



## INQUIRY INTO SERVICES FOR PEOPLE WITH AUTISM SPECTRUM DISORDER

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## ***Introduction***

The Health and Community Services Union (“HACSU”) welcome the Victorian Government’s inquiry into services for people with Autism Spectrum Disorder.

HACSU, which was first registered in 1911, is the Victorian Number 2 Branch of the Health Services Union Australia and represents the professional and industrial interests of Victoria’s Disability workforces and Nurses, Allied Health Professionals and support staff working in Mental Health services and Alcohol and Other Drug services.

All views articulated in this submission are those of the Branch and do not represent the views of the broader Health Services Union beyond the Victorian Number 2 Branch.

Our members are employed across all areas of health and community services in the public, private and not-for-profit sectors. HACSU’s main aim is to improve member’s working lives by negotiating improvements in wages and conditions and protecting workers rights.

HACSU will always campaign tirelessly for the rights, entitlements and protections of workers engaged in the health and community services sector in Victoria, no matter their employment status, employer, workplace or birthright.

HACSU exists in order to give our members a voice, and as such this submission contains many personal stories from our membership

This submission will primarily be focusing on the following:

1. The prevalence of autism spectrum disorder in Victoria.
2. The availability and adequacy of services provided by the Commonwealth, State and local governments across health, education, disability, housing, sport and employment services;
3. The adequacy of services to be provided under the National Disability Insurance Scheme (NDIS);

## **The prevalence of autism spectrum disorder in Victoria.**

As stated previously, HACSU represent many members who are engaged in both the Disability and Mental Health Sectors who care for people with autism spectrum disorder.

All recent studies that HACSU have come across reflect the comments from our members, that there is a rise in the prevalence of autism spectrum disorder in Victoria, especially since the late 1990's. Our research has indicated that this is most likely due to a change of the diagnostic criteria and an increase in public awareness.

However, in saying that, although HACSU believe that although there is a general increase in public awareness about autism spectrum disorder, there is still a general lack of awareness concerning the diversity of people with autism spectrum disorder, and where they may be on the spectrum. Our research indicates that it is more widely acceptable for children to be diagnosed with autism spectrum disorder than it is for an adult.

Our disability members predominately care for adults with autism spectrum disorder. Our members inform us that the majority of clients that they care for, have some form of autism spectrum disorder. The spectrum in the disability sector is wide and varied with some clients being very high functioning, and others who are clearly low functioning.

It is our members' experience that those high functioning clients can fall through the gap, and do not have access to the type of support they require.

## **The availability and adequacy of services provided by the Commonwealth, State and local governments across health, education, disability, housing, sport and employment services**

Many of the services provided by the Commonwealth, local governments and particularly by the State of Victoria seem to cater to the needs of children with autism spectrum disorder in a more superior way than they do for adults. For example, the Aspect Vic Positive Behaviour Support Program is funded through the Department of Human Services and is offered free to parents/carers only of children and young adults diagnosed with autism aged 6–25 years of age and living at home. The demographic for adults in the disability sector with autism spectrum disorder are adults over the age of 25 years old, and living in a Government funded, or a Not for Profit care facility, under with the care and support of our disability support members.

One member has reported her experiences that when accessing the services that do exist for adults, those people who have autism spectrum disorder, but are high functioning (such as people with Asperger's disorder), do not receive adequate support, as most of the resources go to assisting those lower on the spectrum. Our members report that the high functioning clients with autism spectrum disorder who do attend the limited services available to them do so to feel more included within society, and yet they are actually made to feel isolated within these services, as the support is directed at those who are low functioning. Our members report that clients feel lost and abandoned by the services.

Most of our members who work in Disability find that services are more accessible in metro areas, whilst those clients in rural areas seem to have less contact with services. This is most likely due to a combination of there being less services catering for adults with autism spectrum disorder in rural regions, as well as their being a lack of adequate access to transport as the vast majority of the clients who live in DHHS residents or not for profit services, do not have driver's licenses.

*A Members story:*

*I am a Disability Support Worker and sister to two siblings with diagnoses on the autism spectrum. While, according to their diagnoses, my brothers are quite close to each other "on the spectrum," their experiences of ASD could not be more different. The same can be said for their support needs.*

*One sibling observed that support services seemed to be focused on children, with little available to adults, particularly those who are high functioning yet still experience barriers to access particularly in regards to education and paid employment. Both siblings and my mother commented that services showed a lack of awareness and did not cater to the diversity of people with ASD, their varying levels of cognition, approaches to communication, socialisation, and sensory needs.*

*The sibling who has attended various social groups felt that he did not connect or identify with other members and that they seemed more affected by ASD than he was. Both my siblings reported having felt condescended or patronised by support staff.*

*One sibling is currently attached to a Job Network specialising in finding work for people with various barriers to accessing paid employment. He feels that his current JSO recommends unsuitable jobs and does not acknowledge his intelligence, aspiration, and capacity to learn new skills. He also had difficulty understanding and complying with Centrelink requirements and unknowingly incurred a debt which caused anxiety and financial instability. Further awareness and support in this regard is required for people with ASD receiving Centrelink benefits and seeking employment.*

*My mother, who lives in regional Victoria, also noted the lack of access to respite services for families, particularly in rural and remote areas.*

Amy Turton, HACSU member.

Our members who are employed in Mental Health Services across Victoria report that the services are predominately aimed at children, and those who are diagnosed during childhood, for example, the Child and Adolescent Mental Health Service (CAMHS) at the Royal Children's Hospital are skilled at assisting children, up to the age of sixteen, with social interaction skills as well as coping mechanisms.

However, once the child with autism spectrum disorder reaches the age of sixteen, they are placed in the disability sector, where our members report it is more difficult for those clients to access the services they require.

### **The adequacy of services to be provided under the National Disability Insurance Scheme (NDIS)**

The National Disability Scheme (NDIS) is supposed to be a new jointly funded program which will largely replace and allegedly enhance existing disability support services provided by the Commonwealth and the States.

The NDIS is set to fundamentally transform the disability sector. It will change the way services are funded, change the way they are provided and change the way our members work. However it is vital that the NDIS doesn't change the quality of care and support provided to the clients.

HACSU have grave concerns about the adequacy and quality of services that will be provided under the National Disability Insurance Scheme (NDIS) due to the underfunding of the scheme.

Packages under the NDIS arrangements are based on a concept of what is 'reasonable and necessary' for an individual client. It is not clear on how people with autism spectrum disorder are going to be assessed, but it is clear that there is a real possibility that these people, especially those who are high functioning, may continue to fall through the gaps and will not have the support that their particular condition requires.

Further, our concerns are that the State Government has announced that they will be contracting out parts of the disability service, despite the Labor Party Platform commitment of: *"Labor will....enhance choice and service options for people by continuing to support the existing balanced service system between direct government and non-government "not for profit" service provision and avoid further privatisation or contracting-out of existing disability services".*

Significantly, this decision reduces choice for people with a disability. Getting rid of government services will reduce choice and reduce quality by substantially removing the major service provider and leadership with a reputation for better quality services and support for people with autism spectrum disorder. It is HACSU's submission that this announcement means that the adequacy of services to be provided under the National Disability Insurance Scheme will not be sufficient for people with autism spectrum disorder.

The decision will make it even more difficult to sustain a quality workforce during NDIS implementation, with the confidence of the workforce trashed, absenteeism and retention will worsen, adding to the pile-up of structural difficulties in implementing the NDIS. This will be impacted further by the absence of a workable strategy to maintain decent wages and conditions as a consequence of the low "efficient price" to which Victorian Labor has shown no leadership in publicly arguing the issue.

The contracting out of the public disability services will mean workers will be forced into a sector, which is reliant on low minimum award wages and lesser employment conditions. Potentially, under current industrial arrangements, whilst some may be able to maintain their entitlements in the short term, they will ultimately be subject to reductions via freezes on wage and conditions.

What this means for those people with autism spectrum disorder is that the people who are delivering the services, may not be the same people every week as it will become a highly casualised workforce, and there will be no attraction for the highly qualified people to enter the sector as wages and conditions will be so low, therefore affecting the service and the care that those with autism spectrum disorder will receive.

## **Conclusion**

The decision to contract out and privatise public disability services will mean the following:

- Less choice of service providers and less capability, expertise and experience in delivering support and care to vulnerable people with high levels of behavioural support and complex needs.
- Up to 6,000 workers and services for 3,000 people with a disability to be contracted out / privatised under Victorian Labor – Public sector workers' job security, employment conditions and capacity will be trampled over time.
- Service quality will be reduced if transferred to a lower capacity and highly casualised sector
- Risk, accountability and transparency for quality and effectiveness will be undermined

This can only mean that the current issues regarding access and adequacy of services for people with autism spectrum disorder is only going to become more amplified under the NDIS. Those who are high on the autism spectrum disorder are already falling through the gaps, and will continue to do so under NDIS.

## **Recommendations**

1. That the DHHS remains a provider of services for people with autism spectrum disorder, and that the services are not contracted out to private bodies who will not provide services that are adequate.
2. More rural services need to be available to people with autism spectrum disorder.
3. More services need to be catered specially for people at different levels of the autism spectrum, in order to ensure that everyone with autism spectrum disorder is supported.

4. More services within the Mental Health system for people with autism spectrum disorder in addition to other illnesses.
5. More training and development of staff in both the Disability and Mental Health Sector to assist people who have autism spectrum disorder.

**HACSU**

**18<sup>th</sup> March 2016**