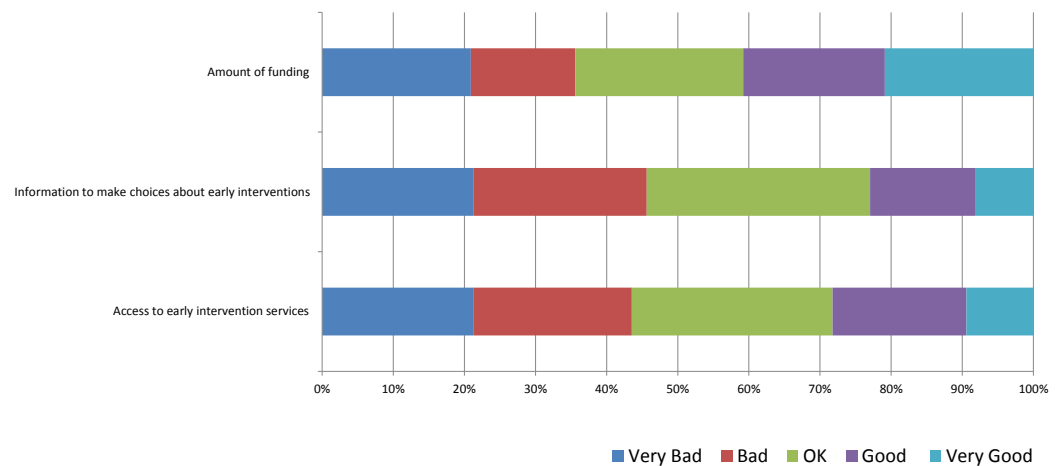
The provision of evidence based early intervention for people on the autism spectrum has been shown to greatly increase the lifetime trajectory for a person on the autism spectrum, greatly increasing opportunities across their lifetime, such as education outcomes at school and employment participation. There are a number of different funding sources for the provision of early intervention available to people on the autism spectrum from both the Commonwealth and State Government.

Through Amaze's consultation, we asked the autism community a number of questions relating to early intervention with the following results:

- 66% had access to early intervention;
- The overwhelming majority accessed the Commonwealth's Helping Children with Autism program;
- A large number also accessed State funded services such as Early Childhood Intervention Services;
- A significant number also stated they had supplemented Government provided service with privately funded services; and
- The average age of commencement of early intervention amongst respondents was just under four years old.

Furthermore, we asked the community to rate a number of aspects of early intervention provision, which can be seen below:

HOW WOULD YOU RATE THE LEVEL OF THE FOLLOWING IN RELATION TO EARLY INTERVENTION?



The above responses alongside the experiences shared with Amaze clearly articulate many of the key issues that have been identified within the domain of provision of early intervention. A number of which we will expand on:

Ensuring best practice and evidence based autism specific early intervention

The provision of effective early intervention for children on the autism spectrum is key to ensure the increase of a child's developmental trajectory over their lifetime, allowing them to participate in community and social life to their full potential. There are numerous schools of thought on what intervention practice is most effective, with a large number having some degree of evidence supporting them and their outcomes. This is an ever evolving area but there have been a number of recent systemic reviews of the evidence base of early intervention approaches, which are widely referenced and referred to for provision of early intervention services that are able to attract government funding. These include:

National Autism Center (NAC) (2015). Findings and conclusions: National Standards Project, Phase 2. Retrieved from <http://www.nationalautismcenter.org/national-standards-project/phase-2/>

National Collaborating Centre for Mental Health (2013). Autism. The Management and Support of Children and Young People on the Autism Spectrum. London (UK): National Institute for Health and Care Excellence (NICE). Retrieved from <http://www.nice.org.uk/guidance/cg170>

Prior, M. & Roberts, J. (2012). Early Intervention for Children with Autism Spectrum Disorders: 'Guidelines for Good Practice'. Retrieved from <https://www.dss.gov.au/our-responsibilities/disability-and-carers/programs-services/for-people-with-disability/early-intervention-for-children-with-autism-spectrum-disorders-guidelines-for-good-practice-2012>

2012 Schreibman, L., Dawson, G., Stahmer, A. C., Landa, R., Rogers, S. J., McGee, G. G., & Halladay, A. (2015). Naturalistic Developmental Behavioral Interventions: Empirically Validated Treatments for Autism Spectrum Disorder. *Journal of Autism and Developmental Disorders*, 1-18.

Schreibman et al., 2015 Weitlauf AS, McPheeters ML, Peters B, Sathe N, Travis R, Aiello R, Williamson E, Veenstra-VanderWeele J, Krishnaswami S, Jerome R, Warren Z. Therapies for Children With Autism Spectrum Disorder: Behavioral Interventions Update. Comparative Effectiveness Review No. 137. Rockville, MD: Agency for Healthcare Research and Quality; 2014.

2014 Wong, C., Odom, S. L., Hume, K. Cox, A. W., Fettig, A., Kucharczyk, S., ... Schultz, T. R. (2014). Evidence-based practices for children, youth, and young adults with Autism Spectrum Disorder. Chapel Hill: The University of North Carolina, Frank Porter Graham Child Development Institute, Autism Evidence-Based Practice Review Group.

Amaze, as an independent organisation does, not preference one therapy over another, consistent with the recommendation of the above reviews, and draws from the available evidence and research base on the efficacy of different early intervention approaches. It is however important to note, that given the individuality of people on the autism spectrum and how autism presents differently in every person, it is not possible to say one approach to therapy is suitable or effective for every person on the autism spectrum.

Regardless of what early intervention approach is taken, ensuring and maintaining best practice is vital not only to ensure the greatest impact is achieved but also for value for money. Given the growth in the autism early intervention industry over the past decade following significant government investment, balancing best practice with supply of services in the face of growing demand has been difficult. This was evident in the early days of the *'Helping Children with Autism'* program when only multidisciplinary early intervention teams, and not sole providers, were able to provide services. After a dramatic increase in waiting lists for supports, this was amended to allow sole providers to provide services. This is indicative of ensuring that a balance is struck between restricting supply and ensuring best practice is maintained. This will become an ever growing concern as the NDIS continues rolling out into full scheme, where it is estimated that there will be a doubling of disability services required to meet demand. Therefore to ensure there is clear and consistent best practice in the delivery of early intervention supports, the NDIS in conjunction with experts have developed a number of products to guide best practice and specifically in autism. These are:

- Autism spectrum disorder: Evidence-based/evidence-informed good practice for supports provided to preschool children, their families and carers, J. Roberts and K Williams, 2016
- National Guidelines, Best Practice in Early Childhood Intervention, Early Childhood Intervention Australia, 2016 (release on 19 April 2016)

Amaze is supportive of these guides and their findings to ensure national consistency of best practice in early intervention within the NDIS, and wants to ensure that compliance with the guidelines is maintained for those delivering early intervention services. Furthermore, Amaze wants to ensure that those providing early intervention to children on the autism spectrum have autism specific experience.

One respondent suggested a compliance mechanism and public accountability on the quality of the services offered:

It would be good to know that the services are assessed on a regular basis by AMAZE or some equivalent body. I have heard more than one parent complain about the quality of some services that are provided. It's hard to compare and there are so many entities out there trying to get their slice of the funding pie.

Recommendation 12: Early interventions that are eligible for Government funding, including in an NDIS plan, have a sound evidence base as outlined in the efficacy systemic reports outlined.

Recommendation 13: Autism specific early interventions are delivered in a manner that is in adherence with: Autism spectrum disorder: Evidence-based/evidence-informed good practice for supports provided to preschool children, their families and carers, J. Roberts and K Williams, 2016.

Recommendation 14: All early intervention providers must comply with the National Guidelines, Best Practice in Early Childhood Intervention, Early Childhood Intervention Australia, 2016.

Recommendation 15: Early intervention providers wishing to provide services to children on the autism spectrum must demonstrate autism specific experience in order to offer services, either through Government funded or privately funded.

Adequacy of funding for the provision of best practice, evidence based early interventions

The current opportunities for early intervention funding provided by Government are limited and do not satisfy the best practice guidelines referenced above. There have been a number of subsequent publications produced for the purpose of informing the Commonwealth Government and the National Disability Insurance Agency (NDIA) on best practice for early intervention for children on the autism spectrum.

The most current report, 'Autism spectrum disorder: Evidence-based/evidence-informed good practice for supports provided to preschool children, their families and carers' was released in February 2016. It recommends a number of key points for consideration within this Inquiry, a key one being 'Children who have received a diagnosis of autism should receive 20 hours per week of early intervention that involves interaction with them'. The current funding streams that are available to children on the autism spectrum in Victoria are the 'Helping Children with Autism' program that provides \$12,000 of funding for early intervention per child to use before their seventh birthday, and a maximum of \$6,000 per year, children may also be eligible for the Victorian 'Early Childhood Intervention Services' that is a rationed program and currently has a waiting list, but with a maximum of \$5,500 per child per year.

It is clear that both of these funding options are inadequate to fund the level of intervention recommended by the best practice guidelines. Families have widely reported having to privately fund additional early intervention to great personal expense. This has been clearly communicated to Amaze through our day to day work and also through our consultation in the inquiry, as further illustrated by the following:

There should be more funding from the Government to –not only pay for early intervention but also for the primary and secondary school years. Kids need more help as they grow older.

The funding for early intervention is greatly inadequate. If we were not able to pay the majority of costs our son would not be receiving the quality and quantity of therapy he is.

Give more to parents - a child with ASD in early years needs as much as possible to gain independent living skills

More funding. \$12000 isn't near enough and autism doesn't stop at 7 years of age. It needs to be more intensive and consistent.

More of it !!!! More choice. More individualised more support.

Greater early intervention available, for the amount of hours these kids need to make a difference to them. More information on where to go and what is available.

Another issue to be considered is the current standardised funding approach, with all children on the autism spectrum, regardless of functional need, receiving the same amount of funding. As every child on the autism spectrum is different each therefore requires an individualised approach to assessing their individual needs based on a functional assessment and subsequently allocating the necessary amount of early intervention funding.

The NDIS is currently designed to provide for the individual needs of participants, and therefore Amaze is hopeful that this issue will be addressed through the implementation of the NDIS. However given there isn't a clear diagnostic criterion for entry into the NDIS, we want to ensure that all children on the autism spectrum are eligible to receive the supports and interventions they require.

Funding criteria being restricted by age limits

The early intervention funding streams mentioned above are also limited by age: the 'Helping Children with Autism' program only allows access to the funding before a child's seventh birthday, and 'Early Childhood Intervention Services' only allows access to children until entry into school. Amaze recognises that the need for intensive early intervention in the lead up to school entry is the priority for the policy rationale but it is unrealistic to assume that once children on the autism spectrum are in educational settings they will no longer need continuation of therapies they have been accessing.

Another consideration about the age limit on early intervention funding is following a delayed or late diagnosis many families are missing out as their child is too old to access these funding opportunities. This gap has led to many families having to personally fund early intervention, having a great personal financial cost.

Many parents have highlighted this to Amaze:

We were lucky that we got access when Patrick was so young, many kids are much older before they gain access and I fear they don't get the same benefit as the others, early intervention services should be available from whenever diagnosis occurs, no matter what age.

It would have been good for this to extend beyond my child's seventh birthday. We had to fit a lot into two years and since then have been left on our own. This has caused significant financial pressure on our family and resulted in some therapies not be able to be used simply due to cost. Make it for older bracket too!

Between our son's paediatrician and ECIS, we got a lot of advice that was really helpful. Early Intervention is great but it feels like once your child turns 7 they are on their own (and so are we to a degree).

It would have been better to have the funding for the 2 year timeframe, irrespective of when the child turns 7. This is particularly relevant when children have been on waitlist so long to get assessed - many miss out.

There needs to be more for over 7 years. Autism doesn't just disappear at age 7!!

Yes, just worried about what to do once she turns 7 as the financial aid ceases but our daughters needs don't.

Because the autism diagnosis came when our son was 6 and a half, and the cut-off was 7 years we received no early intervention or funding through the autism funding.

Very upset when my son started school, as received a letter straight away saying we no longer get early intervention because my son had started school. My son was 4 yrs and 9 mths at that stage. Did not know where to go to access services etc once dropped from E.I who were very helpful in accessing resources, equip, info. The school did not offer the same support services.

Currently the 'Early Childhood Intervention Services' has a waiting list that doesn't allow for children on the spectrum to access interventions immediately after intake. This delay can have a significant detrimental impact on the trajectory of outcomes a child on the autism spectrum may achieve. One parent outlined this experience:

I would have registered for early intervention as soon as I had suspicions instead of waiting for the diagnosis. The early intervention people called us just after diagnosis to say the waiting list was so long that we wouldn't get to the top before school starts, so they were taking us off the list.

Not having to wait! There is so much emphasis on EARLY childhood development - that if you are sitting around waiting for your toddler to access help for months on end, it causes panic that you'll miss the golden window of opportunity! The panic can spiral out of control and permeate every facet of daily family life.

The time waits available through DHS were unworkable and way too long....also, I had doubts about the level of specialisation, knowledge and skill set offered by DHS at the time.

Provision of trusted and independent information to families about choices of early intervention options

As outlined previously, the time following a diagnosis can be an overwhelming, stressful and difficult time for many parents and families. Having to become educated about autism, what this means for their child and then having to make decisions about therapy options can be incredibly difficult for families. Amaze, through the Autism Advisor service assists parents in developing a greater understanding about therapy options and explaining what they are and what they mean.

Given the diverse range of therapy options available, including those that are both evidence based and not, there is a clear need for trusted and independent advice and information provided to families to assist them in making informed decisions. Many respondents reported to Amaze that a single source of reliable, independent and evidence based information would have greatly assisted in supporting their journey in making decisions about therapy:

All information regarding services and funding was fragmented, departments would refer you to other services who would then say they had funding cuts then you would be referred back to the original department it was very frustrating being on a merry go round this took up most of my energy trying to get help to find it did not exist lots of people on phones doing nothing I wish I just left the phone out and just helped my son myself what an awful waste of precious time.

There should be better laid out options for parents, counsellors that help you with programs you should undertake and how much early intervention is required.

I had no support to help know what interventions would be the most useful, and I had never accessed most of the interventions before. Having a longer time to use the funding would have taken the pressure off worrying about wasted opportunities.

It is widely reported that autism attracts a number of 'alternative' therapies that are not evidence based, and some that have the possibility of causing harm. It is encouraging that the funding streams mentioned above only allow for the provision of evidence based therapies, as per their operational guidelines, it has not stopped the marketing of alternative therapies to families. Given parents can be very vulnerable following diagnosis, and sometimes in denial of the diagnosis and searching for answers, these alternative therapies that make unrealistic claims about their impact and efficacy can appear very attractive. It has been illustrated by a number of responses to Amaze:

More options locally and more advice not from the service providers who can have ulterior motives.

There are some charlatans who are unscrupulous about how well suited their services are for your individual child. Happy to take the HCWA funding despite their offerings not necessarily being well targeted for your child. Parents need to be very savvy and switched on to avoid wasting their funding.

Additionally, having information presented from a strengths based approach, without an overly 'medicalised' manner and delivered from peers or adults on the autism spectrum has been identified as preferential:

More information for parents, specifically from autistic adults. I would like to know what therapies / services they find valuable and to gain their insights into how to help my son.

It is an extremely medical system, very much based on identifying my son's supposed deficits and how to "fix" them. There is no sense that it is okay to be autistic.

On respondent articulated that if it wasn't for their level of education, resourcefulness and resources they would have found it very difficult to navigate the options available.

We're grateful for it. But if one isn't as educated or as determined as us it would have been a very confusing time. I fear many missed out on getting available help due to these reasons.

Recommendation 16: Single source of broadly accessible independent, reliable and evidenced based information for families outlining all their options regarding funding streams, evidence based early intervention programs, supplementary mainstream services, support services, peer-to-peer supports etc.

Recommendation 17: Information presented in accessible formats for all.

Recommendation 18: Information to be strengths based not deficit, not overly medicalised and including personal experiences from both people on the autism spectrum and families.

Meeting demand and reducing waiting lists

As outlined above, availability of best practice early intervention service providers are not keeping up with the demand in the market – and this demand will continue to grow as the NDIS rolls out to full scheme. Currently, waiting lists can extend to over 12 months, with some families reporting the length in waiting list 'aged them out' of eligibility. Additionally, this issue is exacerbated for those living in regional and remote regions. Some experiences shared with Amaze highlight this:

It took just under 12 months for us to be able to access it. We were lucky to be able to afford private services in the meantime - many don't have that option.

No the wait list is too long to access early intervention.

Eliminate extended wait list times and provide more expert support for the waiting duration. The 'support' provided by the ECIS wait list case worker was extremely vague and obviously unskilled in anything that was particularly relevant to autism. The effort was good though would not be my first option for seeking guidance.

Shorter wait list times so my son could actually get EI before he started school.

Not initially (eligible for early intervention) but privately was fantastic but very expensive and had to travel a long way.

We accessed everything that we could. Public early intervention took years and wasn't very much when we did get it but the funding enabled us to access help early.

Given the importance of children on the autism spectrum receiving timely early intervention, more needs to be done to address the shortfall in supply of early intervention services. Unfortunately this cannot happen overnight but will require a strategic medium-long term intervention by Government's to facilitate growth and training of appropriately skilled workforce to deliver quality early intervention. This will need input and investment across Governments and portfolios including vocations higher education, community services, industrial relations, disability services/NDIS, finance and treasury. A consideration in addressing this demand should also be through skilled migration.

Recommendation 19: The development of a skilled workforce development strategy to increase the supply of skilled early intervention practitioners to meet the anticipated demand of early intervention services within full scheme NDIS – this could be facilitated by the Productivity Commission given their prior experience with the NDIS

Despite the challenges and issues that we have brought to the attention of the Inquiry, the significant positive impact of effective early intervention needs to be highlighted. Below are some positive early intervention experiences shared with Amaze:

El changed him significantly. Jon was nonverbal and was totally in his shell. He was also very selective with his habits and diet. El helps him to open up and speak, He also learned to interact socially and participate in physical activities. Today Jon communicates both verbally and in written form. He takes public transport and manages his own money as well as works in open employment. This would not be possible without early intervention.

Our experience was a mess. But if it is done early and the diagnosis and access to good specialists is there it makes a huge difference.

Yes I think it (early intervention) was crucial. Without it, I feel Jordan would be a different child now.

His (early intervention) made such a difference only wish diagnosis had been made at earlier age.

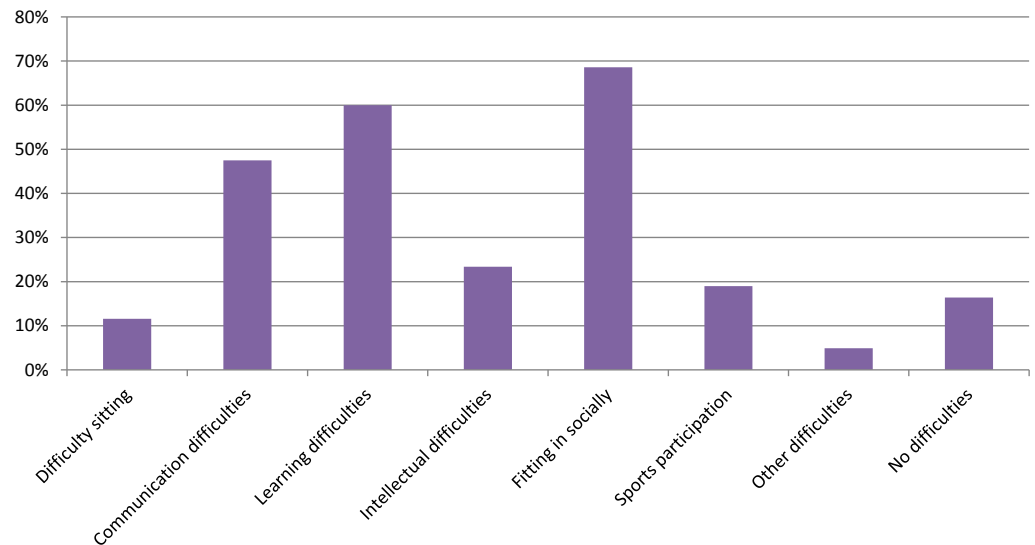
I think we had a better experience and better outcome than many. But that's partly luck and partly the wonderful character of my son.

2.3 Education

The school environment can be very challenging for students on the autism spectrum, inside and outside of the classroom. This is due to the challenges students on the autism spectrum face with communication, social interactions and their unique learning styles. Evidence shows that students on the autism spectrum are significantly more likely than their typically developing peers to be suspended or excluded, to be targets of bullying, to suffer depression and anxiety and to under-perform academically relative to their level of intelligence. Students on the autism spectrum are often misunderstood by educators, peers and the wider community.

In 2012, 95% of students on the autism spectrum experienced educational restrictions, with 6% of these not able to attend school due to being on the autism spectrum and 44% needed to attend either a special class in a mainstream school, or a special school¹¹. For those who were attending school, 86% reported 'having difficulty' at school, the majority having difficulty fitting in socially, learning or communication; see below:

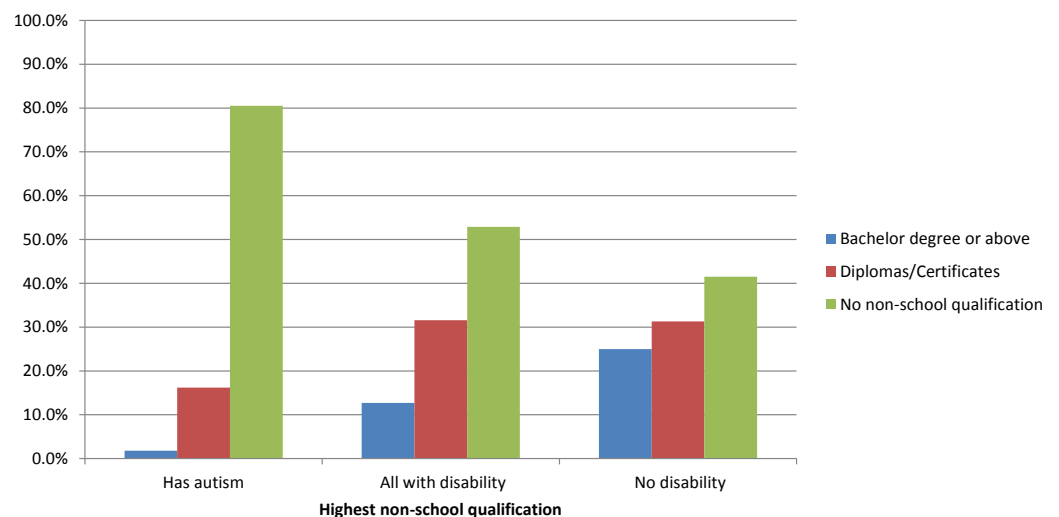
PROPORTION OF PEOPLE AGED 5 TO 20 YEARS WITH AUTISM, by Type of Difficulty experienced at school-2012



Source ABS Survey of Disability, Ageing and Carers, 2009 and 2012

Educational attainment rates for students with autism at primary and secondary school has not recently been measured, however contemporary data shows that 26% of people with disability do not go beyond Year 10 compared to 18% of people without disability¹². Beyond school, educational attainment for people on the autism spectrum is stark in comparison to the broader disability community and those without disability see below;

**ALL PERSONS AGED 15 YEARS AND OVER -
highest non-school qualification by whether has autism and disability status-2012**



Source ABS Survey of Disability, Ageing and Carers, 2009 and 2012

⁷ Barnard et al., 2000

⁸ van Roekel, Scholte & Didden, 2010

⁹ Kim, Szatmari, Bryson & Wilson, 2000

¹⁰ Ashburner, Ziviani & Rodger, 2010

¹¹ Autism in Australia, 2012, ABS

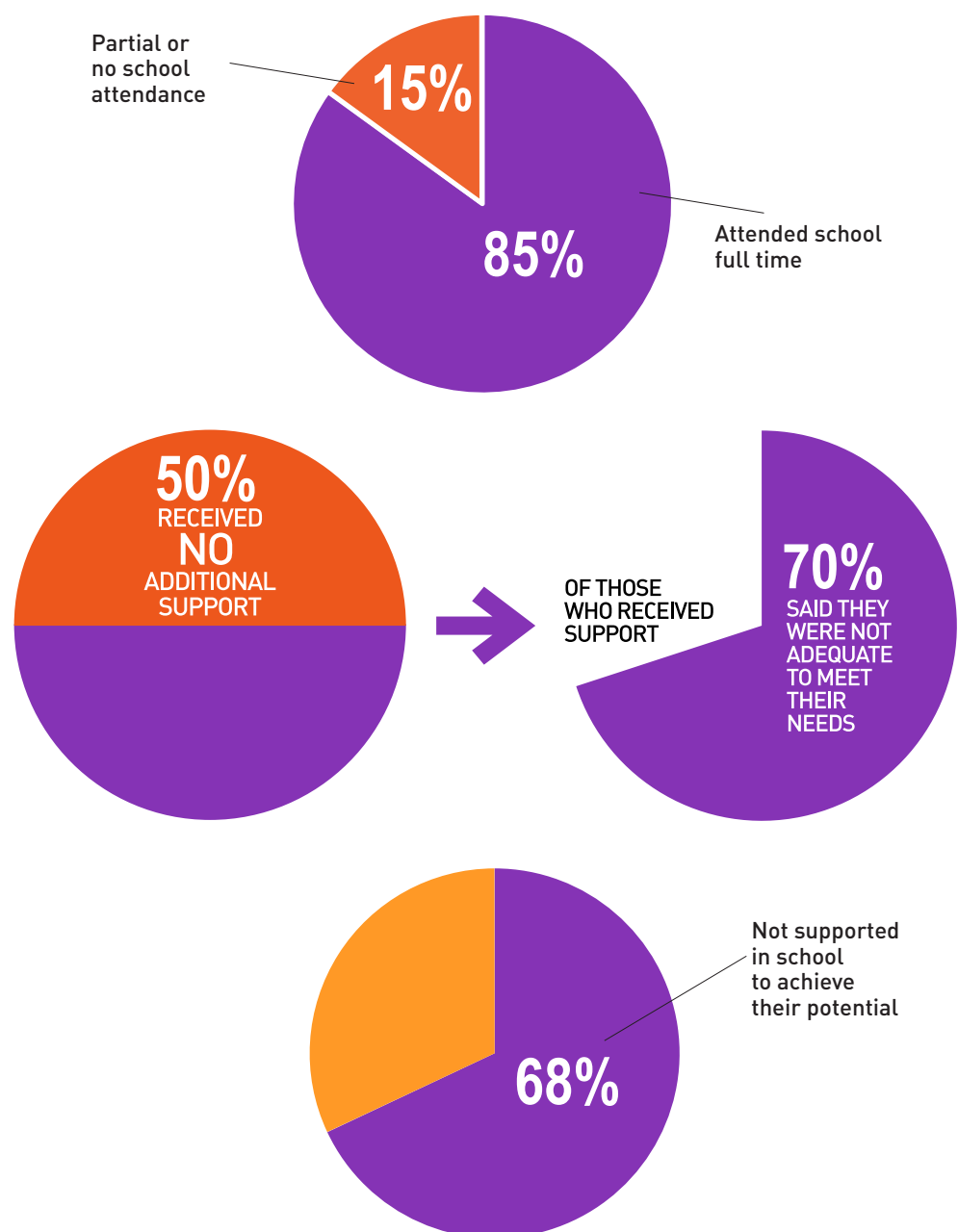
¹² ABS 2009, 'Persons Aged 15-64 years, selected characteristics - by level of highest educational attainment, 'Survey of education training and experience 2009: State and Territory Australian tables, Commonwealth of Australia, Canberra

We have seen recently through a number of reports and inquiries, listed below, that the current education system is not adequately meeting the specific learning and support needs of students with disability and more specifically students on the autism spectrum, and as a consequence students on the autism spectrum are not achieving a level of educational attainment to which they are entitled, but are also restricted from the workforce and broader community participation.

There is no simple solution to this issue, and there are a number of systemic factors and barriers to change that need to be addressed. A holistic approach is required to bring about systemic change within the education system to achieve greater inclusion and equity for students on the autism spectrum.

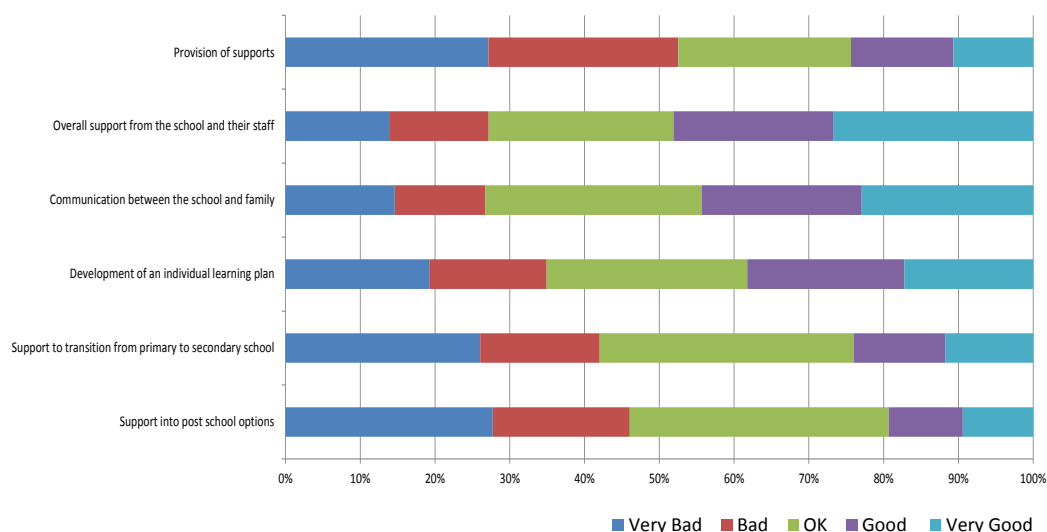
Amaze consultation results

Amaze sought information on the educational experience through our consultation with the following outcomes (n=387):



We also asked respondents to rate a number of factors relating to their education experience:

HOW WOULD YOU RATE THE FOLLOWING IN RELATION TO YOUR SCHOOLING EXPERIENCE?



Previous reports and reviews

Recently within Victoria and nationally there have been a number of inquiries directly relevant to the educational outcomes of students on the autism spectrum and which contain a number of recommendations which have not been acted upon. Amaze will not seek to replicate this previous work in nature or in content - and nor should any other body. As such, we have listed below a number of preceding documents which provide important findings and background as a resource to the Inquiry:

- Inquiry into the Education of Students with Disability, Senate Standing Committee on Education and Employment – 2002
- Shut Out: The Experience of people with disabilities and their families in Australia, National People with Disability and Carers Council - 2009
- Review of School Funding, Commonwealth Government – Dec 2011
- Program for Students with Special Learning Needs, Victorian Auditor General Report – Aug 2012
- Held back: The experiences of students with disabilities in Victorian schools, Victorian Equal Opportunity and Human Rights Commission - Sep 2012
- Inclusive Education for Students with Disability – A review of the best evidence in relation to theory and practice, Australian Research Alliance for Children and Youth, prepared for the Commonwealth Government Department of Education, Employment and Workplace Relations - 2013
- Bracks Review – Emerging Issues and Ideas Report, Victorian Government – Sept 2015
- Schools for all Children and Young People, ACT Government – Nov 2015
- Access to real learning: the impact of policy, funding and culture on students with disability, Senate Education and Employment Reference Committee, Australian Parliament – Jan 2016
- Greater returns on investment in Education: Government Schools Funding Review, Victorian Government – April 2016
- Review of the Program for Students with Disabilities, Victorian Government – April 2016
- Inclusive Education for all Students with Disabilities and Additional Needs, Victorian Government – April 2016

Current best practice in making schools work for students on the autism spectrum

Professor Jacqueline Roberts of the Autism Centre of Excellence at Griffith University recently published a paper titled *Autism and Education in Australia*¹³. Within the paper she identifies the key elements that are needed for successful educational experiences for students on the autism spectrum. She wrote:

Individualised approach and program

Comprehensive identification and assessment of the unique combination of characteristics is required for each student to enable relevant individualised planning and instructional support. Each student's program will address their unique preferences, interests, behavioural presentations, and learning style with relevant goals and strategies to ensure they experience educational success (Ivannone, 2003).

Focus on strengths based engagement

Engagement refers to the amount of time that the student is attending to and actively interacting in his or her social and nonsocial environments. Engagement and participation are critical to success at school and have been cited as one of the best predictors of positive student outcomes (Rogers, 1999). Engagement of students with ASD will be unlikely unless there is some deliberate instructional program design incorporating preferred materials and activities, and capitalising on a student's interests and preferences (Hurth, Shaw, Izeman, Whaley & Rogers, 1999) and focus on strengths and weaknesses to determine the most appropriate supports and intensity to meet individual goals (National Research Council, 2001).

Ecological management

In addition to developing a program for the student to facilitate skill acquisition, we need to consider ways in which we can adapt the environment to make it more comprehensible and manageable for students with autism. This involves managing the physical and the social environment to minimise factors that are disruptive or disturbing to the student. To do this, attitudinal and social as well as physical supports are essential, including the management of change and facilitating transitions. Attitudes across the school community towards inclusion of students with autism in regular classroom have a direct impact on the success of placements for students with autism (Simpson, de Boer-Ott, & Smith Myles, 2003). Leadership, a positive attitude, shared ownership and flexibility on the part of the whole school community are key to successful inclusion.

Multidisciplinary

Students with autism typically have complex needs across many domains—communication-speech-language, motor, sensory, behavioural and academic—and require multidisciplinary team input in a comprehensive program planning and implementation process. Multidisciplinary input is also required to work with classmates and the whole school community to develop the communication and social skills required to understand and support students with autism (Simpson, de Boer-Ott, & Smith Myles, 2003).

Functional Positive Behaviour Support (PBS)

PBS is a well-established, effective framework that involves functional assessment based on understanding the purpose of, and environmental triggers for, a specified problem behaviour in order to identify variables that reliably predict and maintain problem behaviors (Horner & Carr, 1997). Functional behaviour assessment (FBA) using data gathered through indirect measures (e.g., interviews) and direct measures (e.g., observations of antecedents, behaviors, and consequences) is used to develop individualised support plans. The primary goal of PBS is to

¹³ Autism and Education in Australia, J. Roberts, Australian Clinical Psychologist, 2015

enhance the individual's quality of life by expanding his or her existing behaviours and adjusting the learning environment. The secondary goal is to make problem behaviour ineffective, inefficient, and irrelevant (Carr et al., 1999).

Systematic instruction, structure, routine, visual supports

Systematic instruction involves carefully planning for instruction by identifying goals, outlining procedures for teaching, implementation, evaluation of effectiveness, and adjusting instruction based on data (Westling & Fox, 2000). Students with autism do better in classrooms and programs that are structured and predictable (Olley & Reeve, 1997) and where the curriculum (activities, schedule, environment) is clear (i.e., comprehensible) to both the students and educators. Systematic instruction also provides a structured teaching plan for transition, generalisation and maintenance of learned skills. Students with autism typically have better visual than auditory processing, poor comprehension skills and poor or organisational abilities. As a result students with autism respond best when information is presented visually as well as aurally (Rogers, 2013).

Collaborative, family involvement and support

Programs should be implemented consistently across home school and community environments to have maximum effect. Involving the family is the best way to achieve this. In the US, family involvement in the individual planning process is mandated. This is not the case in Australia. However good practice in autism education emphasizes the importance of considering family preferences and knowledge of the child when determining the goals to be taught and the methods by which instruction will be delivered (Ivannone, 2003). A collaborative partnership with the family can contribute to the effectiveness of interventions and programming, particularly when the strategies are used in multiple environments.

Academic curriculum adaptations and adjustments

Curricular modifications, general education classroom support and instructional methods underpin all placements of students with special needs in classrooms (Simpson, de Boer-Ott, & Smith Myles, 2003). In Australia instructional adjustments proscribed by the Australian Curriculum Assessment and Reporting Authority (ACARA) which are relevant for students with autism include:

- Provision of alternative representations of teaching and learning materials (e.g., visual representation) and explicit, systematic instruction;
- Motivating students through engagement with personal interests;
- Organising and connecting knowledge, skills and values to promote generalization and
- Using naturally occurring learning opportunities to enhance individual learning goals (ACARA, 2013).

Specific curriculum content for students with autism

Communication and social interaction problems are core deficits in individuals with ASD. Children with autism display particular difficulties in the development of social reciprocity. Specialised curriculum should include systematic instruction in social engagement skills, including initiating and responding to social bids, appropriate recreational or leisure skills, and language comprehension and communication. In addition, educators should consider the functionality of the skills targeted within the curriculum. Focus should be on those skills that (a) are most likely to be useful in the student's life to control his or her environment, (b) will increase the student's independence and quality of life, and (c) will increase the student's competent performance (Dunlap & Robbins, 1991).

Data based evaluation and review

Comprehensive evaluation should include evaluation of the provision of services and supports, evidence of benefit from participation and education, evidence of facilitation of membership in class/school, demonstration of appropriate participation (Simpson, de Boer-Ott, & Smith Myles, 2003).

In summary educational programs for students with autism are most effective when they are developed by a multidisciplinary team working closely with parents and other key people in the child's life. Effective programs are based on the strengths and needs of the individual and take into account the priorities of families and resources available in their environment. Programs should support the participation of students with autism in both academic and non-academic activities at school, include strategies to maintain and generalise mastered skills and facilitate independence. Effective programs will be evidence based, functional, holistic, and motivating for students, will reflect the student voice and be developed with respect.

Support for school communities

Tobias (2009) noted that teachers require knowledge about the nature of ASD in order to understand and to interpret students' behaviour correctly, as well as needing to acquire the skills needed to deal with complex issues that may arise. Children with ASD require more specialised teaching techniques than those typically included in general teacher education and specialist training in SENS (National Autistic Society 2006)]. Recent evidence suggests that teacher knowledge of specialist, individualised approaches to teaching children with ASD is one of the keys to successful inclusion (Keane, Aldridge, Costley & Clark, 2012).

Building capacity in schools to improve educational outcomes for students with autism

Examples of effective strategies at a whole school level include; reduced class sizes, provision of adequate teacher planning time, appropriately trained support personnel and provision of relevant staff professional development. The leadership, vision and capacity of the school principal to support the inclusion of students with disability including autism, is critical and principals need to be supported by the educational system. Despite recent renewed emphasis on the implementation of the Disability Standards¹⁴ in schools nationally, outcomes for this population continue to be poor compared to both typical and non-typical peers. A targeted, consistent, autism-specific approach based on school leadership and capacity building at a national and a state level is required to improve educational outcomes for this population to enable young people with autism to participate and contribute.

¹⁴ Disability Standards on Education clarify the obligations of Australian education and training service providers, and the rights of people with disability, under the Disability Discrimination Act 1992.

The current experience

There are a number of issues that are systemic within the education system that have been identified over a period of time through research, acknowledged in the reports above and shared by families with Amaze on day-to-day basis and also through our consultation. We will address a number of these:

Attendance

Despite all children having the right to attend school full time, with the same standing as children without disability, which is enshrined in the Disability Standards for Education 2005, many children on the autism spectrum face challenges in accessing schools. Many families are told that the schools doesn't have the funding to support their child, or only for a number of hours.

These experiences shared with Amaze further illustrate this:

His funding only covers him for an aide until 1pm each day.

Currently the school is only funded for an aide for 20 hours in the week, the school is reluctant to extend my son's attendance beyond this yet, unless we fund the extra aide hours.

Due to being sent home after 2 hours each day last year. Was only at school for his aided time. Once his aide left him he wanted to go home.

Bullied by the school to leave because we don't attract funding. Appalling treatment of all families with children who are non-funded.

Amaze is increasingly being informed of students being home schooled due to the inability of finding a suitable learning environment, one parent described:

My son is now 9.5 and he is about to attend his 6th school! I think this says it all really. If the 6th school does not work out, home schooling will be the only option and I'm tired enough as it is. This will mean finding money to pay someone else to come and teach him. Yes the schooling system has really let us down.

Furthermore, students on the autism spectrum are more likely to be suspended from schools compared to their peers¹⁵. However information and data on the number of students on the autism spectrum excluded in Australian schools is scarce.

Recommendation 20: Greater awareness and training to be provided to all staff within the education system on the Disability Standards for Education 2005

Recommendation 21: Greater information provided to all parents and families on the Disability Standards for Education 2005.

Recommendation 22: The establishment of an independent Schools Commissioner, to receive and investigate complaints from parents and students. The Commissioner should also consider the need to capture an increasing level of data relating to attendance, incidence of suspension and expulsions, educational outcomes and incidents investigated regarding students with disability, which are published annually.

Fostering inclusive culture

Currently there is a pervasive culture of low expectations for students on the autism spectrum within the education system, and this needs to be addressed to ensure that students are provided the same opportunities to reach their full potential.

¹⁵ Barnard, Prior and Potter 2000

Fostering an inclusive school culture within the education system, from individual schools to the Department of Education and Training more broadly, is imperative to changing current attitudes and improving educational outcomes of students on the autism spectrum. Leadership in implementing and modelling an inclusive culture is a key enabling factor to improving the educational outcomes for students on the autism spectrum. A number of respondents touched on this:

The best school can still have ordinary teachers who can make your child's experience a nightmare. I appreciate that I had support from the senior staff, but wish more autonomy could be given to principals to manage staff who aren't suited to their culture.

Inclusion and understanding are key for a child to feel wanted and a valuable part of the classroom.

The need for addressing culture within Victorian Schools has been addressed recently in the Victorian Governments Review of the Program for Students with Disabilities. It has recommended the need for principals and school leaders to model inclusive practices in schools and the creation of an 'Inclusive Schooling Index'. Amaze is supportive of these recommendations in principle and looks forward to working with the Department of Education and Training in implementing these recommendations.

Recommendation 23: The Government work closely with Amaze and other key stakeholder groups in implementing the recommendations of the Review of the Program for Students with Disabilities.

Recommendation 24: The Government ensure that the Inclusive School Index, once developed, is mandatory for all schools and the results are publicly available.

Bullying

Current evidence shows that students on the autism spectrum are more likely to be the targets of bullying, with 75% of students on the autism spectrum in the US experiencing bullying at school, four times more than students without disability¹⁶. Students who experience high levels of bullying (once or more a week) tend to exhibit higher levels of anxiety, hyperactivity, self-harming behaviours and elevated emotional sensitivity. Many respondents reported bullying in their educational experience:

We started at a school that managed my daughter and her needs so poorly, she regressed and ended up in a worse position than when she was first diagnosed. She was also subjected to horrific bullying from both students and staff. Over a period of three years, they literally broke her. We eventually understood the scope of the damage (when she tried to commit suicide at age 8) and we removed her from the school. Since then, she's come along in leaps and bounds. We are now in a supportive school that value her as an individual and ensure she's supported. They've helped put our little girl back together again.

At public school my son was teased and bullied and expected to be like the majority of children. He was taken aside into a psychology session in grade 4 by a man that was not qualified, and without my permission, to discuss problems he was having at school. This person told him he should get out into the playground and get 'dirty'. I moved twice after this to find the best school for my son which I finally found at a private school. Within a year of starting there he received a performing arts scholarship and made many friends. This year he is in year 12 and is performing arts captain as well as deputy house captain. He loves school and still has issues but is well accepted by his peers and teachers, and I have been a stay at home mother for some years due to ill health.

I am concerned about my son's future in school, particularly with bullying and also worry about him slipping through the cracks as he isn't funded. I am also worried about him with anxiety

¹⁶ Peer victimization of children with Asperger Spectrum Disorders. Little L, Journal of the American Academy of Child and Adolescent Psychiatry. 2001

and depression issues as school becomes more difficult and social interaction becomes more complex - he is already having some issues with anxiety and he is only 8.

In primary school when I was bullied teachers wouldn't let me stay inside they would make me go outside so I would sit by myself or wander around aimlessly. When a student is clearly struggling like I was something to help me socially should've been implemented. With learning it should be encouraged that if a student lacks the confidence to admit when they're struggling in class or just don't "get it" to either write a note or talk to their teacher. Create a friendly environment where an undiagnosed and diagnosed autistic kids feel like their input is IMPORTANT!!!

My daughter's primary years were very harrowing with the bullying she was subjected to for being different & the complete disregard for her safety.

Stop bullying outright and punish the perpetrators openly.

My partner had the worst time at school! Been hated, belittled, knocked out, the list goes on.

Various anti-bullying and anti-vilification policies for schools exist across the states and territories. These often target specific types of vilification such as racism and sexism. Further, the National Safe Schools Framework provides guiding principles to support the creation of safe and supportive school communities. In particular, it focuses on bullying, harassment, aggression and violence in schools¹⁷. Many of these however are limited or do not address bullying or harassment towards children with disability.

Amaze is supportive of the development of policies that specifically address bullying on the basis of disability, including autism, and promotes students to rethink negative and discriminatory attitudes of students with disability.

Workforce Capacity

Workforce capacity is of critical importance in ensuring access to a quality education for all students. Educational staff, particularly teachers and leadership positions within schools such as principals and year level coordinators, are key gatekeepers in terms of access to education. There is a lack of expertise within the education system regarding inclusive practice and meeting the educational needs of students on the autism spectrum. This lack of understanding and capacity is commonplace, and underpins current negative attitudes.

Amaze is regularly informed by both parents and educators of the lack of autism expertise within schools to meet the specific educational needs of students on the autism spectrum. In many cases, this involves inadequate knowledge of the individual student, developing individual learning plans, putting in place supports and adjustments to ensure opportunities for learning, all of which represent a major barrier in students on the autism spectrum in reaching their educational outcomes.

There is evidence of good practice in some schools, modelling effective inclusive practice that are achieving greater educational outcomes for students on the autism spectrum. There is a need to harness these pockets of good practice, model and profile it across all schools to demonstrate the positive impact it has, not only for those students but for the entire school community.

Amaze received a large amount of feedback relating to capacity within schools, some of which are below:

More education for staff. People to realise that autism is real.

Informed teaching staff who understand and can recognise autism. Appropriate educational plans put to action. Appropriate communication between school & home.

¹⁷ Peer victimization of children with Asperger Spectrum Disorders. Little L, Journal of the American Academy of Child and Adolescent Psychiatry. 2001

Teachers just weren't aware when I was at school. Teaching courses need to include autism experience not just the theory.

More education for teachers about the huge range of kids on the spectrum and the need to dispel the myth of "taught one ASD kid, now I know about all ASD kids". Also, some teacher education about ASD girls!

More education, communication and acceptance of individual needs.

Training for the teachers and aides, some public resources such as psychologist, speech /OT therapist, who can visit school regularly to help teachers and aides. Currently we pay private therapist for school visit. It's very helpful, but we cannot afford it very often.

Mainstream schools and teachers to be more educated in Autism.

Teachers understanding they need to differentiate work tasks for all learners - teachers need PD and to understand they need to adapt their behaviour to the student.

All the staff should have mandatory training in ASD.

Despite informing the school that my son had autism and an aid at kinder we had no extra support from the school in prep. I tried hard to communicate his issues to the school, along with reports from his OT, speech path, early intervention. It wasn't until he was violent towards others that they started to take action. It was very poorly managed from the school. He was suspended several times for aggressive behaviour. It only punishes the parent not the child. It was a horrid experience. How do you explain this to a 5 year old with autism and ASD.

Teachers have been reluctant to make adjustments to classes to accommodate our child's learning due to ASD, i.e. writing skills being enforced instead of allowing ICT assisted delivery of assessments.

More education for teachers about how to get the most out of kids on the spectrum. The few we have had who already knew or who took the time to find out have been wonderful. The rest have been a hindrance.

Get all new teachers to take a special needs course so they know what to look for and what they might face.

Some of the positive accounts included:

The school is terrific. Its a small school that looks after my son well. They have taken on the challenge well.

The school itself has been amazing. The classroom teacher and school wellbeing officer have gone all out trying to make school a more comfortable environment for my daughter and she is improving. Having various recess and lunchtime clubs as alternatives to braving schoolyard politics has also been a godsend.

Amaze is encouraged by recent commitments by the Victorian Government in its response to the Review of the Program for Students with Disabilities to address the current capacity issues within Victorian Schools. These include the commitment to the development of an Inclusive Education Workforce Capacity Strategy, extending professional learning opportunities, developing greater guidance on individual approaches to learning and focus on a strengths based engagement with students. This is in addition to the 'government's commitment that all registered teachers will undertake professional development in disability to renew their registration and the inclusion of requirements of pre-service teaching courses to include content on teaching students with disability.

Amaze supports these recommendations and looks forward to working with the Department of Education and Training to implement these recommendations.

Recommendation 25: Funding to develop autism specific professional development material and courses to build the capacity of educators across Victoria.

Resourcing for learning

The provision of funding to support adjustments required by student's disability in schools primarily comes from the Student Resource Package which schools receive for all students; however the PSD provides additional funding to assist in meeting the needs and adjustments for students with disabilities gauged as moderate to profound¹⁸.

Two recent Reviews have investigated the current funding arrangements in Victorian Schools, the *"Greater returns on investment in Education: Government Schools Funding Review"* and the *"Review of the Program for Students with Disabilities"*. These extensive reviews have identified that the current funding model is not adequately providing the adjustments and supports to meet the needs of students with disability. A key finding from the *"Greater returns on investment in Education: Government Schools Funding Review"* and the *"Review of the Program for Students with Disabilities"* had a key finding of:

"In Victoria, while reporting on the performance of students with a disability has been problematic in the past, students generally experience lower school completion rates and transitions to further education, as well as poorer labour market outcomes."

Amaze highlighted the issues regarding funding for students on the autism spectrum in its submission to the Review of the Program for Students with Disabilities, see appendix A – a number of the recommendations made by Amaze will be stated below.

The Review of the Program for Students with Disabilities identified many of the issues identified by Amaze and adopted a number of our recommendations. In responding to the report, the Government has not accepted a number of recommendations pertaining to reforming the Program for Students with Disability and making the additional funding available more equitable, targeted and based on functional need.

The frustrations of the Victorian autism community regarding the current funding arrangements, are articulated below:

Funding dried up for my son at school as he was rated too verbal to qualify.

The entire funding application experience is so negative. Schools are forced to share aides from kids with funding with kids with none (eg dyslexia sufferers) and it is such a shame.

The funding criteria is so restrictive that our sons were not able to access any additional assistance at school.

My child was deemed too intelligent to qualify for any funding at school. He is currently in Year 6 and heading into high school next year - I am worried that his comprehension level is not up to standard due to his autism.

Government schools could look at behavioral and social criteria for funding more. And have more support offered for this.

PSD funding system needs to be changed. Speech should not be a requirement to determine funding.

Amaze is of the strong view that the recommendations not currently adopted by the Government in response to the Review of the Program for Students with Disabilities need to be implemented without delay to underpin the ambitious reform agenda the government is embarking on. Without it more students on the autism spectrum will continue to be left behind.

¹⁸ Program for Students with Disability Guidelines, Department of Education and Training, Victorian Government

Recommendation 26: Implementation all 25 recommendations from the Review of the Program for Students with Disabilities, specifically those relating to the development of a new funding model based on functional needs.

Recommendation 27: Implementation of all recommendations from the “Greater returns on investment in Education: Government Schools Funding Review”, specifically those relating to updating the SRP to better meet the needs of students with disability.

Accountability

Reporting on educational outcomes for students with disability, including those on the autism spectrum, in Victoria is scarce. It is a consistent theme in almost all of the reports listed above, and was echoed in Amaze’s Submission to the PSD Review (<http://www.amaze.org.au/2015/10/amaze-submission-to-the-victorian-government-review-of-the-program-for-students-with-disabilities-psd/>).

This was acknowledged in the Review of the Program for Students with Disabilities, which found:

There is a lack of accountability and transparency for outcomes for all students with disabilities, including those students supported under the PSD and for the use of targeted PSD funding provided to schools.

A lack of available data on the performance and outcomes of students with disabilities undermines efforts to strengthen accountability. This gap means success cannot be measured and analysed at the school level or across the system in relation to student outcomes and the impact of support. Improved data collection, linkage and analysis would enable enhanced planning, reporting and accountability at the school, area, regional and state level.

These findings lead to a strong recommendation in the Report for greater accountability, including outcomes measures, improved data collection, transparency on the use of funds and student wellbeing, which the Government has accepted. Amaze supports the Government’s decision and looks forward to working with the Department of Education and Training to implement these recommendations.

Transitions

Transitions of any kind can be difficult for people on the autism spectrum, with transitions from primary to secondary school and the transition from school to post-school options are often very difficult for all parties involved. The transition to secondary school often increases the student on the autism spectrum’s vulnerability, places them under additional stress and results in increased levels of anxiety.

Best practice transitional arrangements for students on the autism spectrum between primary and secondary school are well documented and proven¹⁹; however current practice is patchy at best and relies on the understanding and capacity of individual teachers. Often the good will of teachers at a primary school driving effective transitioning will be met with passive resistance by receiving teachers at secondary schools.

Secondary school presents a far more challenging learning environment for students with autism with multiple teachers and classrooms, a heightened sensory environment, larger schools, more demanding academic curriculum and an increase in social interactions.

The transition process can also be made more difficult for students on the autism spectrum attracting additional funding, who following the eligibility review that occurs in Year 6, have the funding removed. For a student on the autism spectrum the current Year 6 review occurs in an environment that is familiar to the student, where patterns of routine and support have

¹⁹ Autism Spectrum Disorders: Planning a successful transition to secondary school, Brereton, AV, Bull, KJ 2012

been established. This review cannot predict the extent of the challenges the student may have moving into a new secondary school environment at this time. Amaze strongly supports of moving the time that this review of eligibility occurs to Year 8.

These issues were illustrated by experiences shared with Amaze:

The transition from grade 6 to 7 is massive and to have funding literally halved at this time is not helpful. the only reason our child was managing in a mainstream setting was due to funding level and then because they are managing to a degree the funding is stripped away. And at a time of high anxiety - new school, new faces, new teachers, hormones etc... At the time of transitioning to secondary education we as a family thought it would have been good to have a secondary school specifically for students with Autism.

Transition from primary to secondary school was promising but the secondary school hasn't followed through and don't seem to care about the needs of an unfunded student.

The transition from primary school to high school was not the best with teachers and some Aides expecting way too much. Just getting him to the school was a nightmare every day! We were just happy for him to be at school. Once most of the staff had a better understanding of his issues/anxieties (thanks to our psychologist), removed the pressure to do the class work and modified his work he made amazing progress. He went from barely being able to function in the classroom to doing the work and contributing to class discussions (when he felt comfortable). He was even able to do the odd presentation to the class.

No supports in secondary school once they had more challenging students to cover. Student left to flounder!!!! Coordinator make promises she is not keeping! No speech, OT or any other allied health provided or homework group so the student is not taking homework home to do. Primary school was a dream compared with the brick wall I have hit in year 10 with my student and there doesn't seem to be anyway around it!

The topic of transitions was addressed in the Review of the Program for Students with Disabilities, but found that there would not be significant benefits to moving the review to a Year 7-8 review. The review did however recommend providing additional support for those students who lose funding following this review to transition into Secondary school. However, Amaze recommends the review of eligibility is best undertaken after a student on the autism spectrum has transitioned into secondary school and had time to settle into their new environment.

Recommendation 28: The current eligibility review for PSD funding is moved from Year 6 to Year 8, to allow time for the student to adjust to his/her new school environment and his/her teachers have sufficient time to observe the student's needs.

Recommendation 29: Consideration of the best method of reviewing additional funding eligibility in the development of a new funding model, in conjunction with prior recommendation.

Post school transitions

People on the autism spectrum experience poorer post-school outcomes compared to people with other disabilities and those without disability. As stated above, 81% of people with autism who had finished school had not completed a post-school qualification, well above the rate for both the rest of the population with disability and people with no disability.

A recent Issues Paper from Children with Disability Australia investigated this issue and reported "Many young people with disability however have extremely poor post school transition experiences. This is impacting negatively on life outcomes where there is low participation in employment and tertiary study and social exclusion remains high. While there are pockets of good post school transition practice, generally programs and preparation for this transition are fragmented with minimal coordination and guidance regarding what should occur during this time."

This is reflected in a comment Amaze received in asking how the educational experience could be improved:

More knowledge about transition to post school options - and ability to choose the right one - now there are expos - not at my time through.

This is an area that the recent Victorian Government reviews did not include in the current reform agenda. It is also a key gap that was missing from the Autism State Plan, and other policy initiatives.

The Issues Paper from Children with Disability Australia made a number of recommendations that should be considered in further policy development to address this key issue.

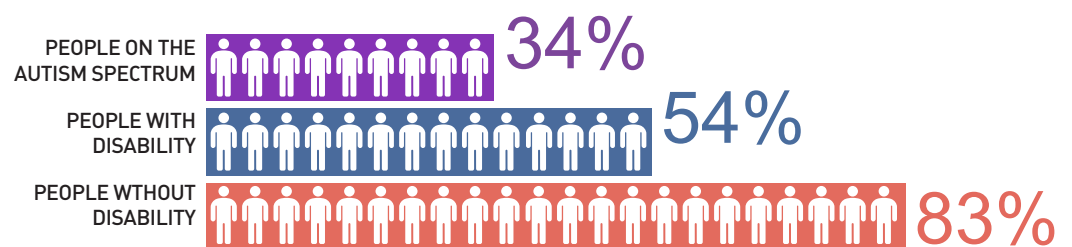
Recommendation 30: Development, implementation and funding for a Post-School Transitions Policy for students on the autism spectrum, to include: best practice transition planning guidelines, work experience opportunities, individual career planning, and ongoing support following school and focusing on achieving the person on the autism spectrum's full potential.

Recommendation 31: Identify and investigate current best practice Transition To Work programs around Australia to support the previous recommendation.

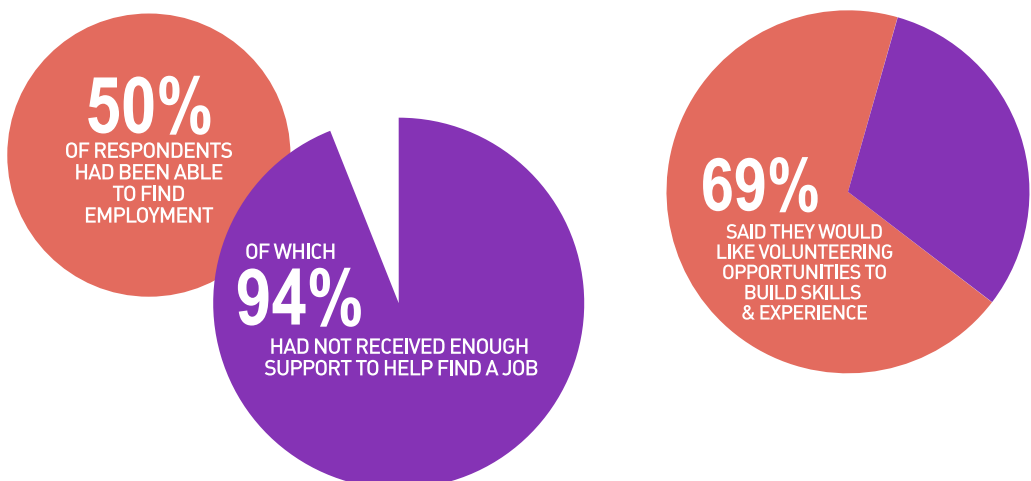
2.4 Employment opportunities for people on the autism spectrum

The current experience

People on the autism spectrum experience poorer outcomes in relation to workforce participation.



This is further supported by the information that Amaze collected through consultation.



A number of respondents to Amaze's consultation addressed the issues that they have faced in finding employment, along with offering suggestions for reform:

Understanding autism from an employers perspective and how to work with the individual and place them in an appropriate setting or task analysis.

Someone who is prepared to find out my son's strong points and keep knowing he needs constant direction.

Having time and space for autism, as well as understanding. Adapting sensory environment to individual needs.

Employers do not have the time/resources to ensure requirements are understood.

Having someone recognise your strengths and having enough self-confidence to present well in an interview.

It's normal for people to get anxiety before a job interview but when you have Autism and have anxiety all day and everyday when you go for job interviews it is 100000000 times more anxiety than neuro-typical people. Employers need to have avenues for special needs.

Anxiety and Social Anxiety are the biggest barrier to finding employment. There needs to be employers that encourage special needs to apply and have a quiet environment to work in. For people to have a better understanding of invisible disabilities like ASD and the types of accommodations that would help and an understanding of neurodiversity.

Preparation on Job selection practices – interviews, information on social norms of workplace and getting assistance/accommodations with organisation/prioritising and sensory needs taken seriously.

Volunteering I believe is a very effective way to build skill sets and confidence.

Be mentored into the workforce by someone who will take you on, knowing your intelligence and ability to learn quickly and think with acuity, but not needing to go about the normal process of job applications, Centrelink etc.

Employers need education about ASD and abilities.

I have attempted to use 7 different specialist disability employment services, all supposedly accredited by the government. The last one said "the most we can hope for is an employer willing to tolerate having you around and that is unlikely". They even wrote that in a report to Centrelink and I am now not allowed to access any more employment services as I have been assessed as unemployable on the basis of those words said.

A key issue that has been identified in numerous reports, research and inquiries regarding barriers to employment for people on the autism spectrum relates to negative attitudes about disability. For example, the report *Shut out: The experience of people with disabilities and their families in Australia* stated that by "far the biggest barrier (to employment) identified was employer attitudes ²⁰."

Discriminatory attitudes from employers are reflective of broader attitudes within the Australian community that associate disability with inability. It may be assumed that people on the autism spectrum will be less capable employees or that it will be burdensome or costly to provide any required assistance, modifications or adjustments in the workplace. Employers may therefore cite that they 'do not have the capacity, expertise or skills' to employ people on the autism spectrum. These views have been found to be common in surveys of employer attitudes by various industry groups ²¹.

²⁰ *Shut out: The experience of people with disabilities and their families in Australia*, National People with Disabilities and Carer Council 2009 Commonwealth of Australia,

²¹ *Recruiting people with disability: An employer perspective*, Australian Human Resources Institute 2011; *Employer perspectives on recruiting people with disability and the role of Disability Employment Services*, Government Department of Education, Employment and Workplace Relations 2011, Commonwealth of Australia

Many people on the autism spectrum also face issues associated with social interactions and the 'soft skills' related to employment and may struggle with anxiety that affects the ability for people on the autism spectrum to succeed in standardised employment practices such as interviews.

Addressing employer attitudes about autism is therefore an important element of reducing employment discrimination. However, this will ultimately require change that is community wide. Leadership is required on a number of levels, including from government, the non-government sector, business organisations and specific employers. At the government level, a whole of government approach to adopting the principles contained in the National Disability Strategy is one option. Leadership from Government in hiring people with disability in the public service would also send a strong message and ensure the Government's own hiring practice is reflective of the principles contained in the Strategy.

It is often proposed (for example in the discussion paper for the new Disability Employment Framework)²² that public 'awareness raising' campaigns be undertaken to address employer understanding and attitudes of disability. It is vital that any potential 'campaign' carefully considers messaging and process to ensure desired outcomes are achieved.

There is also a need to ensure greater awareness of rights, legal obligations of employers, discrimination and what and available employment support options exist within a range of stakeholders. These include employers, employment services, business associations and disability services.

A further barrier to employment for people on the autism spectrum is also encountered when there are difficulties in establishing flexible workplace arrangements and negotiating reasonable adjustments. What is required to support employment will of course depend on the specific needs and circumstances of each person on the autism spectrum. It may involve adjusting the physical and sensory nature of the workplace environment, using aids and equipment, ensuring communication is accessible, providing additional training or support, allowing flexible hours or many other considerations.

In addition to working to increase the capacity of employers to better understanding autism and how to support people on the autism spectrum, the use of wage subsidies to incentivise employer to take on board employees on the autism spectrum is recommended. Amaze notes that the possible use of wage subsidies would need to ensure that they adequately safeguard the employees and that they are placed into meaningful work across a wider range of occupations and employers, including skilled occupations.

Current supports and services

There are a range of current services and programs that aim to support people with disability, including those on the autism spectrum, entry and maintenance of employment. Some of these are listed below:

Support for People with Disability in Open Employment

Services funded by the Australian Government to support people with disability access employment in the open labour market include:

- Disability Employment Services (DES) - Non-profit and for-profit organisations funded by the Commonwealth to provide training and recruitment to people with disability who require both short and long term assistance in gaining employment²³;
- Employment Assistance Fund - Provides financial assistance to purchase a range of work-related modifications and services for people with disability who are commencing work or are currently working²⁴;

²² National Disability Employment Framework: Discussion paper, Department of Social Services 2015, Commonwealth of Australia, Canberra,

²³ Australian Government Department of Employment 2015, Disability Employment Services, Commonwealth of Australia,

²⁴ JobAccess 2015, Employment Assistance Fund, Australian Government, Commonwealth of Australia

- JobAccess - Information and advice service funded by the Australian Government to provide assistance and workplace solutions for people with disability and employers ²⁵; and
- National Disability Recruitment Coordinator Program – Works with larger employers to increase their knowledge of Disability Employment Services and other government services available to support employees with disability. The Program also assists in implementing workplace supports for employees with disability and provides training for staff ²⁶.

A key program that has been the focus of significant recent focus and review is DES. Amaze's understanding is that there is high variability in the provision of DES services and that certain cohorts, such as people on the autism spectrum and those with intellectual disability, experience poorer outcomes in that system.

The Commonwealth Government is currently trialling an initiative to assist up to 200 young people with mental illness find employment through the DES system. This includes a more intensive and individualised program of support along with a \$5,000 'Career Account' to invest in their choice of goods and services such as counselling, training, transport, paid work experience or clothing and equipment, to help them overcome non-vocational or vocational barriers and further their employment goals.

Amaze will be following the outcomes of this trial as it has clear applicability to young people on the autism spectrum.

Recommendation 32: The Federal Government expands its current trial of greater support to young people with mental illness program to young people on the autism spectrum.

Supported Employment Options for People with Disability

Services that provide supported employment options for people with disability:

- Australian Disability Enterprises (ADEs) - Commonwealth-funded non-profits with charitable status that provide supported employment opportunities to people with disability. Many ADEs operate commercial or industrial businesses where people with disability work in areas such as packaging, assembly line production or cleaning services with the supervision of a support worker. Employees in ADEs can be paid award wages, however productivity-based wages can also be used. ADEs are currently in the process of being transitioned to the NDIS ²⁷.

It is hoped that a simplification of these services and programs will be achieved through the current reform process underway.

Disability Employment Framework Reform

A taskforce established by the Australian Government Department of Social Services is currently reviewing the entire disability employment system to develop a new national Disability Employment Framework for a staged implementation from 2018 ²⁸. This includes DES, ADEs and other government-funded programs that provide employment assistance for job seekers with disability.

The NDIS is a significant social reform that introduces a new system of funding disability support focused on the needs and choices of people with disability. Underpinning the NDIS are principles that aim to increase the social, community and economic participation of people with disability in the Australian community.

²⁵ Australian Government 2015, JobAccess, Commonwealth of Australia

²⁶ Australian Government Department of Employment 2015, National Disability Coordination Officer, Commonwealth of Australia

²⁷ Department of Social Services 2015, Australian Disability Enterprises, Commonwealth of Australia, Canberra, viewed 4 December 2015, <https://goo.gl/RquMtv>.

²⁸ Department of Social Services 2015, National Disability Employment Framework: Discussion paper, p. vi.

Recommendation 33: An education campaign for employers be developed to dispel the myths about employing people on the spectrum, showcasing their strengths as employees and what reasonable adjustments can be made to accommodate them.

Recommendation 34: The development of capacity building training for employers on how to best support employees on the autism spectrum, including the development of an accessible resources to support the training.

Recommendation 35: Well-coordinated and accessible information regarding rights, responsibilities and services and supports is available for employers and employees.

Recommendation 36: Leadership from the Victorian Government shown by hiring people on the autism spectrum and developing policies to support positive workplace cultures.

Recommendation 37: The investigation of the efficacy of wage subsidies for employers of people on the autism spectrum.

Recommendation 38: Government to facilitate and incentivise additional volunteering opportunities for people on the spectrum as pathways to employment – and to increase the capacity of employers to cater for people on the autism spectrum.

Recommendation 39: The Disability Employment Framework engages with people on the autism spectrum to provide lived experience of specific needs of people on the autism spectrum relating to employment.

2.5 The National Disability Insurance Scheme

The National Disability Insurance Scheme (NDIS) is the largest social policy reform in Australia since the development of Medicare. It was launched in 2013 following decades of discussion about the need for fundamental reform of disability services within Australia.

In 2011, the Productivity Commission (PC) released its landmark report outlining the foundations for reform of disability services across Australia, proposing a NDIS that was nationally consistent, based on social insurance principles, provided services that are demand driven, individually tailored to a person's needs and passed choice and control of services to people with a disability. It is also worth noting that there was a considered move away from diagnostic specific eligibility to a functionality based model – in alignment with global trends. Following the release of the PC's report, the Council of Australian Governments (COAG) agreed to the need for a reform to disability services and worked towards trialling the NDIS in all States and Territories from 2013. Initial trial sites included the Barwon (Victoria), the Hunter (NSW) NSW, 15-24 year olds in Tasmania, children under 6 years old in South Australia. Further sites were launched progressively in ACT, Northern Territory, Western Australia and Blue Mountains (NSW).

At 31 December 2015, 22,281 people have received individualised funded plans from the NDIS in the eight current trial sites, equating to \$1.5b.

Of all plans issued, the highest proportion have been made for people with a primary diagnosis of Autism Spectrum Disorders or related disorders, accounting for 31% of participants nationally.

Primary Disability	NSW HTR	SA	TAS	VIC	ACT	NT	WA	NSW NBM	Total
Autism and Related Disorders	23%	48%	30%	22%	25%	2%	37%	48%	31%

In the two years since the trials commenced, Governments have been working towards agreements for the full rollout of the NDIS. The first of these agreements were finalized in NSW and Victoria, who each signed a bi-lateral agreement with the Commonwealth in September 2015. The agreements provide for a staged rollout in both states from 1 July 2016 through to 1

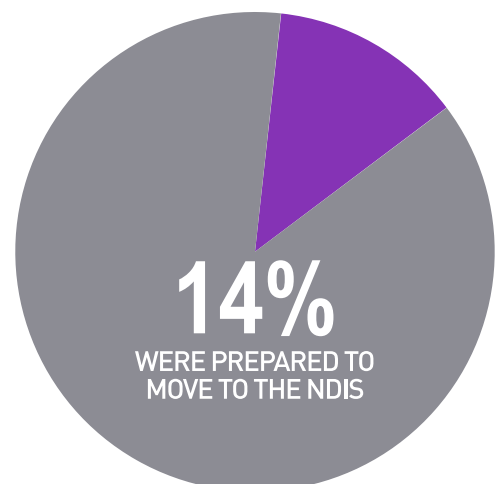
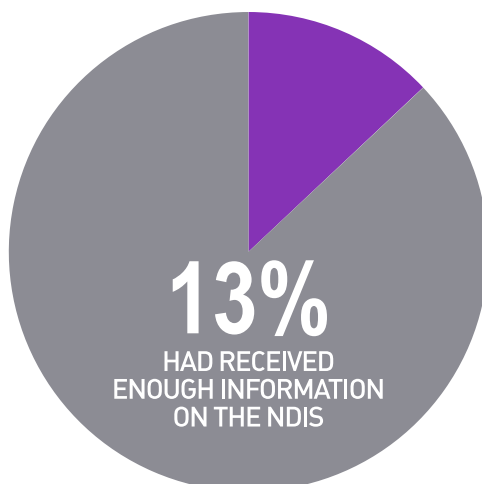
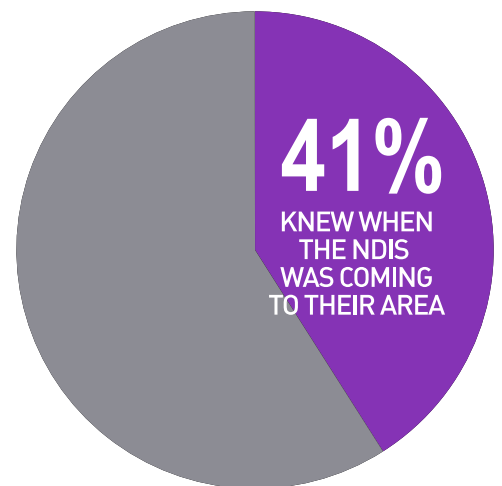
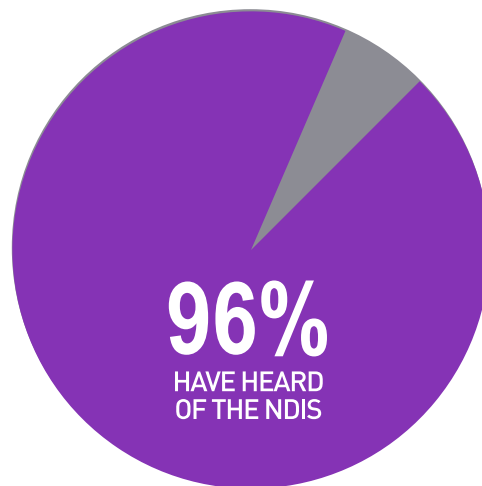
January 2019. In December 2015, Tasmania and March 2016, Queensland reached agreement for full scheme rollout.

Once the NDIS has been fully rolled out, it is anticipated to provide individualised direct funded support to 410,000 (as estimated by the Productivity Commission) Australians with significant and profound disability.

Getting ready for the NDIS

As with any large-scale reform and change, there can be hesitancy and fear about the unknown – this is no different for the NDIS. Amaze, through its provision of Autism Advisors, day to day engagement with the autism community and also as a funded NDIS Disability Support Organisation (DSO) engages with as many as 13,000 members of the Victorian autism community on a regular basis – and overwhelming so, the community is unclear on the basic details on the NDIS, including who it will cover and what it will provide.

In its consultation, Amaze asked a number of questions regarding the NDIS including (n= 404):



Respondents shared what additional information they would like to be available, such as:

There is no info on (the) NDIS website telling us when it is coming to our area. I learnt about it through Amaze.

Who qualifies? And for what?

I've been to one seminar and it seemed more of a spin to get us to be happy with the prospect of NDIS. All they have really mentioned is that it is individual to each person and that you have to have a plan or goal to apply for funding. It is more like insurance than funding.

I don't understand a single thing about it and how it will impact my family. There was been no clear information.

Everything! When, where, how much, are we able to get it? Will it be enough to help cover costs of therapy? For how long?

Why the change? What will improve. Why is it going to take so long to roll out?

How to plan.. what is covered.. how to access.. The DSR is hard to get. Will this be the same?

Have been to quite a few sessions and peer support so well informed. But full scheme rollout is still unknown. Lots of questions unable to be answered until scheme rolls out. Creates anxiety not knowing. Lots of wondering and lots of discussion.

What it will cover and whether my 14 year old will be able to access services.

This clearly demonstrates significant issues exist with the provision of information regarding the NDIS. This is detrimental to the smooth transition of potential NDIS participants into the scheme. The information published by the NDIS website is unclear and confusing and not "autism friendly". Common experiences reported to Amaze are: the use of bureaucratic or esoteric language; the need to search through large amounts of information to find what is applicable to a situation; or having to contact innumerable organisations.

There is also a clear lack of authoritative information regarding autism and the NDIS, this is analogous to the issues that the submission prosecuted earlier in relation to early intervention and diagnosis – current information is scattered and difficult to find. Information available should avoid the use of jargon and meet accessibility requirements, including the Australian Government Web Content Accessibility Guidelines.

Through Amaze's work as DSO, we have gained significant experience in working with autism peer support groups and building their capacity and understanding of the NDIS. We have learnt that having access to independent, credible information and having support from other people like them, particularly those who had been through the NDIS process was vital.

As the NDIS shifts the provision of disability services from a rationed system to an entitlement based system based on the needs of the individual – there is a lack of understanding of what this means from a potential NDIS participants perspective. Given the current restrictions and shortcomings of disability services there is a level of scepticism and misunderstanding about who the NDIS is for and what it will provide. Amaze often hears that people think the NDIS is only for younger children (a hangover from the age cut off for current early intervention supports), meaning they will lose their current supports or access to NDIS will be means tested. There is an urgent need for a clear and concise provision of information, to explain what the NDIS will provide, for who and how people access it and how to get ready for it.

Terms like 'reasonable and necessary' and 'choice and control' have important relevance and meaning in relation to the NDIS, however there is a clear need to create a shared understating of these concepts without the jargonistic terms that are currently in use.

Whilst there is a significant amount of information available for families and parents of children on the autism spectrum – albeit dispersed as outlined earlier – there is a distinct lack of information for people on the autism spectrum themselves. This has been highlighted to Amaze on a number of occasions and Amaze is currently undertaking research with people on the autism spectrum to find out what specific information they would like available, in what format and how to access it.

Given that autism is the single largest diagnostic grouping of participants within the NDIS, and the NDIS rolling out into the North East Melbourne Area from 1 July 2016 there is an urgent need for such resources to be developed and available ASAP.

Whilst Amaze acknowledges this responsibility will fall to the Local Area Coordinator (LAC) providers, there is considerable risk that duplication and inconsistency of information will occur creating further confusion for a community seeking clarity and instruction. Therefore Amaze recommends that a trusted, independent and experienced organisation is commissioned to develop these resources for the autism community – in partnership with the Victorian Government and NDIA to ensure accuracy of information, and also utilising a methodology of co-design with people on the autism spectrum to ensure the useability of the end products.

Recommendation 40: Development and distribution of accurate, detailed and accessible information on the NDIS, specifically in relation to autism. These resources should be developed for a number of different audiences including people on the autism spectrum, families and carers and disaggregated into the different life stages and for CALD and Aboriginal communities. The development of such resources should through co-design with people on the autism spectrum and include partnerships with the Victorian Government and NDIA to ensure accuracy of information.

Recommendation 41: Regular review of the resources developed following recommendation 40, should occur to ensure accuracy of information given the fast changing environment of the NDIS.

Early Childhood Early Intervention Approach

The NDIS has released its Early Childhood Early Intervention (ECEI) Approach, which details the NDIS intention to establish a nationally consistent approach to supporting children under seven with developmental delay or a diagnosis of a disability. The documentation relating the ECEI approach is available: <http://www.ndis.gov.au/news/ndia-announce-first-nationally-consisten>.

The approach is to be facilitated by 'Access Partners', who will meet with families following a referral to them from a range of referral pathways (including general practitioners, maternal and child health, child care, early childhood and education institutions). The Access Partner will discuss and determine the interventions and supports needed for the child and the family and work with family in supporting them. The aim of this approach is to provide interventions and support to a child and his/her family as soon as possible, to increase the positive impact that early intervention services provides.

Amaze is supportive of the ECEI approach in principle, with the caveat that there is a significant amount operational detail still to be released. Amaze endorses a holistic family based approach for early years, and that interventions can be put in place before the need for a diagnosis.

However, of concern is the lack of clarity within the ECEI approach regarding the point at which a diagnosis of autism will be obtained. Whilst there is a clear benefit in children who are showing signs of developmental delay to enter the ECEI to receive services that previously weren't available to them, it is unclear what steps will be taken if the initial presentation of developmental delay progresses to autism, and when a diagnosis will be sought. Amaze recognises the benefits of the ECEI putting interventions in place before a diagnosis of autism, however it doesn't remove the need for a diagnosis to be made if there is a clear presentation of autism. The risks of a delayed diagnosis are a delay in improvement at a time when the child is most receptive to intervention.

In line with Amaze's previous recommendations, it is our view that a diagnosis should not be delayed once a clear presentation of autism is identified. Given the diversity in how autism presents, this may occur after a child is referred to the ECEI with developmental delay, or autism being clearly identified prior to coming into contact with the ECEI.

Given the current level of NDIS participants with autism in the early intervention trial sites of South Australia and NSW Blue Mountains sits at 50%, it is critical that those performing the function of Access Partner for children aged 0-7 possess the expertise and capacity to accurately identify autism as early as possible.

Recommendation 42: The ECEI Access Partners have autism specific expertise relating to identification of early signs of autism, diagnosis of autism, all evidence based clinical and therapeutic autism specific interventions and supporting families before and after diagnosis.

Recommendation 43: The ECEI Access partners should not be registered providers of supports in the NDIS to mitigate perceived and real conflicts of interest.

Local Area Coordinators

The role of Local Area Coordinators (LAC) has changed significantly since the initial PC report on the NDIS. With approach to market by the NDIA in late 2015 for the role of LAC's in the first three NDIS roll out areas, the role of the LAC had expanded to include provision of information to potential NDIS participants prior roll out, pre-planning/goal setting, planning, plan implementation, plan review and assisting this ineligible for the NDIS access mainstream supports.

The role of the LAC is clearly very broad, and as the NDIS shifts from roll out to scheme maturity there will be a shift in the function and workload for the LAC. It is anticipated that the priority for the LAC's initially will be intake and plan provision to meet the requirements of the bi-lateral agreement. This is however not an excuse for the preplanning and planning functions to be rushed.

Amaze's experience with the DSO project has shown that pre-planning can take a number of hours for individuals and that it is beneficial to have support from others, particularly those who had been through the NDIS planning process previously. Another key learning from the DSO project and from the current NDIS trial sites is the need for planners to have autism specific understanding and experience.

Given that the autism is the largest diagnostic specific group within the NDIS, Amaze would argue that autism therefore has enough critical mass to justify this requirement. With the LAC now undertaking both of these roles, we recommend that all LAC providers increase their capacity in autism to ensure that people on the autism spectrum entering the NDIA are catered for adequately.

In Victoria, the NDIA will continue to provide planners for approximately 20% of participants with complex needs. Amaze also recommends that the NDIA staff possess specific expertise and experience in autism.

Recommendation 44: LAC provider staff possess specific expertise and experience in autism.

Recommendation 45: NDIA planners and frontline staff possess experience and experience in autism.

Recommendation 46: Pre-planning for people on the autism spectrum, their families and carers includes access to individuals on the autism spectrum and their families/supporter who have been through the NDIS planning process.

Workforce capacity, quality and safeguards

With the roll out of the NDIS and a doubling of the funding available for disability services and supports, significant growth will be needed in the disability service sector. The requirement for growth in the disability service sector to meet anticipated demand of services is necessary for the fundamental NDIS principle of choice and control of services by people with disability to be achieved. Given the rapid intake of NDIA participants over the next few years as full roll out is achieved, there is a need for a concentrated effort by Government to stimulate growth in the skilled disability workforce. Amaze has already a number of recommendations in relation to the increase in skilled early intervention therapists, which are in the context of this issue.

Accessing services in regional and remote locations for people on the autism spectrum is currently very difficult, with people often reporting to Amaze having to travel many hours to access specialist services, often only if they have the means to pay for them privately. This issue will be exacerbated within the NDIS in a purely market based model, especially for highly skilled staff such as early intervention practitioners in regional locations, with the clear potential for market failure leaving people on the autism spectrum without services. This is a major issue and Amaze recommends that the Victorian Government and the NDIA investigate alternative methods, such as an element of block funding for services in regional areas, to mitigate potential market failure in the short term.

Emerging research supports the efficacy of delivery of therapeutic services to remote locations via videoconferencing facilities that can be accessed within people's homes. Amaze recommends the Victorian Government further investigate the potential of these innovative service delivery methods such as utilising telehealth models.

There is also the need to ensure a level of quality in staff that will provide services to people on the autism spectrum through the NDIS. The provision of a wide range of support to people on the autism spectrum requires a skilled workforce that has specific understanding of autism. This extends beyond those providing higher skilled roles such as allied health professionals, through to all staff working with people on the autism spectrum in residential housing, day centres and staff providing other personal care and support. Not only will this ensure that the quality of services that people on the autism spectrum receive, but within a market based system of disability supports, it provides a competitive advantage to disability service organisations. Amaze recommends that autism specific training and capacity building is available to register providers of supports.

Given the vulnerable nature of people on the autism spectrum, protecting them and safeguarding them from potential abuse is paramount, especially within a rapidly growing workforce. Amaze strongly supports the need for a highly skilled autism workforce, and that a requirement that all disability support staff undertake relevant and required pre-employment checks and receive training and ongoing professional development in regard to the prevention of abuse, neglect and violence towards people with disability. Amaze supports a zero tolerance culture being instilled across the workforce.

It should be noted that the Committee undertaking the Inquiry is currently completing an Inquiry into the Abuse in Disability Services, and the recommendations coming from that Inquiry should be considered within the context of workforce development.

Recommendation 47: Victorian Government and the NDIA investigate alternate funding methods, such as an element of block funding for services in regional areas, to mitigate potential market failure in regional and remote locations – with focus on higher skilled workforce to deliver early intervention.

Recommendation 48: The Victorian Government with the NDIA further investigate the potential of innovative service delivery methods such as utilising telehealth models.

Recommendation 49: The development and open accessibility of autism specific training and capacity building is available to registered providers of supports.

Recommendation 50: The requirement of all staff delivering disability services to be required to undergo pre-employment checks to ensure they are of fit and proper character.

Information Linkages and Capacity Building funding

Within the NDIS framework described by the PC, there is a cohort of people with disability that would not be eligible to receive a package of supports under the NDIS, but would need assistance in accessing mainstream services, some help in increasing their social and community participation etc. The funding to support this group, formally described as Tier 2, is now called Information, Linkages and Capacity Building (ILC), and is guided by the NDIS ILC Policy Framework and a Commissioning Framework that is currently in draft format.

There are a number of streams within the ILC Policy including; Information, linkages and referrals, Capacity building for mainstream services; Community awareness and capacity building; and Individual capacity building.

Funding available for ILC activities is currently estimated at \$132 million when the NDIS is fully rolled out. It is still unclear how the phasing of this funding will be available.

Amaze supports the intent of the ILC policy and seeks to ensure that it is appropriately used to support people on the autism spectrum, in the provision of specific information for them, but also in building the autism capacity and literacy of mainstream services and the broader community.

The shift within the ILC Framework to measuring outcome is also encouraging, however Amaze is concerned that across many of the ILC Policy areas, the need to assess collective or community outcomes is needed, and expertise is needed to identify what measures will be used to assess this.

NDIS and Interface with other service systems

The Council of Australian Governments' NDIS Heads of Agreement and the NDIS rules clearly articulate what support the NDIS will and will not provide in relation to other service systems, however the work to date around the NDIS interface with a range of other areas, such as health and education, is not significantly advanced and involves a complex range of considerations across multiple jurisdictions. Consequently there is much to be established regarding the role of the NDIS in relation to education, post school transition, employment, health and transport systems.

Addressing interface issues, where people are most at risk of 'falling through the cracks' will involve defining clear roles and lines of responsibility, funding arrangements, present gaps in service provision and ensuring effective collaboration occurs. It will, for example, be critical to determine whether the NDIS or the employment system will fund particular supports accessed by participants in schools and in the workplace. There is a critical need for a clear articulation of the role of the NDIS and relevant interface areas.

Recommendation 52: The Victorian Government work with the NDIA to define the interface between the NDIS and other service systems (health, mental health, early childhood, school education, higher education and vocational education and training, employment, housing, transport, justice and aged care), recognising that not all people on the autism spectrum will be participating in the NDIS.

2.6 Restrictive Practices

Restrictive practices involve the use of interventions and practices that have the effect of restricting the rights and freedoms of movement of a person on the autism spectrum. These primarily include restraint (chemical, mechanical or social) and seclusion²⁹ but also include psycho-social restraint, consequence driven strategies and environmental restraint. Currently people on the autism spectrum (and people with disability more generally) who display 'challenging behaviours' or 'behaviours of concern'³⁰ may be subjected to restrictive practices in a variety of settings including: schools, disability services, supported accommodation and group homes, hospitals, mental health facilities and prisons.

Such practices may infringe on a person's human rights³¹. The United Nations Committee on the Rights of Persons with Disabilities recently raised concern about the current use of restrictive practices within Australia, especially for those with intellectual impairment or psychosocial disability, in various settings. The Committee recommended that Australia take steps to end such practices, including the establishment of an independent national preventive mechanism³².

Current evidence concludes that restrictive practices have a negative effect on health, wellbeing and quality of life for people with disability³³, and can give rise to serious adverse consequences, including death³⁴.

Amaze supports the working towards the elimination of restrictive practices of people with disability, including those on the autism spectrum, consistent with the United Nations Convention of the Rights of Persons with Disabilities.

Amaze acknowledges that this is a complex and multifaceted issue. We recognise that people have the right to receive safe and effective care, support and services, and to work in an environment that is safe and supportive.

Amaze believes that the use of restrictive practices should occur only in very limited and specific circumstances, as a last resort and utilising the least restrictive practice and for the shortest period of time possible under the circumstances. Restrictive practices should only be used where they are proportionate and justified in order to protect the rights or safety of the person or others³⁵.

The regulation of restrictive practices arises primarily under state and territory disability services and mental health legislation, and under a range of policy directives, statements and guidance materials³⁶. There is variation in the regulation of restrictive practices across states and territories, and there is fragmentation and inconstancy between service systems.

²⁹ National Framework for Reducing and Eliminating the Use of Restrictive Practices in the Disability Service Sector, Australian Government, 2014

³⁰ Equality, Capacity and Disability in Commonwealth Laws, Australian Law Reform Commission, 2014

³¹ United Nations Convention on the Rights of Persons with Disabilities; United Nations Convention on the Rights of the Child

³² Committee on the Rights of Persons with Disabilities, 'Concluding Observations on the Initial Report of Australia, Adopted by the Committee at Its Tenth Session (2–13 September 2013)' (United Nations, 4 October 2013) [35]–[36]

³³ Sigafos, Arthur, & O'Reilly, 2003; Singh, Lloyd, & Kendall, 1990

³⁴ Miles & Irvine, 1992; Paterson et al., 2003 ³⁵ National Framework for Reducing and Eliminating the Use of Restrictive Practices in the Disability Service Sector, Australian Government, 2014

³⁶ Ibid

Recent work reviewing the efficacy, regulation and use of restrictive practices has been undertaken within a number of different services systems including disability services, NDIS, education and mental health. This includes:

- A Case For Change' position paper, The National Mental Health Commission 2015 ³⁷;
- 'Equality, Capacity and Disability in Commonwealth Laws', Australian Law Reform Commission Report 2014 ³⁸;
- 'National Framework for Reducing and Eliminating the Use of Restrictive Practices in the Disability Service Sector' endorsed by Commonwealth, State and Territory Disability Ministers 2014 ³⁹;
- Draft 'NDIS Quality and Safe Guards Framework', currently being drafted by Commonwealth, State and Territory Governments; and
- 'Held back: The experiences of students with disabilities in Victorian schools report', Victorian Equal Opportunity and Human Rights Commission, 2012 ⁴⁰.

Recommendation 53: Amaze supports the recommendations of the Australian Law Reform Commission's enquiry into Equality, Capacity and Disability in Commonwealth Laws and the National Mental Health Commission's position paper in calling for a nationally consistent framework governing restrictive practice across all services systems.

Recommendation 54: The framework should be facilitated by the Council of Australian Governments and be binding in nature. Such a national framework would build on current practice and include:

- A national approach to the regulation and use of restrictive practices across all Government and Non-Government service systems, including, but not limited to, the National Disability Insurance Scheme, disability services, education, health, mental health and prisons;
- A national approach to the reduction and elimination of restrictive practices in Australia, guided by current evidence;
- Consistent definitions for seclusion, physical restraint, mechanical restraint, social restraint chemical restraint, environmental restraint, psycho-social restraint, and consequence driven strategies; and
- A reporting and accountability framework that collects nationally consistent data to provide an accurate measure of instances of use of restrictive practices.

And to support the governing framework, appropriate government investment should be made in:

- Development of standards and guidelines to support national consistency in approach to reducing the use of restrictive practices;
- Capacity building and education within service systems to operationalise the framework and guidelines;
- National independent monitoring and reporting across services; and
- Awareness raising of issues relating to restrictive practices amongst key stakeholders, including people with disability, their families and carers.

2.7 The economic cost of autism

There have been a number of reports looking into the economic cost of autism within Australia directly and another group of supporting reports, which whilst not specifically addressing autism, nonetheless provide insights into other elements such as the cost of unpaid care and the economic benefits of the NDIS.

In 2011, Synergies Economic Consulting prepared a report for the AEIOU Foundation on the economic costs of autism in Australia. The review estimated that the annual economic costs of autism in Australia were between \$8.1 billion (low prevalence) and \$11.2 billion (high prevalence).

³⁷ <http://www.mentalhealthcommission.gov.au/our-work/national-seclusion-and-restraint-project/our-position-paper-a-case-for-change.aspx>

³⁸ Ibid

³⁹ Ibid

⁴⁰ <http://www.humanrightscmission.vic.gov.au/index.php/our-resources-and-publications/reports/item/184-held-back-the-experiences-of-students-with-disabilities-in-victorian-schools-sep-2012>

This range reflected prevalence estimates of between 36.9 and 62.5 per 10,000. The study examined three categories of costs:

- Direct costs: health care, social services, education;
- Other tangible costs: reduction in income from lost employment; and the cost of informal care for adults with autism;
- Intangible costs (impacts on quality of life - “the burden of disease”).

The total direct and other tangible costs were between \$4.2 billion and \$7.3 billion, with the most significant costs arising from reduced employment and the cost of informal care for adults with autism.

The burden of disease contributed an additional \$3.9 billion. A number of costs were not included in the study due to a lack of data: e.g. the cost of early intervention programs, and the informal costs of caring for children with autism (only the costs of caring for adults with autism were included in the estimates). The report noted therefore that the estimates were likely to understate the full costs of autism.

A more recent study conducted in Western Australia in 2014, set out to measure whether a delayed diagnosis increased long-term costs for families. It found the median family cost of autism was estimated to be \$34,900 per annum with almost 90% of the sum (\$29,200) due to loss of income from employment. For each additional symptom reported, approximately \$1,400 cost for the family per annum was added. While there was little direct influence on costs associated with a delay in the diagnosis, the delay was associated with a modest increase in the number of autism symptoms, indirectly impacting the cost of autism.

Carers Australia recently released a report on *The Economic value of informal care in Australia in 2015*⁴¹, whilst not autism specific does provide an insight into the economic costs associated with the provision of informal care, to which a significant amount can be attributed to autism. It reported that in 2015, over 1 in 8 Australians (2.86 million people) are estimated to be providing informal care, providing an estimated 1.9 billion hours of care in 2015. This equated to replacement value of informal care would be \$60.3 billion (equivalent to 3.8% of gross domestic product).

In the Productivity Commissions recommending the development of the NDIS it modelled the benefits of the NDIS reform. It identified a number of key quantifiable factors, and also some that were unidentifiable give the lack of data and information. They included ⁴²:

- The net economic cost of the NDIS is not the budgetary cost of around \$6.5 billion (which is a transfer of resources from one group to another). Rather, the economic costs reflect the distortionary impacts of raising the revenue. That represents a cost of around \$1.6 billion. Given this, the NDIS would only have to produce an annual gain of \$3,800 per participant to meet a cost-benefit test. Given the scope of the benefits, that test would be passed easily;
- The most important of the economic benefits are the welfare impacts for people with a disability and their carers. While not counted in official statistics about the performance of the economy, these are genuine and large economic gains. One, partial way of assessing these gains is the value of the implicit income transferred by the NDIS to people with disabilities. Commission estimates suggests benefits of around \$7.8 billion annually. This is likely to significantly understate the benefits;
- By 2050, the collective impact of employment gains would be around a one per cent increase in GDP above its counterfactual level, translating to around \$32 billion in additional GDP (in constant price terms) in that year alone.
- However, it is important to note that some of the economic impacts of the NDIS measured in official statistics of employment and output do not include the offsetting reductions in unmeasured informal employment and output.
- The bottom line is that benefits of the NDIS would significantly exceed the additional costs of the scheme.

⁴¹ <http://www.carersaustralia.com.au/storage/20151014-carer-income-support.pdf>

⁴² <http://www.pc.gov.au/inquiries/completed/disability-support/report>

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