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Family and Community Development Committee



**Autism Family Support Association (AFSA)**

**Submission to**

**Parliament of Victoria**

**Family and Community Development Committee**

**Inquiry into Services for people with Autism Spectrum  
Disorder**

**April 2016**

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## **AFSA - OVERVIEW**

The purpose of the Autism Family Support Association (AFSA) is to assist and support individuals with an Autism Spectrum Disorder (ASD) by providing emotional and practical support for parents, carers and families. AFSA is an incorporated, state wide voluntary parent based support group. Through parent to parent support our aim is to improve the outcomes and quality of life for individuals with ASD and their families and carers. By supporting carers better we can help those with ASD live more fulfilling lives.

People with ASD have the same rights to social inclusion and benefits as all other citizens, but, unfortunately, they remain some of the most vulnerable in our community. As adults, they have the right to live independent and full lives of their own choosing, with the appropriate supports. It is time to eliminate the attitude that it is the responsibility of the parents of the person with ASD to remain their carer for life. As a community, it is imperative that education is provided to change attitudes towards those on the autism spectrum, with improved understanding of their unique needs and challenges. We need to promote acceptance that all people with ASD (regardless of their level of ability) deserve and have a contribution to make to society. People with ASD should have an expectation to live a good life, the same as any person would expect.

AFSA's submission seeks to represent the voice of parents, carers and families, on behalf of or together with, their loved one with ASD, and highlight some key issues from their perspective and make recommendations that we believe fall within the terms of reference.

AFSA represents the lived experience of those who love and care for those with ASD. AFSA would like to see a comprehensive, effective, appropriate and sufficient system of support and services for those with ASD. Such a system would be tailored to the different needs and abilities of people within the ASD population.

Many parents and carers are tired and "burnt out" and need more support. AFSA believes much more needs to be done to support those family members and other carers who look after those with ASD. Evidence would suggest that people with ASD are over-represented within the system as being relinquished due to lack of support and families being overwhelmed and unable to continue to cope in their caring role. Parents/carers must be appropriately consulted with and allowed input into policy development and the implementation of programs.

While it might seem unnecessarily emotive, it needs to be remembered that there are regular and often tragic reports of individuals with ASD dying through misadventure such as drownings after "absconding", or subject to restraint and violence. This is often despite heroic efforts and struggles by parents/carers to keep their children safe. In April 2015 there was a "happy ending" when an eleven-year-old boy with autism was found safe after being lost for four days, but it could easily have had a tragic outcome.

It is emotive, very emotive, as that person with ASD is somebody's child, and are a part of the diversity of being a human being ... not less than.

Sadly, there remain many reports of abuse of the disabled, including those with ASD, in supported accommodation, schools and various other areas of the system and the community. AFSA wants to see some of these bad stories turned around, by comprehensive action that involves all the stakeholders working together across all parts of the system, for the benefit of those with ASD.

AFSA played a key role in the development of the **Autism State Plan** and agrees that the Inquiry should draw on the work done in that Plan to assess how well the intent of that Plan has been carried out in Government policies and practices. In brief AFSA believes that progress has not been as good as it could be in implementing the letter and spirit of the Autism State Plan and the subsequent Disability State Plan.

AFSA has been part of a number of reference and advisory groups on disability related issues over recent years. AFSA has been in existence for 30 years and is a registered charity. Committee members provide their time and expertise on an honorary basis.

AFSA can make representatives available to address the Inquiry in person. We would include some personal testimonies and case studies of issues and concerns to support our recommendations.

## **THE COMPLEXITIES OF ASD AND THE CHALLENGE OF THE NDIS**

The Australian Advisory Board on Autism Spectrum Disorders (AABASD) in its 2013 submission on the NDIS stated that Autism Spectrum Disorder (ASD) is a complex, lifelong condition that includes severe social communication impairment and restricted interests and repetitive behaviours that substantially interfere with every-day functioning. People with ASD typically face challenges in all aspects of their life, including early childhood centres, school, tertiary education settings, work, and community contexts. They therefore require ongoing support in order to be successfully included in these mainstream settings.

The Australian Autism Advisory Board for Autism Spectrum Disorders (AABASD) maintains that reasonable and necessary supports for people with ASD must include close and ongoing collaboration between disability support services and mainstream services. It is AFSA's hope that the NDIS will show leadership in improving linkages between disability services and mainstream services, and take a lead role in the coordination of these services.

The presentation of ASD varies considerably depending on factors such as cognitive ability (IQ), personality and age. Some people with ASD have learning, sensory, and

communication difficulties. Some people with ASD may have an average or above average IQ, and acquire spoken language at the same age as typically developing children. No two individuals with ASD are the same.

People with ASD often find understanding and relating to other people challenging and anxiety provoking.

Individuals with ASD vary in their communication skills. Some may never develop language. Others might acquire simple language, whilst others will develop fluent and effective language. Some have sophisticated vocabulary and/or the ability to speak with great technical complexity on certain topics, but may still have difficulty understanding or expressing complex or abstract concepts. Sometimes their conversations may be very one-sided, and struggle with the back-and-forth nature of conversations. Some individuals with ASD have comprehension problems, often more so than suggested by their expressive language. Even the most able individuals with ASD report auditory comprehension difficulties at times at some level. Many rely heavily on visual skills to compensate for auditory comprehension problems. Some individuals with ASD may not develop speech but will be able to communicate through alternative assisted communication methods such as signing, picture exchange systems, printed word or communication devices. Some people require intensive assistance to communicate.

As pointed out by the AAARB:

It is critical that the unique and complex characteristics of ASD be considered within all elements of the design and development of the NDIS to ensure that families and individuals experience a service response that improves life outcomes. In particular, the Board has identified the following focus areas:

- The functional assessment of people with an ASD must reflect the unique nature of the disability and ensure access to services that is appropriate to these specific needs
- Families and individuals with an ASD need specific support and resources to navigate the service system
- All people and organisations delivering services to the autism spectrum community must be skilled, competent and trained in the unique supports and interventions required to ensure the best possible outcomes
- The NDIS must support a mechanism for the continued capacity building of autism expertise across Australia
- All people with an ASD in regional and remote locations must receive a level of service that is of commensurate in quantity and quality to that received in metropolitan locations.

## **RECOMMENDATIONS**

### **Recommendation #1**

#### **Improve quality and skill of staff working with people with ASD**

Work in the disability sector needs to be valued. We need to attract and retain skilled and motivated staff. The ASD population, in particular, due to their complex needs and challenges are at a greater risk of receiving inappropriate support. This can lead to abuse and neglect. High levels of staff turnover results in inconsistent levels of care and support. Consistency is so vitally necessary for ASD people who struggle with change, anxiety and difficulties communicating or conveying their needs or frustrations. The never ending requirement to explain the particular needs of the person with ASD due to constantly changing staff creates issues for all stakeholders - remaining staff, parent/carers and the ASD person themselves. This increases the stress and workload of all concerned. We need a “production line” that educates and continues to build a workforce that can adequately support people with ASD.

For the families of those with severe and complex presentations of ASD\*, finding and retaining well qualified and caring support workers remains a major worry. How can our loved ones have a good and productive life without this vital element? We have high expectations of the skills necessary, as we well should have. Most jobs and professions require appropriate skills, qualifications and training, and a level of financial remuneration commensurate with those qualifications.

\* estimated by Amaze to be approximately 25% of the total ASD population cohort

### **Recommendation #2**

#### **Restrictive Practices- Introduce Behaviour Management Strategies and Safeguards**

Education on the rights of people with disabilities should be mandatory within all areas of the disability sector. Failure to abide by these rights by any support worker, therapist, teacher or professional should require mandatory reporting, appropriate and timely action and an independent complaint system that actually works for the person with ASD.

Restraint or seclusion should not be a first resort to deal with the challenging behaviours of a person with ASD. Not only is this practice a denial of a person’s human rights it can cause serious injuries or even death. Evidence shows that restraint or seclusion does not reduce or stop the incidence of the unwanted behaviour. Understanding the ‘what’ and ‘why’ of challenging behaviours of concern is a complex issue that requires appropriate, consistent

and intense therapeutic intervention. The long term impact of the past use of restraint and seclusion on individuals with ASD must be taken into consideration – just one frightening experience can impact negatively on an individual for many years.

Experts in the field of behaviour management should be consulted and provide evidence based support plans developed from a comprehensive Functional Behaviour Analysis. A plan will assist all staff to understand what might be driving certain challenging behaviours, and inform the provision of appropriate training and support. This process should involve a multidisciplinary team of professionals with specific ASD training and expertise comprising a psychologist, an occupational therapist and a speech therapist as many people with ASD have language and communication deficits.

Recent well publicised cases in Victoria and other States highlight the need for better policies and practices to address complex and challenging behaviours.

### **Recommendation #3**

#### **Improve and support Communication Programs**

There is no adequate framework within the education, adult and accommodation services to support language and other forms of assisted communication by those with ASD who have a significant deficit in this area. The education system should provide the foundation communication building blocks for all children, including the ASD population. Literacy and communication is a basic human right, and is a basic requirement for everyone to function and be included in the community.

All people with a language deficit should have a communication assessment by a speech therapist with specific knowledge of ASD and the subsequent development of an individual communication plan. Typically, many schools do not provide this vital resource to support communication programs for students with ASD. Due to a lack of functional speech or assisted communication, many of these children with ASD develop inappropriate and difficult behaviours as their means of communication. These children are then “labelled” as being difficult and/or dangerous. There should be no excuses for this, and as a society, we should be ashamed.

The present government has legislated that teachers will be required to upskill each year to remain registered to teach and this should apply to other professionals who work with people with ASD.

Without a functional method of communication, how can children learn, be a part of the community and have a good life. This is something we all expect, so our ASD loved ones should have those same expectations. It is completely unacceptable and unlawful, given a

person's human right to communicate, in whatever form this takes, to find a person's communication is not supported by staff. It has been reported by parents of people with ASD that communication devices are left unused in bags and cupboards.

It is very unfortunate that these "labelled" children grow up, leave school, and become a member of the adult community, still "labelled." The longer their communication needs are not adequately addressed, their negative behaviours will escalate. Again, adults with ASD are disproportionately represented with "behaviours of concern", requiring high levels of support and very large funding packages. The Victorian tax payer bears the financial brunt.

Evidence suggests that intensive and consistent communication resources and behaviour management strategies for each and every ASD child with language deficits must be provided in the school system. There should be greater coordination of expertise from all allied health experts in the field to provide advice, training and assistance to both families and all providers of services.

Parents and families are an integral element in the life of the ASD person, so there must be greater choice and voice given to them in the use of communication programs. This is vital given the increase in the availability of cost effective and emerging technologies to enhance the life of those with ASD. It needs to be easier for communication aids and devices to be purchased.

Adults with ASD who have not had the opportunity of effective and quality services and support should not be forgotten. It is widely recognised that the earlier interventions are implemented, the better the result for the child. But intervention services can be implemented at any time in a person's life, and, although it may require more intensive intervention due to age and ingrained habits, adults with ASD deserve the same consideration to provide them with the opportunities for a good life. Most people with ASD will require intervention therapy at different times throughout their life, and in particular, during times of transition and periods of great change or challenge.

#### **Recommendation #4**

##### **Effective consultation and communication with parents, carers, families and people with ASD**

Victorian Government agencies like DET and DHHS need to do better at communicating clearly and collaboratively with parents, carers and families of those with ASD. One critical time when this needs to occur is during transition from one setting to another. (See our recommendation #6 on "transition".) If agencies were to listen more attentively to those that know a person with ASD the best – their families - better outcomes will be achieved in day to day care and longer term support for those with ASD.

## **Recommendation #5**

### **Advocacy services to be adequately funded, upgraded and available to all**

As we move into the implementation of the NDIS it is even more critical that the right advocacy services are there to support individuals with ASD when negotiating their care and support plans. The advocacy industry remains unregulated and it appears anyone can call themselves an advocate. This preys on the vulnerability of families, who at times are overwhelmed and desperate, due to the stresses of their caring roles.

There needs to be adequately funded advocacy services which are readily accessible with clear guidelines and adherence to a mandatory code of conduct for provision of advocacy services.

Government funding rests with a limited number of recognised advocacy services. However, most of these are mandated to be involved with systemic advocacy, which is a vitally important element for systemic changes to occur. However, many families at some point will require the services of an independent advocate to support them through their individual negotiations. There remain many obstacles within the disability service sector, including education, that seem insurmountable to many families with an ASD loved one. AFSA believes that government funded advocacy services are limited in the advocacy services they can provide. The peak ASD body in Victoria is not funded to provide individual advocacy. In the absence of individualised support, many families feel abandoned and alone, leading to carer stress, depression and PTSD. A list of service options or a brochure with website links is not an adequate advocacy support service.

Regulated advocacy and support services need to be available for parents/families from diverse backgrounds and in ALL regions of Victoria.

There are many residents with ASD in supported accommodation facilities who no longer have active family involvement to ensure the continued quality of their care, support and wellbeing. Unfortunately, not all support staff working in these facilities have the desire, or at times, the correct expertise to ensure their client's complete care. These residents with ASD are extremely vulnerable to abuse and neglect, and it is imperative that well-resourced advocacy services are provided as an independent safeguard for this group of individuals to ensure their wellbeing and proper care.

As the population of those with ASD and their families gets older, individual advocacy and related support services will be critical to the system.

## **Recommendation #6**

### **Better Transition Arrangements**

Transition from one area of services to another is a critical area needing greater support. This transition for an individual with ASD can be extremely stressful and anxiety provoking.

Some areas, in particular, which a person with ASD can find extremely challenging include moving through the education system from early intervention to school, from primary to secondary school, and then from school into the adult world; or leaving the family unit and moving into independent accommodation, either with partial or full time support.

Preparation is the key and all parties must be involved. At the present time, there appears a lack of co-ordination between the various government departments concerned, the services concerned and the family of or the person with ASD themselves. Is it a lack of funding and therefore personnel, to provide the support required with this transition process, or is it a lack of understanding of the usually complex needs of this group of people?

There needs to be more willingness by government to give support at this critical time. Sometimes, this transition process falls too heavily onto the family, who are often experiencing high levels of stress due to their everyday caring role. The nature and length of the process should be individually tailored to the needs of the person with ASD.

There are some excellent models in the aged care and mental health sectors (that might be applied to people with ASD) where multi- disciplinary teams act promptly and effectively to support the families experiencing difficulties by providing the right level of intervention and support. Why can't some of these models be applied to those with disability at critical times?

Road maps and guides for individuals and their parents/carers are necessary but they need to be supported by the services and expertise that are offered, and actually be available and helpful!

## **Recommendation #7**

### **More Responsive and Accessible Complaints Systems Needed**

We need robust complaints systems that allow for timely and thorough investigations concerning the wellbeing of people with ASD. These systems need to be comprehensive, with the right powers and resources, and the ability to investigate in both public and privately controlled services. Any recommended outcomes from such processes must be able to be implemented quickly. DHHS has an incident reporting system but this does not cover poor service delivery. There is anecdotal evidence that families are unwilling to

complain about problems with services for fear of their family member with ASD being disadvantaged. And it takes a strong, well supported family to pursue avenues of complaint, including the legal system, in the face of crowds of bureaucrats, interminable meetings and hearings and pages of regulation, policy and procedures.

## **Recommendation #8**

### **Make Schools more ASD friendly**

A part of the Autism State Plan (and the subsequent State Disability Plan) that should be focused on and evaluated is whether schools are **sufficiently ASD friendly so that all students with ASD have equal opportunity to access appropriate and inclusive education settings to reach their full potential.**

While there are one or two relatively “good news” stories sprinkled around the system, the sense is that many schools are struggling either through lack of sufficient skilled resources or finding it is “all too hard”.

The recent report by Graeme Innes to the Victorian Government on inclusion of students with disabilities in schools needs to be carefully considered by the Committee.

The recent partnership being developed between DET and the “I Can” network is a positive one. This is a welcome and positive move by DET and AFSA certainly hopes this partnership continues and expands.

Below is the web link to this organisation and the DET website:

<http://icannetwork.com.au/>

<http://www.education.vic.gov.au/about/news/archive/Pages/icanmentor.aspx>

As we understand it, the “I Can” network is involved with the mainstream school system and works with only some individuals with ASD and those diagnosed with Asperger’s Syndrome.

There are some individuals with ASD with challenging behaviours who are mostly attending the special school system, who currently do not get the support they need to be educated. There is a risk that many of these individuals in the special school system will be channelled into generic disability day services (which are typically under resourced and often provide little more than “childminding” for adults) and not given other opportunities.

Individuals with ASD have quite unique challenges and therefore require unique understanding of their view of the world and the supports required. Upskilling of the DET workforce, in particular, to these unique needs of ASD should be a priority, given that the prevalence of ASD is reportedly on the increase.

More intense therapeutic intervention should be given to all ASD children in the school system. Collaboration between therapists within the DET system and private practice is a must for the benefit of the individual. Some schools have a reluctance to embrace this collaboration. These school years, provide the building blocks to set children up for a good and productive life.

AFSA recommend that DET should be asked to report to the Committee on the educational outcomes of ASD students.

## **Recommendation #9**

### **More Accommodation/Housing and Respite**

Anecdotal evidence suggests long waiting lists for people with ASD to access appropriate accommodation. There are long waiting lists or inability to even qualify to get on the “list” or Register for government housing. Victoria is one of the States that has supported residential services and which provides accommodation for those with a disability.

There should be a priority for better models of housing suitable for people with ASD. The present models may not suit the unique challenges experienced by this group of people. Many struggle in the group home setting. More work needs to be done either by government or through government support for groups looking for clever and creative living styles to suit this group of people. Greater transparency is required on demand and supply of accommodation. While there appears to be some willingness on behalf of government and the NDIA to recognise the problem in housing AFSA urges this be a priority as the population with ASD continues to age.

There is a lack of suitable “respite” services to support families with an ASD family member, particularly for parents and families of adult children. A break for these families is vital for their wellbeing, so they can continue their caring role.

There must be better assessment services put in place to prioritise needs for housing and respite.

## **Recommendation #10**

### **ASD One Stop Shop is Needed**

There needs to be an ASD “one stop shop” in Victoria established by government that can provide help and expertise when it is needed. There are pockets of support and information but there needs to be better dissemination of existing information and greater coordination

of support. A Crisis/Hot – Line also needs to be available for parents/carers and people with ASD. DHHS should provide a well-resourced and well-funded crisis line or hotline for parents/carers and people with ASD to assist with advice in emergencies.

These services are needed to help overcome the fragmentation that is endemic in current support systems. We also need a mobile multi-disciplinary team of people with knowledge and understanding of issues for people with ASD and their families that can be deployed as needed, especially in rural and regional Victoria.

## **Recommendation #11**

### **Relevant Financial and Related Advice for Parents/Families of people with ASD**

State Trustees or other Government agencies should pro-actively seek to ensure that all parents/families of those with ASD have access to appropriate financial and other advice to ensure that powers of attorney, wills, guardianship and other arrangements are in place. Often the greatest fear of parents is “what will happen when I/we are gone?” Government can do more to provide this type of practical support that will ultimately benefit not only individuals but save the community money on avoidable expenditure around managing finances and related matters. Preparing a booklet or guidelines is not sufficient – families should to be able to speak to personnel with the knowledge and expertise to advise options that are relevant to each individual family’s needs. No two family’s circumstances are the same – as no two individuals with an ASD are the same.

## **Recommendation #12**

### **Regular Medical Reviews for people with ASD**

Many people with ASD have chronic medical conditions (eg epilepsy; food allergies; skin conditions; diabetes; hearing problems; mental health issues – anxiety, depression, mood disorders, substance abuse, OCD ). It has been estimated in earlier years that up to one third of people with ASD have epilepsy. All people with ASD who also have chronic medical conditions should be offered annual medical reviews to support the management of these conditions. Federal and State Health Departments should consider developing a voluntary database to measure the extent of treatment provided. There is anecdotal evidence from parents/carers that a number of adolescents and adults with an ASD self- medicate to help cope with their anxieties leading to significant substance abuse. This observation needs to be researched to establish the extent to which this occurs. Regular medical reviews (which

occur for residents of government supported accommodation) would also assist in the detection and management of substance abuse.

## **Recommendation #13**

### **Report Card to be produced by DHHS and DET**

A “report card” should be produced to evaluate how much of the allocated monies under aspects of the Autism State Plan and the Disability State Plan (which subsequently incorporated the Autism State Plan) were expended and how effective the spending by DHHS and DET was.

Were there progress reports on implementation of the Autism State Plan, such as the annual report to Federal Parliament on “Bridging the Gap” for Aborigines and Torres Straits Islanders? If there were progress reports these should be released.

Carers Act 2012 – what has the impact of this legislation been? The Committee should ask DHHS to comment on the practical impact of this Act and what difference it has made to the lives of carers.

Better data on the numbers of those with ASD needs to be collected, analysed and regularly updated.

### **Remember the Autism State Plan?**

AFSA played a key role in the development of the **Autism State Plan** and agrees that the Inquiry should draw on the work done in that Plan to assess how well the intent has been carried out in Government policies and practices. In brief AFSA believes that progress has not been as good as it could be in implementing the letter and spirit of the Autism State Plan (and the subsequent State Disability Plan).

As the Committee would know six priority areas were identified in the **Autism State Plan** which were to be addressed in the short, medium and longer term of the Plan’s implementation:

Those six areas were

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

**AFSA asserts that there is still a long way to go to fulfil the aspirations contained in the Autism State Plan and its successor the Disability State Plan particularly in the areas of workforce expertise and transition support.**

## **Recommendation #14**

### **Action Needed -Recent Government Reports**

AFSA would add its voice of support and endorsement of the findings and recommendations of some important recent reports. These reports highlight the need for significant changes including to the culture of various educational and other services and greater professionalism and accountability. The disability workforce needs to be well trained and properly paid to ensure sustainable service provision. All stakeholders in the system should expect and indeed see value for money in service delivery.

The Senate Report of November 2015 into violence, abuse and neglect against people with disability in institutional and residential settings highlighted some key issues.

The Senate report of January 2016 into Access to real learning: the impact of policy, funding and culture on students with disability has also set out some important issues.

We are sure that the Committee would be aware of and will take account of the Victorian Parliament Inquiry into abuse in Disability services tabled as an interim report in August 2015.

AFSA has also made a joint submission (with Amaze) in October 2015 to the Victorian Government review of the program for students with disabilities. We would commend that submission to this Committee also.

## **Recommendation #15**

### **Make it easier for those with ASD and their families and carers to access services.**

The growing numbers of adults with ASD present major challenges for the whole system. Some areas of concern are:

- **Health** - It is extremely common for people with ASD to present with a range of co morbidities which further impact on their functioning, management and progress. Some examples of co morbid conditions include intellectual disability or cognitive impairment, mood disorders, sleep disorders, depression, anxiety, epilepsy, attention deficit disorder, obsessive compulsive disorder. Despite many years of

conversation and review, Disability and Health still manage to pass individuals from one system to the other and not acknowledge that support is required from both service areas working in partnership.

- **Education** - principally in the areas of learning, communicating and social integration. The behavioural challenges of students with ASD are often misunderstood and mismanaged. There are high rates of suspension and exclusion. In TAFE Colleges and Universities, students with ASD also require a high level of guidance and support. This is especially the case for the so called high functioning individuals who despite their intellect, skills and desire to learn frequently flounder in their studies if they are unable to access their institution's disability support services.
- **Employment** – statistics show a low workforce participation by people with ASD and when they are employed it is frequently in low skilled work. Government funded generic disability employment services generally have a limited understanding of ASD. The only ASD specific employment service in Victoria was forced to close when it lost its funding from the Australian Government.
- **Legal system** - support, management, guidance for those with ASD and their families caught up in juvenile, criminal, family – including domestic violence - and civil legal proceedings. This is a somewhat hidden and rarely referred to impact of ASD on the individual and their families/carers.

There are one or two good news stories of individuals with ASD being placed in well run employment programs that uses their abilities and attention to detail. The numbers of those with ASD who are not in employment is however far too high. More needs to be done to tap into the talents that many people with ASD have to offer.

Many adults with ASD attend generic disability day services, as they are unable to participate in employment or further education. These services are typically under resourced and often provide little more than “childminding” for adults. Expectations of all the players in the system need to change so that meaningful programs involving social development, education and work can occur. Staff in these services need to have the resources to make better things happen!

## **Recommendation #16**

### **More needs to be done to address concerns on the implementation of the NDIS**

#### **Eligibility of individuals with ASD**

It has been estimated that around 105,000 of the more than 400,000 in Victoria in receipt of disability benefits will be part of the NDIS. What will this mean in practice for people with ASD? How many will, in fact, be eligible to receive the services of the NDIS? There needs to be a better understanding of what will happen in the transition – who will get less, who will get more, who will miss out, who needs assistance and will the state make up any shortfalls? The range of services involved cross the responsibilities of many government departments and agencies – state and federal. There should be an iron clad **“no disadvantage” guarantee or “grandfather” clause** for people currently in receipt of support or benefits (however adequate or otherwise they currently are) to ensure they do not get less than what they are currently receiving. NDIA and governments should clarify as soon as possible what impact, if any, the NDIS may have on various existing services. Another area that needs greater clarification is what effect there may be on payments, benefits and assistance, both to participants and their carers including disability support pensions, carers allowances and other benefits and concessions currently available. This is to ensure there are no “unintended consequences” and no reduction or loss of benefits currently provided.

**Roles and responsibilities of Victorian Government State Departments** need to be clarified as NDIS is introduced. The announcement by the Victorian State Government in December 2015 about potential outsourcing of existing service provision that may affect the management and staffing of DHHS accommodation creates uncertainty. The Committee should ask the DHHS to outline its plan for transition to the full operation of the NDIS to ensure no gaps remain in provision of its service.

#### **NDIS support for those with ASD - Transport**

Transport to and from services that is tailored to the individual needs of a person with ASD is often a critical component for the wellbeing of both client and parents/carers/family. While unaccompanied taxi travel can work for some with ASD it is not safe for others. Affordable and appropriate transport options need to be provided for people with ASD.

#### **Inclusion**

A broader conversation perhaps needs to happen within society over the “inclusion” of people with disabilities in our wider society. Many now think there should be minimal “separation” or the “channelling” of those with disabilities into discrete educational and employment programs or institutions. In education, for example, there needs to be a focus on what needs to be done to make all schools more ASD friendly.

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