

# Inquiry into Services for People with Autism Spectrum Disorder

## Submission

Submission – April 2016

Attention: Family and Community Development Committee

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Disability Services Commissioner

# 1. Introduction

The Disability Services Commissioner welcomes the Parliamentary Committee's Inquiry into services for People with Autism Spectrum Disorder (ASD) who are often amongst the most vulnerable within our community.

As the independent statutory complaints body for Victorian disability services, Disability Services Commissioner is uniquely placed to contribute to this Inquiry through our access to data and themes arising from enquiries and complaints received by our office, in particular those complaints made specifically on behalf of people with ASD.

As evidenced in this submission, whilst there are many similarities in the issues raised on behalf of people with ASD with those raised on behalf of people with a disability more generally, there are also important differences in the types of issues raised and in the types of services about which complaints are made.

Disability Services Commissioner is pleased to provide the information contained in this submission in order to contribute to the Parliamentary Committee's efforts to achieve improved outcomes for people with ASD.



## 2. Purpose and Areas Addressed By This Submission

The comments outlined in this submission are informed by our experience in disability quality and safeguards in Victoria, including eight years in directly handling complaints, and the lessons learnt from complaints as managed by disability service providers. We provide these for the consideration by the Family and Community Development Committee in order to achieve the best possible outcomes for people with Autism Spectrum Disorder (ASD) and their family members or carers.

The Family and Community Development Committee seek to inquire into, consider and report, on services for people with ASD in Victoria, including but not limited to —

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

From our experience of dealing with complaints and our review of incident reports of staff to client assault and unexplained injury, we specifically address the following areas:

- The prevalence of ASD in Victoria, specifically in relation to the percentage of enquiries and complaints we receive relating to people with ASD ;
- The availability and adequacy of services provided by the Commonwealth, State and local governments across health, education, disability, housing, sport and employment services, using information obtained through enquiries and complaints.

### 3. About the Disability Services Commissioner

The Victorian Disability Services Commissioner (DSC) commenced on 1 July 2007 under the *Disability Act 2006* (Victorian Disability Act) to improve services for people with a disability in Victoria.

This independent statutory office works with people with a disability and disability service providers in Victoria to resolve complaints.

Our resolutions process is accessible and flexible. We encourage people to make a verbal complaint if that is the fastest and easiest way to capture their concerns. This makes it easier for people with a profound or severe disability to raise an issue. We can be contacted by phone on our free call number, email, electronic platforms (web or social media), Skype, TTY, Fax, and in writing. We tailor our communications including agreements in Easy English formats. We encourage the use of support people and advocates.

Our complaints resolution process is free, confidential and supportive. We encourage and assist the resolution of complaints in a variety of ways including informal approaches to resolution, assessment, conciliation, or under certain circumstances through investigations. The process is person-centred and accessible to people with cognitive or communication impairments. We receive a high level of enquiries which we use as an opportunity to coach people to raise issues and ensure the person accesses the 'right door' via warm referral to other complaints bodies.

To resolve complaints we apply an Alternative Dispute Resolution approach within a rights-based legislative framework to achieve outcomes that address both the individual's needs and aspirations, and promotes service improvement through the use of educative and advisory functions. This strengthens our effort in promoting people's rights to raise issues about their service delivery and for staff in responding effectively to complaints.

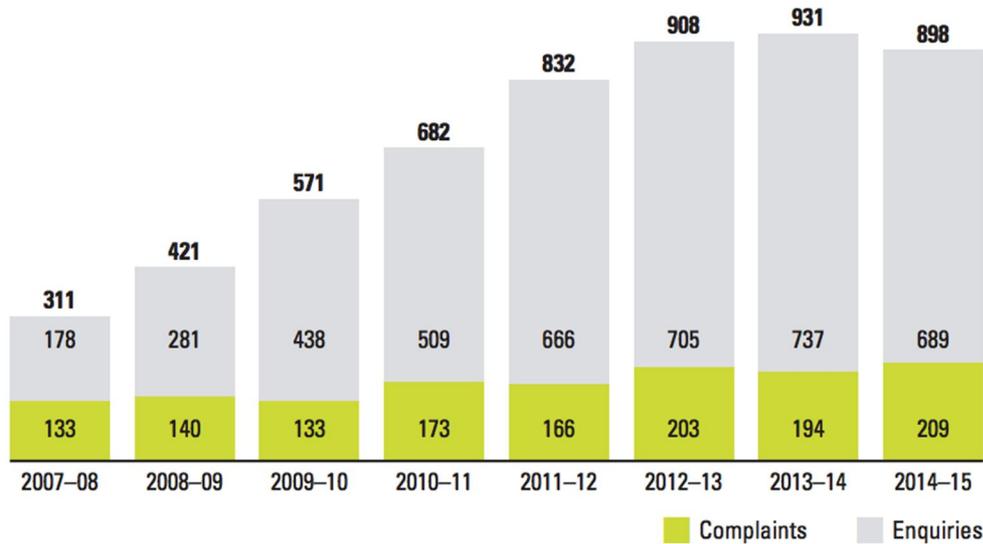
We have designed bespoke training for people with cognitive impairment that engages them in an appropriate way as to understand their right to complain; in addition we publish a quarterly Plain Language newsletter called 'Speaking Up' (available at [www.odsc.vic.gov.au](http://www.odsc.vic.gov.au)).

We research ways to improve outcomes for people with a disability and improve disability services' complaints systems. We also provide capacity development activities for people with a disability, their families and disability services through a variety of education and information. Our approach to our work reflects the objectives of the Victorian *Disability Act 2006*. Our values and principles are aligned to the *United Nations Convention on the Rights of Persons with Disabilities*.

The Victorian Disability Act requires that service providers must advise people using their service about both their organisation's complaint process and that they may raise complaints about service providers with the Disability Services Commissioner.

Since the establishment of this office we have been able to provide comments and proposals based on the evidence and knowledge we have gained in responding to over **5,500 matters to date**. Victorian disability service providers also readily contribute to our growing body of knowledge by reporting each year on the number and types of complaints they received and how they were resolved (as provided for by the Victorian Disability Act). Almost **12,500 complaints were reported by disability service providers** between 2007 and 2015. The information assists to identify systemic issues and inform the ongoing development of the disability service system.

**Figure 1: Total number of new enquiries and complaints**



## 4. Themes of Enquiries and Complaints

### Complaints

In 2014-15 we received the highest number of complaints to our office since we opened in 2007. The proportion of all complaints made directly by people receiving services was 25 per cent for complaints to service providers and 29 per cent for complaints to DSC. The greatest proportion of complaints continues to be made by parents or guardians (45 per cent to service providers and 38 per cent to DSC – see Note 1 below).

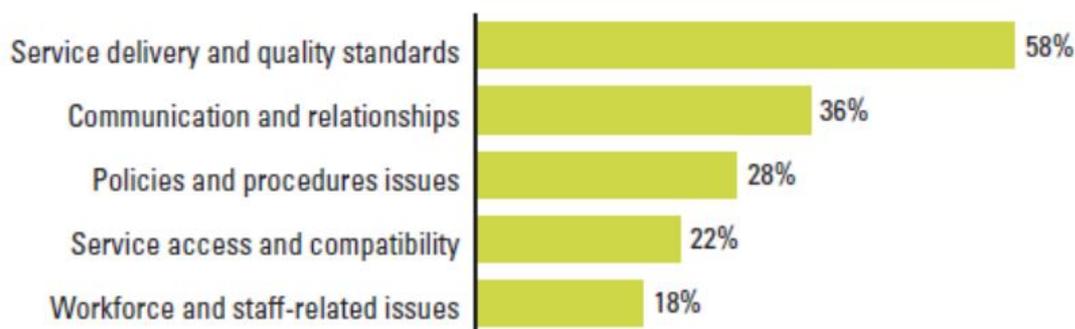
Of all the complaints received by DSC in 2014-15, 33% related to people with Autism Spectrum Disorder. Of all the complaints received by disability service providers in 2014-15, 18% related to people with Autism Spectrum Disorder (ASD).

### Themes of enquiries and complaints made to DSC

People contacting the DSC usually raise multiple issues. These issues have been grouped into five broad categories, as shown in figure 1 below. Our data indicated that these themes were consistent for complaints raised on behalf of a person with ASD.

**Figure 2: Type of issues raised in enquiries and complaints**

(Proportion of in-scope enquiries and complains. Multiple issues can occur for each enquiry and complaint so may not add up to 100 per cent, n = 501)



The main issues raised in enquiries and complaints in 2014–15 were:

- Service delivery and quality standards issues (58 per cent) — mostly regarding dissatisfaction with the quality of service provided, concerns about physical and psychological health and safety and insufficient service or care provided
- Communication or relationship issues (36 per cent) — largely due to insufficient communication from providers and concerns about the quality of this communication.

#### Note 1

In response to the consistently high number of complaints from parents / guardians received on a yearly basis by both our office and service providers, in 2014 DSC released *Occasional Paper No. 2: Families and service providers working together* (Attachment 1). The paper outlined key themes arising from the experience of and complaints raised by families as well as a range of resources targeted at supporting families and service providers to work more effectively together. We have since also released the digital story 'Jane's Story' which tells the story of one mother's experience of placing her son into a group home. <http://odsc.vic.gov.au/janesstory>

## Themes of enquiries and complaints made to disability service providers

All registered, funded and contracted disability service providers must report annually to the Disability Services Commissioner on the number and types of complaints they receive and how the complaints are resolved (ss.105 and 106B of the Victorian Disability Act).

The complaints reporting process elicits the key lessons that service providers have learnt from individual complaints. In 2014–15, a record number [1,512] of lessons were identified, the highest since the establishment of the Disability Services Commissioner. (See Note 2) The lessons from these complaints can be grouped into the following themes:

1. The need for effective communication between all parties, including families of people receiving services and neighbours.
2. The importance of encouraging an open culture that is responsive to feedback and complaints.
3. The need for improved focus on staff performance and ensuring high levels of professionalism.

### Note 2

In addition to collating and reporting on the lessons learned from complaints by service providers, DSC has also developed and provided to the disability sector a range of resources targeted at building the capacity of service providers to respond effectively to complaints. Largely based on the Four A's of resolving complaints, these resources include staff training (often co-presented by a person with a disability) and the publications *Good practice guide and self-audit tool* and *Everything you wanted to know about complaints...*(Attachments 2,3).

## Enquiries and complaints specifically related to Autism Spectrum Disorder

Of the total **enquiries and complaints** received by DSC from 1 July 2008 to 11 April 2016, those related to people with ASD make up 15 per cent. Of all the **complaints** received by DSC in 2014-15, 33% were related to people with ASD.

Overall the themes of enquiries and complaints relating to people with ASD are similar to other enquiries and complaints. However, the profile of services and age groups differ.

Of all the complaints made on behalf of people with ASD, the services that featured most were:

- 1) Shared Support Accommodation,
- 2) Individual Support Package- Day Services,
- 3) Case Management,
- 4) Respite.

Of all out of scope enquiries and complaints received on behalf of children and adults with ASD, one quarter related to education. The concerns relating to education of children and adolescents were about access to school, the use of restraint, verbal abuse, inappropriate support and access to funding for supports. To date there is no independent body in Victoria for complaints relating to students with disability.

There were some differences in the profile of services that were the subject of complaints on behalf of people with ASD. In particular 36% of all complaints made to DSC about respite services from 1 July 2008 to 11 April 2016 were made on behalf of people with ASD.

The other area of difference with respect to complaints made to DSC was with respect to the age of the person with a disability who was receiving a service. Almost one quarter of complaints made to DSC from 1 July 2008 to 11 April 2016 related to people aged 31-45. Almost two thirds of complaints made on behalf of people with ASD in the same period related to people aged 5 – 25.

Our data indicates that families who were caring for young people with ASD relied on respite services and that the services that were the subject of the complaints received, did not meet the individual needs of the person with ASD.

Caring for a child with ASD and high support needs during the transition to adolescence and adulthood can become complex. The capacity of families to continue providing support is challenged and there is an increasing reliance on respite services, individual support, shared supported accommodation and case management.

Some of the common themes of the enquiries and complaints dealt with by DSC involving people with ASD are outlined below.

People with ASD who have limited communication experience difficulty articulating their needs to service providers. Service providers are not always equipped to recognise communication signs from people with ASD. Service providers may not recognise what a person with ASD is trying to communicate through their behaviour. The quality of support offered by service providers is not always tailored to meet the needs of people with ASD.

### Example

A young child in a rural area who was taken to and from school by a school bus. The child would become very distressed in the afternoon when it was time to get back on the bus. It was increasingly difficult to get the child on the bus in the afternoon and the school considered removing the child from the school if he couldn't be controlled. There was a failure to understand how the child experienced the bus travel, having previously always been first on the bus. The behaviour was communication that something was amiss. Advice from a specialist in ASD suggested ensuring that the child was the first person on the bus every afternoon. This was a successful approach that saw the child happily get on the bus.

This example demonstrates how it can be difficult to interpret the communication of people on the Autism Spectrum, however with some understanding, issues can be resolved.

The following issues frequently relate to supported accommodation services supporting people with ASD to have a safe and stable home environment:

- Incompatibility of people who use the services
- High turnover of staff
- A lack of staff understanding of the importance of consistency in approach
- Effective behavioural support plans and the implementation of these plans.
- Failing to engage with people using services, including those that are non-verbal, to ensure that they are living fulfilled lives. This can result in challenging behaviours as caused by boredom and frustration

### Example

A complaint about a supported accommodation service was raised by a day service provider on behalf of a person with ASD. The day service provider advised DSC that the person does not communicate verbally and does not have family involvement. The day service raised concerns about the communication between the day service and accommodation service provider and the decisions the accommodation service were making on behalf of person.

### Case Study

A 19 year old woman, Jane, with an intellectual disability and autism, lives at home with her parents and siblings. Jane has limited verbal communication skills and uses few words. Her comprehension is significantly greater than her verbal expression. She previously attended a special school and had transitioned to a day service.

Jane's parents advised that the issues related to gaining access to a respite service that can regularly provide support workers and transportation for weekend respite activities. They advised that some of the workers were refusing to work with Jane as her behaviour is unpredictable when travelling in a car, raising safety concerns for her and her driver.

The weekend respite that was available was not meeting Jane's needs as there was a high turnover of staff. The family found that this increased Jane's anxiety as she was not comfortable with staff she did not know. New staff did not know how to support her. There was no suitable weekend respite available or access to a suitable vehicle.

Following DSC raising the complaint with the service provider, the service provider met with the parents to discuss the concerns. They identified that the most immediate need was finding support workers to provide respite, particularly for the upcoming holidays. A case manager was appointed and referrals were made to a neuropsychologist, a speech pathologist and an occupational therapist.

Jane was referred to facility based respite to access a psychiatrist with specialist disability experience. This resulted in a review of Jane's medications. The case worker worked on consistent respite options for Jane providing much needed support to Jane and her family.

## Personal safety

Data from complaints managed by service providers in Victoria reveals that issues of physical and personal health and safety, and discrimination, abuse, neglect, intimidation or bullying by staff, were more strongly represented in supported accommodation than other service types.

Of all complaints to service providers about health and safety in supported accommodation, 15% related to people with ASD.

For some complaints made directly to the DSC issues relating to inappropriate seclusion and restraint of children and young people with ASD have highlighted the inadequacy of existing services.

In addition to the insights gained through our work in the resolution of complaints, DSC is also able to identify and provide advice on themes arising from our oversight of critical incident reports relating to allegations of staff-to-client assault and unexplained injuries. (See Note 3) Whilst we do not have access to information that enables us to identify the disability of the people at the centre of the critical incidents, the themes identified are consistent for all people with a disability. The themes identified in 2014-15 included:

- a lack of focus on people's outcomes and safeguarding people's rights during investigations;
- the need for the disability sector to have more proactive engagement with Victoria Police; and
- a lack of clarity and shared understanding of the definitions of assault and abuse.

To drive systemic changes, the Disability Services Commissioner has provided a Notice of Advice to the Department of Health & Human Services on a six monthly basis. This identifies the key concerns and the actions required to achieve and sustain a person-centred human rights practice.

In October 2015 the DSC provided a submission to the Family and Community Development Committee Inquiry into Abuse in Disability Services that outlines the issues for people with disability to be free from abuse.

### Note 3

Based on themes arising from the work of the office, in 2012 DSC published *Occasional Paper No. 1: Safeguarding people's rights to be free from abuse* to provide a resource aimed at supporting disability service providers to identify and address the organisational structures and practices necessary to better safeguard the rights of people with a disability.

## 5. Summary

With respect to the terms of reference for this inquiry:

- a) The DSC is an independent body that receives complaints about disability services from and behalf of people with disability. Of all enquiries and complaints received by DSC in 2014/15, 33% related to people with ASD. For all complaints received by service providers and reported to DSC in 2014/15 18% related to people with ASD.

The DSC receives a high number of enquiries and complaints that are out of scope under the Victorian *Disability Act* 2006. Of all out of scope enquiries and complaints received on behalf of children and adults with ASD, one quarter related to education. The concerns relating to education of children and adolescents were about access to school. The use of restraint, verbal abuse, inappropriate support and access to funding for supports. To date there is no independent body in Victoria for complaints relating to students with disability. It has been widely acknowledged that specialist skills and experience are required to effectively resolve complaints and provide advice to schools and others about strategies to improve participation and outcomes for students with disability.

- b) The support services most frequently included as the subject of the complaint raised with DSC on behalf of people with ASD were respite, supported accommodation, individual support and case management. The majority of these services are funded by the Department of Health and Human Services and, as part of the transition to a National Disability Insurance Scheme (NDIS), a proportion are now also funded by funded through NDIS individual support packages. TAC funds a small proportion of the market.

Many of the issues raised in complaints made on behalf of people with ASD were similar to those raised on behalf of the broader disability sector. However, two areas where the issues raised on behalf of people with ASD varied from the broader sector were:

- people with ASD experiencing difficulty with access to quality service delivery tend to be younger (5-25 years);
- Over one third (36%) of complaints made about respite services were made on behalf of people with ASD.

The ongoing issues of concern for service delivery in respite care are access and availability of an appropriate service, appropriate matching of compatibility for service users, high staff turnover and inconsistency in communication and practice.

These issues indicate that many families/carers of people who have ASD and high support needs are challenged to find and acquire appropriate services.

Support services for people with ASD and other disabilities need to ensure that:

- the child or adult is heard and understood, particularly where communication is challenging;
- needs are identified and supports are reflective of those needs;
- staff with respectful and positive attitudes towards the human rights of people with disability are employed;
- each staff member is trained and equipped to provide person centred and “active” support;
- support staff are consistent in how communication and support is provided;
- people with disability, their families and carers are encouraged to give feedback and raise complaints where supports are not working as they should; and
- organisations use complaints as an opportunity to improve their service delivery.

- A close working relationship is established with the family of the person with ASD in order to maximise communication and consistency between the person's home and service and to enable the service to draw on the intimate knowledge families will invariably have of their family member.
- c) The NDIS is inheriting many of the issues and existing services for people with ASD. The NDIS will also attract new service providers who have varying skills and knowledge to deliver specialised services to people with high support needs. There is an opportunity for new and innovative models of support to be developed and delivered for children and adults with ASD. However the development of evidence based models of support requires early investment and the engagement of university and specialist bodies that have researched and identified the evidence to be relied upon. These resources are generally not available to disability support providers without some facilitation.

It is important that the new national framework for safeguards includes mechanisms to protect against abuse and neglect of people with disability and that appropriate legislative powers are provided. This is canvassed in further detail in Section 6 of DSCs submission to the Family and Community Development Committee's Inquiry into Abuse in Disability Services (October 2015).

- d) The social and economic cost of failing to provide adequate services is reflected in the high costs of emergency and contingency accommodation of people with ASD and high support needs, the emotional toll on families and the breakdown of family relationships. There is no doubt that more effective prevention through early intervention would reduce these costs. The NDIS may provide an opportunity to achieve more early supports. However the success of prevention relies on all mainstream services also taking responsibility for achieving more accessible and improved responses to children and adults with ASD.
- e) From complaints made on behalf of children and adults with ASD it is reasonable to state that the projected demand for ASD disability services in Victoria currently exceeds supply. The supply is also complicated by variable skills, expertise and consistency required of support workers where children and adults with ASD have high support needs.

## 6. Additional Information Relevant to the Provision of Disability Services

- Attachment 1: Learning from Complaints, Occasional Paper 2, *Families and Service Providers working together: Developing policy principles and strategies to support families of adults with a disability and disability service providers to work more effectively together*. Disability Services Commissioner, 2014.
- Attachment 2: Everything you wanted to know about complaints... Disability Services Commissioner, 2013.
- Attachment 3: Good practice guide and self-audit tool: Developing an effective person-centred complaints management culture and process. Second Edition. Disability Services Commissioner, 2013.
- Attachment 4: Learning from Complaints, Occasional Paper 1, *Safeguarding people's rights to be free from abuse: Key considerations for preventing and responding to alleged staff to client abuse in disability services*. Disability Services Commissioner, 2012