

Submission S146

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Family and Community Development Committee

Victorian Disability Advisory Council

Victorian Parliamentary Inquiry into services for people with autism spectrum disorder

VDAC submission

May 2016

Introduction

The Victorian Disability Advisory Council (VDAC) welcomes the opportunity to provide a submission to the *Inquiry into services for people with autism spectrum disorder*. VDAC is an advisory body established under the *Disability Act (2006)*. Its functions include:

- Provide advice to the Minister in respect of -
 - whole of government policy directions and strategic planning and the implementation of initiatives for persons with a disability;
 - the barriers to full inclusion and participation in the community of persons with disability and the strategies for the removal of those barriers;
 - any matter relating to disability referred to the Victorian Disability Advisory Council by the Minister.

VDAC advises the Minister for Housing, Disability and Ageing, the Hon. Martin Foley MP.

This submission draws on the experiences of VDAC members, as people with a disability or as family members or carers of children and young people with a disability. Published academic research, government reports, strategic plans and inquiries are also referred to. In particular, this report draws heavily on the Parliamentary Inquiry into Social Inclusion and People with Disability (Parliament of Victoria 2014); the Victorian state disability plan 2013-2016 (Victorian Department of Human Services 2012); the National Disability Strategy 2010-2020 (Commonwealth of Australia 2011); and the Review of the Program of Students with Disabilities (Victorian Government 2016). Our response is structured around the *key questions* provided as a guide to the Inquiry's investigations. When the responses to questions overlap our responses are combined.

Context

Prevalence of autism

The Australian Bureau of Statistics (ABS) report on Autism in Australia, 2014 (4428.0) based on the 2012 Survey of Disability, Ageing and Carers (SDAC), reported an estimated 115,400 Australians (0.5%) had Autism. Victoria had the highest proportion of autism of all States

and Territories (0.72%)¹. There was a 79% increase in the prevalence of autism between 2009 and 2012². This increase in prevalence has been concentrated in children. In the ABS report there was considerable variation in the prevalence of autism across age groups, with the highest prevalence in the 5 to 9 years age group. Males were also about four times more likely to report a diagnosis of autism than females. (ABS 2014) However, a recent guide from the UK, *Girls and Autism: Flying Under the Radar*, questions whether the extreme gender difference is real. They argue that the difference in prevalence may be due to gender bias in existing screening and referral processes, diagnostic criteria and tools; protective and compensatory factors in females; and gender-specific differences in presentation of Autism Spectrum Disorder. (Nasen 2016)

The most recent estimates of autism in Australian children are from the Longitudinal Study of Australian Children – a nationally representative study of Australian children. They reported among children born in 2004-2005 the prevalence of autism before age 7 was 2.5 per cent (one in 40 children) compared to 1.5 per cent for children (one in 75 children) born in 1999-2000) (Randall, Sciberras et al. 2016). Potential explanations for this rapidly increasing prevalence is lack of consistency in the diagnosis of Autism Spectrum Disorder and increasing diagnosis of milder cases of Autism Spectrum Disorder in part due to awareness that diagnosis may provide access to services (e.g. Helping Children with Autism). This increase in prevalence is similar to that found in other countries which have experienced similar changes to the assessment and diagnosis of people with Autism Spectrum Disorder and is not thought to reflect a real change in the underlying risk of Autism Spectrum Disorder (Polyak, Kubina et al. 2015, Zablotsky, Black et al. 2015).

These rapid rises in diagnosis of autism pose challenges to government, the disability service sector and educational system in responding to the needs of children and adults with autism.

¹ We refer the Inquiry to the ABS data cubes to get Victorian-specific data (<http://www.abs.gov.au/AUSSTATS/abs@.nsf/DetailsPage/4428.02012?OpenDocument>, accessed 26 May 2016)

² In the report, Autism includes Autistic disorder, Asperger's disorder, Rett's Syndrome, Childhood Disintegrative Disorder and Pervasive Developmental Disorder.

Recommendations

Accessing services and quality of service

1. The Inquiry gather a comprehensive picture of Victorian's with autism experiences of services and the quality of those services through extensive engagement with people with autism, their family and carers and representative bodies.
2. Service improvements focus on using best practice approaches to enhancing communication between services and people with autism and to providing additional support in cognitive and behavioural tasks.

Health services

3. In relation to improving the health of people with autism, the Inquiry implements the strategies within the Victorian state disability plan 2013-2016 relating to the coordination and accessibility of health services with specific attention given to the unique needs and experiences of this this group.
4. There is universal and timely access to high quality multidisciplinary assessment and diagnosis.
5. There is evidence-based training and accreditation of practitioners and organisations involved in assessment and diagnosis.

Services in rural and regional Victoria

6. The Inquiry gather a comprehensive picture of the experiences of Victorian's with autism living in rural and regional Victoria on which to base service reform.
7. Resources are allocated to improving access and quality of assessment and diagnosis services as well as early intervention and disability services in rural and regional Victoria.

Integration across government and services

8. The Inquiry considers recommendations 2.1-2.5 of the Social Inclusion and Victorians with Disability report.
9. The Inquiry considers how the Local Area Coordinators can be used to facilitate better integration of services and sectors.

10. The Inquiry focuses on the needs of children and young people with autism aged 0 to 25 years to develop a more holistic, person-centred approach to the coordination of the education, disability and health sectors in the light of the introduction of the NDIS.

Education and housing

11. Consider the specific recommendations 15-20 of the Review of the Program for Students with Disabilities that relate to students with autism and dyslexia.
12. Consider all recommendations of the Review of the Program for Students with Disabilities in relation to the specific needs of children with autism.
13. The Victorian government investigate models of housing that best meet the housing needs of Victorians with Autism Spectrum Disorder focussing on the availability affordable, accessible and secure housing over which Victorians with Autism Spectrum Disorder have choice and control.

Workforce issues

14. This Inquiry considers how the education and disability services sectors workforce capability can be improved to better provide the services and support needed by Victorians with autism
15. This inquiry take into account the findings and recommendations of the Victorian Parliamentary Inquiry into Abuse in Disability Services. (Tabled on 26 May 2016.)

Impact of NDIS and Disability Service Providers / Disability Service Providers

16. Improving access to quality disability services through ISPs for people with autism who will not receive the NDIS until 2017-2019.
17. Disability services extend to people with autism and their families without co-existing intellectual disability who would benefit from such supports.
18. Disability service providers and support workers receive accredited training to improve their skills and capacity to work with individuals with autism.
19. Urgent attention be given to the development of high quality disability workforce that can provide for the therapeutic and support needs of people with ASD accessing NDIS.
20. Investment is made in the development of capacity of the Local Area Coordinators to facilitate the successful integration of mainstream and disability services.

Research into ASD and its prevalence

21. The Victorian government investigate the potential to link health and disability data to obtain more accurate estimates of prevalence and to inform service planning.
22. The Victorian government invests in research to identify the best strategies to facilitate successful post-school transitions for young people with Autism Spectrum Disorder.
23. The Victorian government invests in building the research workforce on Autism Spectrum Disorder.

Community participation

24. This Inquiry consider the findings and recommendations of the Australian Human Rights Commission Willing to Work Inquiry with particular reference to the concerns of people with autism.
25. This Inquiry seek input from people with autism regarding how to make workplaces more accessible, reduce discrimination and promote inclusion.
26. This Inquiry consider the findings of the Parliamentary Inquiry into Social Inclusion of Victorians with a Disability in developing strategies to improve participation of Victorians with autism in sports and recreation.

Responses to Terms of Reference

1. Accessing services and quality of service

What is the experience of people with autism spectrum disorder (ASD), their families and carers in accessing services, information, advice and support?

What is the quality of these services, the standard of advice and the reliability of information given on ASD, and the support provided?

Note: This question overlaps with a number of different questions. Specific responses to overlapping issues are under those headings (i.e. health services (key question 2), disability services providers (key question 5), the education sector (key question 6), the NDIS (key question 8) and community participation (key question 10)).

People with Autism Spectrum Disorder and their families face challenges in accessing services, information and support in Victoria as a result of the pressures on services for people with a disability in general, lack of adjustments to address the specific needs of this group, and attitudinal barriers. Specific evidence regarding the service experiences of Victorian's with autism is lacking, however, the ABS 2014 report on Autism in Australia provides information on the support needs of this group. They found that 73% of people with autism reported having a profound or severe core activity limitation and needed help or supervision in at least mobility or communication or self-care. Some people needed support in multiple areas. The greatest challenge was with communication and 58% of people reported a profound or severe communication restriction. Fifty one percent of people with autism reported having a profound or severe mobility restriction.

Approximately one third of people with autism needed daily assistance with self-care, communication, or mobility and over half needed daily assistance with cognitive and behavioural tasks (such as managing relationships or making decisions) on a daily basis. In most instances, assistance was required several times a day. However, there is a significant gap between need for assistance and receipt of the required assistance. Particular gaps were noted with communication (understanding or being understood by others) where

27,100 people with autism reported needing more help and 48,100 need more help with cognitive and behavioural tasks. (ABS 2014)

Based on the current state of knowledge about experiences of services of people with autism VDAC recommends:

- 1. The Inquiry gather a comprehensive picture of Victorian's with autism experiences of services and the quality of those services through extensive engagement with people with autism, their family and carers and representative bodies.*
- 2. Service improvements focus on using best practice approaches to enhancing communication between services and people with autism and to providing additional support in cognitive and behavioural tasks.*

2. Health services

Does the health system provide adequate access, information and support to people with ASD and their families in Victoria?

What is the accessibility and availability of quality assessments and diagnoses of people presenting with ASD?

Health system

Optimising health and improving access to health care have been highlighted in the Victorian state disability plan 2013-2016 (Victorian Department of Human Services 2012), National Disability Strategy 2010-2020 (Commonwealth of Australia 2011) and the Victorian Parliamentary Inquiry into Social Inclusion and Victorian with Disability (Parliament of Victoria 2014).

There is substantial evidence to suggest that people with disabilities have much poorer health than people without disabilities including chronic conditions such as diabetes, depression, and heart disease as well as more risky health behaviours such as smoking and physical inactivity (Kavanagh, Krnjacki et al. 2012). Although evidence regarding health problems among people with Autism Spectrum Disorder is lacking, we do know that they

experience co-morbidities such as epilepsy and children with autism are more likely to be physical inactive and be overweight or obese which places them at higher risk of chronic diseases such as heart disease and diabetes (McCoy, Jakicic et al. 2016). Problems with sensory integration may also make it difficult to access services such as dentistry.

Improving the health of children and adults with Autism Spectrum Disorder will require a comprehensive approach to their health care which takes into account their unique communication and sensory needs. This approach could include longer appointment times, visual aids, recognition of difficulties in sensory processing (e.g. perception of pain, fear in unfamiliar clinical environments), and training of health care practitioners.

Improving access to primary health care practitioners as well as specialist services is also paramount. There is a need to improve the capacity of primary health care practitioners' to deliver quality preventative health care including information and advice, screening, referral and coordination of care. Better communication between primary health care providers (e.g. GPs, dentists, maternal and child health care nurses) and specialist services is required to attain optimal health outcomes for Victorians with Autism Spectrum Disorder.

Assessments and diagnosis

In this response we draw on the review by Professor Katrina Williams and colleagues on the services for assessment and intervention for people with Autism Spectrum Disorder in Australia. (Williams, Woolfenden et al. 2014) Internationally multidisciplinary team assessment and diagnosis is considered best practice. This includes medical, psychology, speech therapy and, if necessary, occupational therapy. However, accessibility to quality assessment and diagnosis varies widely in Victoria and Australia. Long waiting periods for diagnosis and assessment exist in the public system and outside of major urban centres. The quality of assessment also varies with no consistent approach to diagnosis in Australia. Australia lacks a system of accreditation for practitioners providing diagnoses of Autism Spectrum Disorder although we note AMAZE has developed protocols for accreditation of individual practitioners and organisations however these are voluntary.

VDAC recommends that:

3. *In relation to improving the health of people with autism, the Inquiry implements the strategies within the Victorian state disability plan 2013-2016 relating to the coordination and accessibility of health services with specific attention given to the unique needs and experiences of this this group.*
4. *There is universal and timely access to high quality multidisciplinary assessment and diagnosis.*
5. *There is evidence-based training and accreditation of practitioners and organisations involved in assessment and diagnosis.*

3. Services in rural and regional Victoria

Are there particular issues with service access and quality of service in rural and regional areas of Victoria? What is the accessibility and availability of services that are age appropriate?

There is a serious gap in our knowledge and understanding of the experiences of Victorians with autism living in rural and regional Victoria. Our response is based on the experiences of one VDAC member who has contacts with his own community however it is clear more information is required. People living in regional and rural areas have difficulty accessing high quality assessment and diagnosis services with many having to go privately with significant out of pocket expenses. Accessing inclusive education is particularly challenging in rural and regional areas where there is often a limited choice of schools.

VDAC recommends that:

6. *The Inquiry gather a comprehensive picture of the experiences of Victorian's with autism living in rural and regional Victoria on which to base service reform.*
7. *Resources are allocated to improving access and quality of assessment and diagnosis services as well as early intervention and disability services in rural and regional Victoria.*

3. Integration across governments and services

How well are services across the different levels of government integrated? Is there collaboration and appropriate linking up between service providers, particularly in relation to transitions from one area of the sector to another?

The integration of services across different levels of government and between services remains a concern for all people with disability. VDAC commends the Parliamentary Inquiry into Social Inclusion and Victorians with Disability for tackling this issue. We refer this Parliamentary Inquiry to its findings and recommendations with regard to the integration of different levels of government and the transition points for people with Autism Spectrum Disorder. VDAC specifically refers to Chapter 2 on government leading the social inclusion agenda and its findings.

Through interdepartmental committees various levels of government should align policy frameworks to ensure improved transitioning for people with Autism Spectrum Disorder. VDAC endorses those recommendations that will improve transitions as highlighted by the Parliamentary Inquiry into Social Inclusion;

- Commence a review of the Disability Act 2006 (Vic) by 2019 to ensure it aligns with the National Disability Insurance Scheme Act 2013 (Cth) and reflects the Victorian Government's future involvement in disability. (Recommendation 2.1)
- Request the Victorian Auditor-General undertake an audit of the suitability, effectiveness and implementation, and the monitoring and improvement of disability action plans in local government. (Recommendation 2.3)
- Seek advice from the Victorian Disability Advisory Council (VDAC) on future directions for social inclusion and that it is incumbent on VDAC to ensure it gathers relevant information to be considered in the development of Tier 2 of the National Disability Insurance Scheme. (Recommendation 2.4)
- Work with the National Disability Insurance Agency to clarify the roles and responsibilities of Local Area Coordinators associated with the National Disability Insurance Scheme and Access Officers in the Building Inclusive Communities

Program to ensure their social inclusion interventions are complementary.

(Recommendation 2.5)

VDAC also recommends that government departments use this advisory council as an expert reference point when developing governmental disability policy and/or reviewing programs and initiatives that impact on people with a disability.

Improved transitions for people with Autism Spectrum Disorder will not be accomplished solely through reforms such as the NDIS. Instead it requires acknowledgement and understanding of the issues across all Government services and initiatives; followed by rigorous planning that incorporates participation, inclusion and feedback from people with Autism Spectrum Disorder.

VDAC notes the emerging roles of the Local Area Coordinators in the planning and coordination of disability and mainstream services and recommends the Inquiry consider how they might leverage the capacity of the lack to facilitate better integration of services for people with autism.

Children and young people

Given the high prevalence of autism in children achieving integration of services across all levels of government for this group is particularly important. This involves the intersections between the disability and education sector. This is where demarcation of responsibilities to the State (for education) and Commonwealth (NDIS) may present challenges for governance and people with autism and their families and carers. The NDIS has been one attempt to address the fragmentation of service responses however, it is not aligned with other major factors in children's lives, including school.

A different approach that might be considered is offered by the Children and Families Act (2014) from England. The Children and Families Act has been developed specifically from the needs of children and young people. These reforms are designed to build a coherent and coordinated approach to meeting the needs of children and young people with disabilities across all the major services that they have contact with.

The core propositions in the new Children and Families Act are that:

- Families and young people are to be the centre of the planning process
- There is a focus on supporting children and young people from 0 - 25 years
- Local Authorities advertise their core offer of services for children and young people
- Children with significant needs are to have one combined education, health and care plan
- There will be individual budgets available to those who choose them

There are both similarities between developments in Australia and in the UK. Both focus on an increased role for families and young people in a planning process. There is also a shared commitment to the person for whom the service is created having a much stronger voice.

There are also significant differences. The first is the attempt in the UK to coordinate education, health and care services into one combined package of support. The second is that the UK approach focus across the 0 - 25 years age range, with the intention of developing a coherent approach to supporting children's development from the early years into adulthood. This approach is designed to address a range of transitional issues, including a lack of options for post school leavers or 16 years plus who, like in Australia, are vulnerable to falling through gaps.

The underlying purpose is that a coherent approach to providing services to a person from 0 -25 years is important in supporting young people to develop the skills and having the experiences they need to enter adulthood with the greatest potential for independence and capacity to participate in the community. The economic rationale for these reforms are that if young adults with disabilities achieve greater independence and participation they will be less dependent on services and more able to make their own contribution into the future.

While the mechanisms of government are quite different in Australia and the UK, and the planning approach legislated in the UK cannot be simply replicated in Australia, these reforms suggest that there is room for further reforms in Australia if the complex needs of children with autism are to be met. These include:

- Families and young people having a much greater say in defining what will support them and funding programs becoming more responsive to individual needs
- Those responsible for funding programs adopting a more holistic approach and actively resolving demarcation disputes over funding boundaries
- Developing an approach which values maximising the outcomes for young people with disabilities from more effective uses of limited resources
- Encouraging joint planning involving a range of funding program managers as a mechanism for driving systems change at a broader level.

Without significant additional reform for children and their families then the transfer of disability to the NDIS is unlikely to reduce the complexities and boundaries that families and young people currently have to navigate.

VDAC recommends that:

8. *The Inquiry considers recommendations 2.1-2.5 of the Social Inclusion and Victorians with Disability report.*
9. *The Inquiry considers how the Local Area Coordinators can be used to facilitate better integration of services and sectors.*
10. *The Inquiry focuses on the needs of children and young people with autism aged 0 to 25 years to develop a more holistic, person-centred approach to the coordination of the education, disability and health sectors in the light of the introduction of the NDIS.*

4. Education and Housing

What is the accessibility to, and quality of the education services provided to people with autism? How inclusive is the education sector, at all levels, to people with ASD? What are the resource limitations?

Are the accommodation needs of people with ASD being met? What models of housing represent best practice, and how developed is the sector in providing sufficient and appropriate housing options?

Education

The experience of children in schools suggests that they are not currently getting the *strong foundations in life* envisaged in the Victorian state disability plan 2013-2016 (Victorian Department of Human Services 2012). The ABS 2014 report on Autism in Australia, 2012, found that only 5% of children with autism attended school without any educational restrictions. Some restrictions were experienced by 95% of children with autism, including 6% of children who were not able to attend school because of their disability and 44% who attended either a special class in a mainstream school or went to a special school. 86% of children with autism attending school reported 'having difficulty' at school, including difficulty with socialising, learning and communication (ABS 2014).

We refer the Inquiry to the recently published review of the Program for Students with Disabilities which conducted a thorough review of the needs of children with autism (Victorian Government 2016). While the Program for Students with Disabilities (PSD) provides targeted funding for most students with autism, not all students on the autism spectrum meet the eligibility guidelines. The PSD criteria for autism require a diagnosis in addition to two indicators of student need, and demonstrated deficits in adaptive behaviour and language skills. Children and young people who are assessed as being on the autism spectrum can have a wide variety of strengths and needs, despite having the same diagnosis. Up to 90 per cent of children and young people with autism may have additional conditions (co-morbidity), such as attention deficit hyperactivity disorder, epilepsy and obsessive compulsive disorder (Victorian Government 2016).

While the majority of students with autism are currently captured within the existing PSD eligibility criteria (0.9 per cent of all student enrolments), not all students with autism receive targeted PSD support because the focus of the PSD is on students with moderate to high educational adjustment needs. This results in a number of students who have a diagnosis of autism but do not meet the existing eligibility criteria (such as students with stronger adaptive behaviour or language skills). However, these students may still require additional support in school to achieve their potential. (Victorian Government 2016)

The review found that schools do not consistently use evidence-based interventions when trying to support the learning needs of students with autism or dyslexia. There is scope to improve the awareness of all schools and teachers about evidence-based approaches to support students with autism or dyslexia and how to use these in the classroom. This could be achieved by providing more ongoing disability-specific training to lift workforce capability. Ongoing learning opportunities and training would support teachers to better understand and teach students with autism or dyslexia. An increase to the language support program component of the PSD could provide schools with greater flexibility within their budget to access disability-specific training and implement appropriate strategies. A key advantage of investing in teacher development is that this would benefit all students with disabilities, whether or not they attract targeted funding. (Victorian Government 2016)

VDAC supports recommendations 15-20 of the Review of the Program for Students with Disabilities that outlines specific findings and recommendations to meet the needs of students on the autism spectrum and with dyslexia; and also supports the other recommendations as they relate to all students with additional needs including students with ASD.

VDAC recommends that the Inquiry:

- 11. Consider the specific recommendations 15-20 of the Review of the Program for Students with Disabilities that relate to students with autism and dyslexia*
- 12. Consider all recommendations of the Review of the Program for Students with Disabilities in relation to the specific needs of children with autism*

Housing

Affordable, secure and accessible housing is necessary for people with Autism Spectrum Disorder to access their community and live the life to which they aspire. People with Autism Spectrum Disorder often have restricted housing options and do not have choice and control about where they live and with whom.

The demand for housing for people with Autism Spectrum Disorder, like many people with a disability, has been significantly increased by the NDIS provision of portable and adequate support. The provision of housing response however has been restricted with the NDIA announcing its will only fund the top 6% of NDIS recipients with the highest support needs (with support costs of approximately \$140,000 p.a.+) in Specialist Disability Accommodation (SDA)³. The balance ("the Other 94%") will be directed to seek housing through the State Government managed social housing (which has a significant and lengthening waiting list) and the private rental and private ownership markets (which is only affordable to a few). Currently, the future directions on housing for the majority of people with a disability with funded support, "the Other 94%", are largely yet to be defined by both the NDIA and the State Governments. A large proportion of people with Autism Spectrum Disorder will not qualify for housing through the NDIS. The Victorian government needs to take a proactive role in ensuring the Victorians with Autism Spectrum Disorder have access to innovative housing options over which they have real choice and control. There is evidence that expenditure on housing for people with a disability such as people with Autism Spectrum Disorder is an efficient and effective way to reduce total support costs: a seemingly attractive but unrecognised proposition to an agency like NDIA which is tasked with reducing whole of life costs and has a flexible approach to expenditure.

VDAC recommends that:

- 13. The Victorian government investigate models of housing that best meet the housing needs of Victorians with Autism Spectrum Disorder focussing on the availability*

³ Based on a comparison of: current estimates for number of NDIS participants by 2019 and preliminary forecast number of participants by dwelling type (Specialist Disability Accommodation Position Paper on Draft Pricing and Payments, National Disability Insurance Agency, 1 April 2016).

affordable, accessible and secure housing over which Victorians with Autism Spectrum Disorder have choice and control.

5. Workforce issues

How well equipped is the workforce across the sector in providing informed, compassionate, and professional service to people with ASD? What are the training needs and qualifications necessary to ensure a skilled workforce?

Education workforce

Many of the recommendations of the Review of the Program of Students with Disabilities related to improving workforce capacity to improving learning outcomes for children with autism. The Review found that there is considerable scope to develop teachers' capacity to support students with disabilities. In particular, the Review found that teachers are likely to require training in how to make reasonable and evidence-informed adjustments to teaching practices to effectively include students with disabilities. The Review also found that while there is an inclination for schools to use PSD funding to hire Education Support (ES) staff, there is a lack of understanding among teachers and principals on how to use these staff to maximise student participation and learning (Victorian Government 2016).

There are opportunities to build staff capability to support students with disabilities to achieve learning outcomes. To begin addressing this issue immediately, the Review recommends that current disability-relevant professional learning be more comprehensively rolled out and promoted across the state. At the same time, it is recommended that a workforce capability strategy be developed, which would include a detailed analysis of the skills and capabilities of the teaching workforce, and would develop specific measures to address any gaps. (Victorian Government 2016)

The introduction of the NDIS through trials in most Australian states and territories (including Victoria) has been hailed as a significant re-shaping of disability service provision and one which places individualised support, choice and control at the forefront of its aims.

In order to achieve the goals of the NDIS, however, workforce has been identified as a key issue. As stated in the recent Quality and Safeguards Framework consultation paper

released by the Department of Social Services, "It is anticipated that the disability sector workforce will need to double in size between now and full implementation in 2019-20 as a result of the NDIS. The growth will be across all jurisdictions."

In seeking to grow the workforce within the disability sector, there is a need to be cognisant of the challenges that come with attracting workers to a traditionally low paid and low skilled workforce, as well as the importance of ensuring that workers are equipped with the necessary skills to actually offer the kind of individualised, person-centred care that the NDIS seeks to offer. The need to attract workers to the sector while ensuring quality safeguards are maintained has been the subject of consultations and inquiries at both a State and Federal level.

The disability sector workforce is made up of a wide range of employees, including managers, health and social professionals and non-professionals such as personal support workers, domestic assistants, home workers and community care workers. The 2011 Productivity Commission 'Disability Care and Support' report estimated that there are around 70,000 (34,000 full time equivalents) employees in the disability sector. The vast majority (62%) of these are non-professionals, with managers and coordinators making up 25% and professional staff constituting the remaining 12%.

For the majority of disability workers, there are no specific qualifications necessary to perform the work. Training the disability services sector currently draws on elements of formal and informal training. Training is generally available only for developing minimum core skills and ongoing training is largely client-specific. The majority of non-professional workers have a Certificate level of qualification and the take-up of accredited persons appears to have grown in recent years, indicating that training is taking on a greater importance in the sector. However, community service organisations acknowledge that they currently struggle, or fail to provide adequate staff training on the grounds that they are not adequately funded to do so. There is currently an inadequate supply of skilled workers to support children and adults with Autism Spectrum Disorder and the NDIS is likely to create new inequities unless funding is allocated in recognition of the importance of quality, skilled and accredited workers.

The combination of a traditionally low paid, low skilled workforce and the need to grow the workforce significantly over a short space of time creates a high risk that the gaps will be filled without regard to the pre-requisite skills, attitude and knowledge needed by workers in order for the NDIS to achieve its stated aims. Indeed, the NDIS has acknowledged that risk in the disability sector is likely to increase as the demand for workers grows and competition for staff with aged care and other community services sectors increases. In addition, some self-managing participants will take on responsibility for employing their own workers and the number of self-employed and casual workers is likely to grow.

VDAC recommends that:

14. This Inquiry considers how the education and disability services sectors workforce capability can be improved to better provide the services and support needed by Victorians with autism.

15. This inquiry take into account the findings and recommendations of the Victorian Parliamentary Inquiry into Abuse in Disability Services. (Tabled on 26 May 2016.)

6. Impact of NDIS and Disability Service Providers and 7. Disability Service Providers

What will be the impact of the roll-out of the NDIS on services, and choice of service, for people with ASD and their families? Are there likely to be gaps in service emerging as a result? How will the different levels of government service provision be changed or impacted?

Does the disability service sector provide sufficient and quality tailored services to people with ASD? What is the level of unmet demand for these services? How well do these services perform in meeting the expectations of their clients?

Disability services

Access to quality disability services is an ongoing concern for people with autism. The Commonwealth-funded 'Helping Children with Autism packages' provide up to \$12,000 for children under six years of age to access therapies. This funding does not meet the costs of the extensive early intervention therapies recommended for children with Autism Spectrum

Disorder. The lack of funding for therapeutic support beyond six years of age is of concern as children and adults with Autism Spectrum Disorder may benefit from therapeutic interventions throughout their life.

In addition to therapeutic interventions some people with Autism Spectrum Disorder require support to access the community. Families also require support including respite and professional advice and training regarding behavioural interventions. Many Victorians with Autism Spectrum Disorder and their families face considerable barriers to accessing these services. For example, it is difficult to obtain Individual Support Packages (ISPs) through the Victorian Department of Health and Human Services (DHHS) without families reaching crisis point such as significant mental health problems and potential relinquishment of children. The waiting list for ISPs is long and the processes for obtaining them is arduous and lacks transparency. Many people with Autism Spectrum Disorder and their families have given up on receiving timely support from DHHS and other government and non-government agencies that provide disability services.

As the NDIS gets rolled out access to disability services will vary greatly across Victoria. Given that current disability services are inadequate for children and adults with autism the NDIS is likely to create new inequities with NDIS recipients potentially being able to access more, high-quality services than people with autism who live in areas without the NDIS. It is critical that DHHS Victoria consider ways to improve on current systems, including access to ISPs, to ensure that people with autism that do not have access to the NDIS for some years receive high quality services and supports.

We also note that many of the services for people with autism concentrate on the needs of people with more severe autism and/or co-existing intellectual disability. Children and adults with milder autism may still require disability services and support and are poorly served by the current system. It is unclear what proportion of this group will be eligible for individualised support plans through the NDIS.

VDAC recommends that the Inquiry consider:

- 16. Improving access to quality disability services through ISPs for people with autism who will not receive the NDIS until 2017-2019.*

- 17. Disability services extend to people with autism and their families without co-existing intellectual disability who would benefit from such supports.*
- 18. Disability service providers and support workers receive accredited training to improve their skills and capacity to work with individuals with autism.*

National Disability Insurance Scheme

While the NDIS is a welcome reform for people with Autism Spectrum Disorder, concerns exist regarding the extent to which it will enable people with Autism Spectrum Disorder and their families to exercise choice and control over the services they use so as to achieve their individual goals. Many of the problems with the current system may remain because of lack of specialist services (e.g. speech therapy, occupational therapy) and supports (e.g. personal support workers) for people with Autism Spectrum Disorder.

South Australia greatly underestimated the demand for services by children with autism and have struggled to meet the needs of this group due to the lack of an adequately trained disability workforce. The unanticipated demand is thought to relate to the increasing diagnosis of Autism Spectrum Disorder and the fact that previously services were either unavailable or so poor that people with Autism Spectrum Disorder did not access them. It is possible that Victoria will face similar issues with the rollout of the NDIS. While the NDIS promises choice and control over services this can only be achieved if high quality services are available.

Another area of concern is the interface of disability and mainstream services such as health, housing and employment. For example, only a small proportion of NDIS recipients receive funding to assist with seeking and obtaining employment and this funding is usually smaller than the equivalent level of support provided by Disability and mainstream (Job Active) employment services. A similar concern arises for housing where only a small proportion of NDIS ISP recipients are expected to qualify for funding for housing through the NDIA (see response to housing question). To improve economic and social participation the NDIA will need to work closely with mainstream services to achieve the individual goals of people with NDIS. The Local Area Coordinators (LACs) are responsible for achieving the integration of disability and mainstream services. In the trial sites the NDIA was responsible

for achieving this however it is clear that service integration was not achieved at least in part because of the demands of implementing such substantial reform to disability services. However, for the NDIS to be successful service integration is critical. For people with Autism Spectrum Disorder who may find negotiating complex service environments challenging, the need for clear information and pathways to link disability and mainstream services is required. This information should take into account the specific communications needs of individuals with Autism Spectrum Disorder (e.g. visuals). This will require capacity building in the LACs and disability and mainstream service providers.

In relation to the roll-out of the NDIS for Victorians with Autism Spectrum Disorder VDAC recommends that:

- 19. Urgent attention be given to the development of high quality disability workforce that can provide for the therapeutic and support needs of people with ASD accessing NDIS.*
- 20. Investment is made in the development of capacity of the Local Area Coordinators to facilitate the successful integration of mainstream and disability services.*

9. Research into ASD and its prevalence

How well developed is research into ASD in Victoria? What are the current limitations to knowledge, and the dissemination of knowledge, in this area, and how can this be addressed? Is there an accurate picture available on the prevalence of ASD?

We provided an overview of our knowledge of the prevalence of autism in the introduction to this submission. We note that it has been difficult to obtain accurate estimates of prevalence of Autism Spectrum Disorder in Victoria or Australia because there is no central register of people diagnosed with Autism Spectrum Disorder and because of a lack of consistency in the diagnosis of autism. Linkage of health and disability data would enable us to get a better picture of the prevalence, geographic distribution and service use of people with Autism Spectrum Disorder. This information could then inform service planning.

Victoria has many high quality researchers working on Autism Spectrum Disorder including in the basic sciences, clinical research and public health and social sciences. We encourage

the Victorian government to invest in building this expertise to improve knowledge on which to base service provision. We note the relative lack of research in Victoria and nationally on how to facilitate successful transitions from school into post-school training and employment for young people with Autism Spectrum Disorder and we recommend investment in this area. Without better knowledge about what strategies work to enable economic participation of school leavers with Autism Spectrum Disorder they remain at risk of being socially marginalised and experiencing poor health and wellbeing. There are also significant economic benefits to improving economic participation of young people with Autism Spectrum Disorder.

VDAC recommends that:

- 21. The Victorian government investigate the potential to link health and disability data to obtain more accurate estimates of prevalence and to inform service planning.*
- 22. The Victorian government invests in research to identify the best strategies to facilitate successful post-school transitions for young people with Autism Spectrum Disorder.*
- 23. The Victorian government invests in building the research workforce on Autism Spectrum Disorder.*

10. Community participation

What programs exist to facilitate the participation of people with ASD in the community and in employment? How available, accessible and successful are employment services for people with ASD?

How inclusive are the state's sports programs of people with ASD? What are the opportunities for participation in sport and recreation?

Employment

Australians with disabilities have one of the lowest levels of labour force participation in the OECD (OECD 2009). Improving economic participation of people with disabilities will bring

significant social, economic and health and wellbeing benefits for individuals as well as society.

The ABS 2015 Survey of Disability and Carers found that 53% of people with disability were participating in the labour force, compared with 83% without a disability. People with disability were also more likely to be unemployed and experience longer periods of unemployment. Importantly many Australians with disability reported that discrimination from an employer was common. In 2014–15 the Australian Human Rights Commission received 3,529 enquiries and 742 complaints about disability discrimination. More than a third of enquiries (35.4%) and complaints (41.0%) were in the area of employment. (Australian Human Rights Commission 2016) People with autism have particular difficulties participating in the workforce. In 2012, the labour force participation rate of people with autism was 42% compared to 53% of people with other disabilities and 83% without a disability. People with autism were also more likely to be unemployed than other Australians with a disability and Australians without a disability. (ABS 2014)

Deloitte Economics has shown that closing the gap between labour market participation rates and unemployment rates for people with and without disabilities by one-third would result in: \$43 billion increase in Australia's GDP over the next decade in real dollar terms and that GDP will be around 0.85% higher over the longer term, which is equivalent to an increase in GDP in 2011 of \$12 billion (Deloitte Access Economics 2011). These improvements would bring us in line with similar countries such as New Zealand.

The Parliamentary Inquiry on Social Inclusion and Victorians with Disability found that discrimination in employment was high and that many people with autism reported similar barriers to employment as people with other types of disability. For example, Aspect Victoria expressed its view that during 'the life area of transition from secondary school... [m]any teenagers with ASD [autism spectrum disorder] who are nearing leaving school age feel there aren't the pathways out there to keep them included within society and their local communities.' (Parliament of Victoria 2014)

We draw this Inquiry's attention to the recently released Australian Human Rights Commission 'Willing to Work Inquiry' which found that discrimination against people with disabilities in relation to employment is endemic and that many people with disabilities want to work. They found that discrimination occurs at many levels such as access to training; low expectations by family, teachers, and others; attitudes of employers; lack of accessibility of workplaces; inflexible workplaces and hiring processes; and lack of opportunities for career development and promotion. The Inquiry's report includes a number of case studies relating to successful initiatives to include people with autism in specific workplaces. The Inquiry made recommendations across three areas: 'Priority Government Commitments'; 'Improving existing systems' and 'What employers and business can do'. Priority Government Commitments refer to Federal initiatives as well as recommendations regarding government as a buyer of goods and services; community education campaigns; and government as an employer. Improving existing systems includes issues such as accessibility of Centrelink and access employment services and the Inquiry recommends that employers demonstrate leadership in issues such as building workplace flexibility and targeted education and training. (Australian Human Rights Commission 2016)

We also note that the Commonwealth Government is currently undergoing a review of Disability Employment Services and are likely to emphasise a 'person-centred approach' in line with the NDIS. People with autism are also likely to face particular barriers to economic participation related to communication (e.g. need for visual supports) and sensory needs (e.g. noisy workplaces or environments). Internationally there have been innovative approaches to drawing on the strengths of individuals with autism to work on tasks and in environments that enable them to work productively in meaningful employment.

VDAC recommends that:

- 24. This Inquiry consider the findings and recommendations of the Australian Human Rights Commission Willing to Work Inquiry with particular reference to the concerns of people with autism.*
- 25. This Inquiry seek input from people with autism regarding how to make workplaces more accessible, reduce discrimination and promote inclusion.*

Sport

People with disability are less likely to participate in sports and recreation. In 2009 24% of people with a disability participated in sport compared with 65% of people overall.

(Parliament of Victoria 2014) People with autism and their families and carers face considerable difficulties in participating in sports and recreational programs. Mainstream sports programs do not adapt well to the specific requirements of people with autism. Parents and children may be ostracised and made feel unwelcome. Yet many people with autism want to participate in sports teams and recreational programs. The Parliamentary Inquiry on Social Inclusion and Victorians with a Disability considered participation in sport and their findings will be of use to this Inquiry.

VDAC recommends that:

26. This Inquiry consider the findings of the Parliamentary Inquiry into Social Inclusion of Victorians with a Disability in developing strategies to improve participation of Victorians with autism in sports and recreation.

Concluding remarks

VDAC commends the Parliament of Victoria for conducting this Inquiry into services for people with autism. We are keen to participate in the Inquiry further if needed. We recommend that the Inquiry see VDAC as a resource that they can use to gain more knowledge of the lived experiences Victorians with autism.

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