



Autism Family Support Association (AFSA)

Submission to

Australian Government Department of Social Services

Discussion Paper

NDIS CODE OF CONDUCT

June 2017

AFSA Overview – who we are and who we represent

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, Victorian based 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 on the discussion paper on the NDIS Code of Conduct 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 on what is required to make the code effective.

AFSA represents the lived experience of those who love and care for those with ASD. The NDIS should be tailored to the different needs and abilities of people within the ASD population.

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.

Sadly, there remain many reports of abuse of the disabled, including those with ASD, in supported accommodation 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.

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.

Other Areas of concern for those with ASD as they enter the NDIS

The growing numbers of adults with ASD present major challenges for the whole system. Particular areas of concern that AFSA has identified 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.

Key Issues identified by AFSA that need to be considered to ensure the NDIS Code Of Conduct works effectively.

In order to ensure better lives for people with disabilities including those with ASD, AFSA believes it is imperative that there be an improvement in the quality and skill of staff working with people with ASD. Work in the disability sector needs to be valued. The NDIS Code of Conduct should hold workers and service providers accountable, but should also reflect the obligation of the NDIA to ensure training and staffing standards can be realistically met by the sector.

We wish to acknowledge the role that emergency services, disability support workers and school staff play in addition to families and parents in keeping safe those with ASD who abscond.

It is AFSA's view that the following elements of disability service provision need specific attention:

- We need to eliminate restrictive practices and introduce behaviour management strategies and safeguards.
- We need to improve and support communication programs.
- There needs to be effective consultation and communication with parents, carers, families and people with ASD.
- Advocacy services need to be adequately funded, upgraded and available to all.
- We need better transition arrangements when people move between services.
- We need a more responsive and accessible complaints system.

Analysis of Scenarios outlined in the Discussion Paper.

We consider that a number of the scenarios included in the Code of Conduct Discussion Paper need substantial modifications to highlight some of the real issues faced by those with ASD and their families. The scenarios in our view need also to contain stronger messages about the potential action that might be taken and sanctions applied by the Commission against providers who do not meet standards.

AFSA would be happy to assist in preparing new scenarios or providing further input on revised scenarios in an updated paper, based on the lived experience of our members and some of the difficulties people with ASD face in communication.

We would like to see modifications to some of the scenarios in the draft and some extra scenarios that reflect realities. These may also educate people about what will be done where problems and issues are detected.

(1) The example provided in scenario 2.1.2 is not good enough to highlight the real issues faced by many with ASD. Similarly the scenario 2.2.1 is also not good enough to spell out what should be done to rectify the problem identified.

In AFSA's view these scenarios should be expanded to refer to follow up action by the Commission to actively monitor performance of the providers and have regular reviews. These scenarios should also refer to the implementation of real sanctions against providers who fail to deliver proper services and support.

(2) A scenario should be developed with a person with a language deficit having a communication assessment by a speech therapist with specific knowledge of ASD and the subsequent development of an individual communication plan. Due to a lack of functional speech or assisted communication, many people with ASD develop inappropriate and difficult behaviours as their means of communication.

(3) Parents and families are an integral element in the life of the ASD person, so there should be recognition of their role in supporting a loved one with ASD in one or more of the scenarios.

(4) 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. Some 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. In one or more of the scenarios there should be mention of the Commission taking active steps and requiring an appropriately qualified advocate to be introduced into a situation to assist an individual with ASD to get the support they need.

(5) There should also be at least one scenario that includes transition from one service to another and the issues that can arise during this process.

(6) There should also be at least one scenario (beyond that contained in 2.7.1 where police are involved and strong sanctions taken against a provider around sexual misconduct) where police are involved over reports of violence and the interactions with the legal system that can follow for residents.

(7) There should also be at least one scenario that recognises many people with ASD have chronic medical conditions (eg epilepsy; food allergies; skin conditions; diabetes; hearing problems; ADHD; 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. A scenario could involve the Commission requiring a provider to ensure that a person with ASD who also has chronic medical conditions being 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. Regular medical reviews

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

Recent Government Reports

AFSA would add its voice of support and endorsement of the findings and recommendations of some important recent reports. The NDIS Code of Conduct Discussion Paper recognises these 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 Code and Transitional Arrangements

What will be the transitional arrangements before the NDIS Code of conduct is finalised? The paper should set out how this will work in practice for NDIS participants and their families. The paper should confirm that current State Government regimes will apply until this code is approved and in place.

NDIA Accountability

There should be annual progress reports on the operation of the Code of Conduct and the Framework generally, such as the annual report to Federal Parliament on “Bridging the Gap” for Aborigines and Torres Straits Islanders. These progress reports should be released to the public. This will help demonstrate the Commission’s commitment to properly manage complaints and ensure decisions and recommendations are followed through.

Submitted by the Autism Family Support Association Inc.

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