

COMMISSION FOR CHILDREN AND YOUNG PEOPLE

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CCYPD/16/280

Committee Secretariat
Family and Community Development Committee
Parliament House Spring Street
East Melbourne Vic 3002
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Dear Committee Secretariat Officer

Re: Inquiry into services for people with Autism Spectrum Disorder

The Commission for Children and Young People would like to thank the Family and Community Development Committee for the invitation to make a submission to the *Inquiry into services for people with Autism Spectrum Disorder*. The Commission's objective is to promote continuous improvement and innovation in policies and practices relating to the safety and wellbeing of children and young people generally, and in particular those who are vulnerable; and the provision of out of home care services for children. It is in this context that the Commission (and its predecessor, the Office of the Child Safety Commissioner) has regularly received enquiries in relation to concerns about children diagnosed with Autism Spectrum Disorder (ASD) being unable to access specific or appropriate services for their needs. The Commission and its predecessor have also participated in a range of policy initiatives in relation to the needs of children with ASD including making a submission to the *Autism State Plan 2007* and co-planning a seminar presented by the Victorian Safe Communities Network on *Children who wander: Keeping those with Autism Spectrum Disorder and/or other additional needs safe* on 29 October 2013.

Given the Commission's role, many of the issues that have been raised in relation to children with ASD have concerned access to full-time education that is flexible and responsive to their needs. Given the focus of the current inquiry and a specific theme on education and housing, it is assumed that these issues will be addressed in detail by the relevant department and service providers, and community advocates. The Commission is heartened that the recent Review of the Program for Students with Disabilities (PSD) has highlighted the difficulties for children with autism spectrum disorder and a consequent increase in funding is aimed at improving intervention services and development of a dedicated strategy for those with learning difficulties.

The need for greater focus on assisting students with disabilities to transition from primary to high school would appear to be especially relevant for children with ASD for a number of reasons. There have been suggestions of a link between ASD and precocious (early) puberty, although further research is required to explore this. Recent research by Mensah and Gordon (2013), discussed in the new literature and policy review, *One Foot in Each World: Challenges and Opportunities for Children and Young People in the Middle Years* (GSANZ, 2016), suggests that poor mental health in children may trigger the early onset of puberty, and conversely that the early onset of puberty can trigger emotional and mental health issues. This needs to be kept in mind when considering the mental health concerns that can be associated with ASD.

The transition from primary to secondary school is known to be a very sensitive period when students must rapidly adapt between two vastly different educational systems and cultures (GSANZ, 2016), moving from a smaller, generally protective environment with a single, key teacher, to a much larger environment which must be moved around within every day, punctuated by dealings with many



teachers. For children with ASD, who find adapting to change extremely difficult, transition to secondary school would seem to present a 'perfect storm' of these factors combining, creating high risk for educational disengagement and the need for focus on tailored intensive support.

Although the stressors on families of children with disabilities are well known, and the situation of parents in extreme distress voluntarily placing their disabled child in out of home care were well described in the landmark report, *Desperate measures: The relinquishment of children with disability into state care in Victoria* (VEOHRC, 2012), little is known about the prevalence of ASD in the population of children and young people in out of home care generally. However, it would seem likely that children with disabilities, including those with ASD are likely to be over-represented and possibly not formally diagnosed. When a child has a family environment where abuse and neglect have been sufficiently serious to lead to placement in out of home care, it may be difficult to disentangle the impacts of trauma and underlying ASD in behavioural functioning. We know that well-functioning families find it difficult to navigate the service system to ensure their children receive timely and adequate support from education, health and other services, and these are families that strongly advocate for their children leading to formal diagnosis and eligibility for the services and programs available. But children in the out of home care system largely lack this individual advocacy when the state is their guardian, to ensure that health assessments are completed intensive support is regularly accessed from government services, as starkly demonstrated in the Commission's recent inquiry report, "...as a good parent would..." (CCYP, 2015).

The Commission's work on *Taskforce 1000* would suggest that Aboriginal children and young people in out of home care may be even more over-represented amongst the cohort of children with disabilities including ASD, but for whom a formal diagnosis has not been made. The Commission has raised with the Department of Health and Human Services (DHHS) the needs of Aboriginal children with a disability in out of home care, including the needs for their foster carers or kinship carers to have training and support in relation to the child's disability and the disability sector, as well as timely access to early intervention and support packages. Community members with disabilities, carers, Elders and community advocates are also concerned about the cultural safety and wellbeing of Aboriginal children and young people with a disability who are living in out of home care. The Commission is also aware of work done by services such as the Rumbalara Autism Support group, with the Aboriginal Commissioner for Children and Young People attending the launch of the children's picture book, *Djambi - The Different Kookaburra*, which was the result of a collaboration between Positive Partnerships and the Rumbalara Aboriginal Corporation. The story is about the adventures of the Jones family and how each family member's talents contribute to the family's success (CCYP Annual Report 2014-2015).

Sexual Behaviour Problems

Since early in its inception as the former Office of the Child Safety Commissioner (OCSC), the Commission has been aware of the emergence of children with ASD amongst the population of children and young people being treated for sexual behaviour problems, and this continues to be an issue of significance. A decade ago, on 20 March 2006, Dr Howard Bath (later to become the Northern Territory Children's Commissioner) and Dr Jenny Howell presented a full day seminar on *Asperger's Syndrome and Sexual Behaviour Problems*. They spoke about the diagnostic and clinical issues including co-occurring conditions and misdiagnoses, prevalence rates for normative and forensic populations and explored reasons for the apparently increased risk of sexual behaviour problems. The features of a sample of 28 young people with ASD who had sexually abused others were discussed and principles for effective intervention based on research and clinical experience were explored. The need to establish supportive community networks to maintain new and safe patterns of behaviour was emphasised, along with the need for clarity and consistency from all adults involved in their lives, which has important implications for service delivery.

In reflecting upon the Terms of Reference of this Inquiry, it would seem instructive to consider the current status of a sample of this population given their specific needs highlight the challenges for

integration of service provision in education, disability support, health, community services and youth justice to support children and young people with ASD.

Prevalence

The AWARE Program conducted at SECASA (South East Centre Against Sexual Assault) provides assessment and treatment of sexually abusive behaviour and problem sexual behaviour of children and young people aged up to 17 years. A review of the AWARE program's client data demonstrates that of the 91 clients in total, 14 were presenting with ASD (strong evidence and diagnosed) and three were strongly queried as having ASD, giving a prevalence rate of 18.5% of this client population, equivalent to the rate of 18.5% presenting with an intellectual disability. In comparison, over the previous nine months, the Gatehouse Centre has had a referral rate of 58 clients formally diagnosed with ASD from a total of 968 referrals, indicating a prevalence rate of 6% amongst referrals. This agency was already providing a service to 81 clients with a formal diagnosis of ASD out of a total of 1,338 clients in the past year. These figures suggest that 6.05% of all clients receiving a therapeutic service from the Gatehouse Centre in the past 12 months had a formal diagnosis of ASD, indicating consistency in the rate amongst referrals compared to the previous year. It is also noted that 1-2% of clients of this service exhibit traits of ASD, but have not had this diagnosis formally confirmed. Clinicians report that many parents of these children are not formally diagnosed with ASD, but exhibit behavioural traits of such a diagnosis, which has a significant and at times detrimental impact upon their parenting.

Service Provision

Education, family and social supports are the services most critical for the client population of children and young people with ASD who have problem sexual behaviour or demonstrate sexually abusive behaviour. This makes sense when the key clinical symptoms of ASD are considered as:

- Deficits in social behaviour
- Abnormalities in language
- Delays in cognition
- Restricted and repetitive interests

The intense nature of the work required can be seen in *Sam's story – a child's perspective of therapeutic treatment* (Attachment 1).

Educational Aides

Echoing the recommendations of Bath and Howell (2006), clinicians currently argue that the provision of aide time is crucial to allow individuals with ASD to develop their skills across all these areas. They find that clients in mainstream primary and secondary schools do not have the aide time available to teach skills in these very important areas.

Social Skills Development

In particular, social skills deficits are key in their client presentations. There is a dearth of affordable (ie. not fee for service) social skills development programs for children and adolescents with ASD. Clinicians would like to recommend that youth groups in local government areas with skilled ASD trained facilitators would provide opportunities for "normal" adolescent social experiences. The clinicians also report that the adolescent with ASD sees their higher functioning siblings going off to social functions with friends, causing them to have lower self-esteem and the build-up of resentment between siblings. The adolescent with ASD needs the opportunity to practice experientially with support given the way that they learn about social rules and obligations. There is the need for these opportunities to be provided in a safe way for them.

Support for Families

Clinicians report that many of the families they see have multiple siblings with ASD. This makes it very difficult in running a household that caters for the needs of multiple family members, including those with ASD, as it places enormous emotional and financial stress upon the family. Due to the nature of

ASD, many of the children and young people concerned do not cope well with the change to routines or the people and environments they may interface with. The siblings who do not have ASD often report that they also become highly stressed, as family outings are frequently cancelled as the child or adolescent with ASD is unable to manage the intensity of an activity or environment. It is not unusual for these siblings to report feeling unsupported, as families struggle to balance the needs of all of their children, which is exacerbated when there is a need for parents to attend multiple meetings with paediatricians and schools, etc. It is therefore proposed that support/activity groups for siblings of children with ASD, potentially using the CANTEEN model for siblings of children with cancer, would be of great benefit.

Outside School Hours Care

In addition to childcare options which understand the needs and are skilled in the provision of care for young children with ASD, there is also a need for greater accessibility to affordable after school and school holiday program options for those families lacking adequate family support. Young people in secondary school settings also continue to need such support, which is currently not available unless paid for privately.

Parent Education

Parents who have ASD also have high needs in terms of understanding and managing their own behaviour and responses in the context of parenting their children and adolescents. Thus parenting programs for parents with ASD (many of whom are undiagnosed), would be highly beneficial.

Out of Home Care

In the event that a child is removed from their family, children and young people with ASD placed in out of home care through Child Protection do very poorly. They are perceived to be the most vulnerable of the vulnerable, given that the staffing models, client mixes, environments and the expectations placed upon these children and young people to take too much responsibility for themselves will fail them significantly. Although accurate numbers of young people with ASD within the youth justice or prison populations is unknown, the strong likelihood is that they will be over represented.

Adequacy of NDIS Services

The Commission is aware of concerns amongst those clinicians providing behavioural therapy for those families with children and adolescents with ASD and/or Intellectual Disability, that at face value the services to be provided by the NDIS would be more limited than those available under the previous Disability Services umbrella. In contrast, the NDIS would appear to offer greater support to those people with high physical support needs rather than those with behavioural difficulties.

Social and Economic Costs

The failure to provide adequate services for those children and young people with ASD has both serious social and economic costs for the individual, their family and the broader community. Young people with ASD are over-represented both within the population of children and adolescents who have been sexually abused and among those who exhibit problematic and harmful sexual behaviour. Whilst it is not always the case, the experience of sexual abuse may predate the exhibition of problem sexual behaviour or harmful sexual behaviour, due to those with ASD having an increased propensity to mimic/develop obsessional and repetitive behaviour in the context of high anxiety. Highly sensory in nature, they are vulnerable to repeating sexual stimulation which happened to them in the context of sexual abuse, both towards themselves and others. The Gatehouse data discussed above includes both populations as referred to Gatehouse. The failure to provide a range of accessible and affordable therapeutic and social and family support programs for these children, adolescents and families, are predicted to result in:

- A heightened sense of failure for all members of the family, included diminished capacity for meaningful family relationships

- Low expectations both for and by children and young people with ASD to achieve to the best of their potential
- Increased episodes of mental health conditions such as anxiety disorders and depression in these young people and their siblings, placing increased stress upon the child and adolescent mental health system
- Family breakdown/dysfunction, including increasing numbers of children relinquished into out of home care
- Entrenched patterns of behaviour that are harmful to themselves or others

Projected Service Demand

On the basis of expected figures that 1-2% of the population will have ASD, there would be a predicted exponential increase in service demand. The Gatehouse Centre alone has figures consistently close to 6%. Therefore it would be expected that the demand for services would continue to increase in line with this projection.

A decade ago, Howard Bath provided a case example that starkly highlighted the necessity for informed and skilled education provision. The boy's father had asked him to do the dishes, and then threw him across the room for "having a lend of me". His son had only washed the plates, and left the cups and cutlery. The vital role of skilful intervention in preventing abuse and family breakdown is clear.

If you would like to discuss further any of the issues raised in this submission, please contact Dr Virginia Dods, Senior Policy Adviser at the Commission on 8601 5285 or at Virginia.Dods@ccyp.vic.gov.au

Yours sincerely



Liana Buchanan
Principal Commissioner

References

Bath, H. and Howell, J. (2006). *Asperger's Syndrome and Sexual Behaviour Problems*, ANZATSA seminar presentation, 20 March 2006.

Commission for Children and Young People (2015). *"...as a good parent would...": Inquiry into the adequacy of the provision of residential care services to Victorian children and young people who have been subjected to sexual abuse or sexual exploitation whilst residing in residential care*, Victorian Government.

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McGuire, M. (2016). *One foot in each world: Challenges and opportunities for children and young people in the middle years*, Good Shepherd Australia and New Zealand (GSANZ), April 2016.

Mensah, F. and Patton, G. (2013). *Growing up too fast: Early puberty and mental illness*, The Conversation, 3 April 2013.

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Sam's story – a child's perspective of therapeutic treatment

Three weeks after Child Protection commenced their involvement with 11-year-old Sam, the Therapeutic Treatment Board agreed with Child Protection's recommendation that Sam be placed on a therapeutic treatment order.

A best interests case plan was developed with all the professionals involved and the parents participating in the decisions that were made.

Throughout the life of the therapeutic treatment order, Child Protection and the Sexually Abusive Behaviours Treatment Service maintained regular contact, ensuring the case plan was implemented, reviewed and updated as required. Sam's parents commented that although the process was stressful they appreciated being kept informed of what was occurring at all times and being involved in the process.

Sam was formally diagnosed with a learning disability. This meant that, while his clinicians were able to follow the usual program guidelines, adaptations and modifications were made to suit Sam's specific needs. These focused on using his particular strengths.

Sam is a gifted storyteller and artist. Here is Sam's story told by him.

***I am Sam.** I am the same as other kids but I have a learning disability. This means that I have a different way of thinking, seeing, hearing and doing things. Well, my type of character is like a more mental one. Let's just say I like to do things (in my point of view) logically, unlike the lazy-minded people who go for the easy stuff. I like to do different things, like in a project [I did for school] – you have a range of different categories of the human body, and all but two of the class chose the digestive and the skeletal system. HOW BORING! I chose the circulatory system. I dislike being told what to do, but I love having the last word. I would say I like the stage more than sports, but I do like sport. I like to collect things and I love LEGO!*



Worry and anxiety

The most frustrating thing is having a sudden change from routine. Not knowing what will happen next and all the time the anxiety is saying: Am I going to let the team down?

I worry a lot:

- *about school tests*
- *about coming home and getting told off for something I don't remember doing*
- *that things are going to go wrong.*

I know when I am anxious because my brain gets busy trying to sort everything out.

Sam's Band of Angels

Sam chose to have a band of angels to help him understand his good and bad sides, and to help him make good choices.

My Good Angel is the one that helps me in choices with the Bad Angel and helps me decide on the right answer. My Good Angel is always at my side to help me make decisions.

My Confidence Angel is nice and big. The trident is to get rid of bad feelings and to gain confidence. The trident is used only for good and always gets rid of evil!

My Bad Angel makes the wrong decisions all the time but he is hardly ever around anymore. He keeps getting knocked out by the other Angels. He is the one that is always trying to rebel against the Good Angels.

My Stupid Angel sometimes he sits on top of my head and gets me into trouble. This one gets wrecked in almost every situation possible. This guy can't even fly straight! He just makes plain old dumb choices.

My Good Angel and the Confidence Angel work together to defeat the Bad and Stupid Angels.

The Good, the Bad and Me

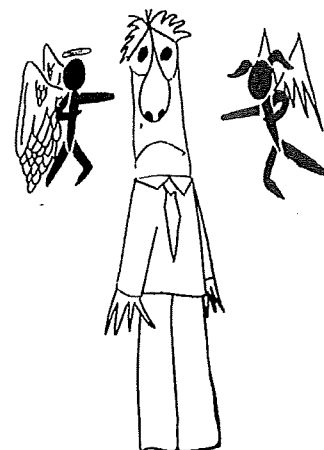
This is me with the Good and the Bad Angel, Each one is telling me what to do. Who will win?

The **Good Angel** most definitely, because what good are you going to get out of that? Seriously, **HAVE A THINK!**

Bye Bye Trouble

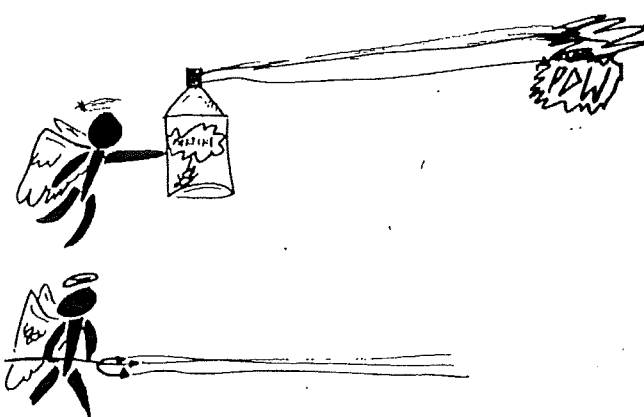
The Good and the Confidence Angels grow and work together to get rid of the Bad and Stupid Angels. Life is tough for the red team.

GET USED TO IT!



BYE BYE
TROUBLE!

NOT
AGAIN!



Making choices

STOP – what you are about to do.

THINK – about what would happen afterwards.

DO – listen to the Good Angels and make good choices.

Some of the things that trigger me are:

- *not being able to understand my friends*
- *being told NO.*

Sometimes when people ask me to do things I have trouble understanding what they mean but I care about people and now I care about other people's feelings.

In the past year, our journey together has brought a lot of fun. For instance, handball and the illustrations, but it has brought a few challenges too. But the main thing is the change. That is the most important thing. I now have an advantage in some things. I feel that I have come a long way through the year, although the year has gone so fast. I thank everyone for their contribution and help, especially Jenny. Goodbye now.

Sam and Jenny (Sam's clinician)

At the completion of the therapeutic treatment order, Sam had successfully completed his treatment and his parents, therapists and Child Protection practitioners were extremely pleased with his progress. His parents have grown more attuned to his needs for support, boundaries and supervision and Sam's sexually abusive behaviors have ceased. His school teachers are relieved and commented on the remarkable changes in Sam and the positive social skills he has learned.

