

Australian Senate Select Committee on Autism

SUBMISSION

Positive Youth Incorporated

Executive summary

This submission draws on **positive youth development** (PYD) theory and practice to frame proposals for change. PYD is a strengths-based approach that emphasises the role of communities and relationships in guiding the development of young people. The focus of the submission is on young people aged between 10 and 16 years old who are justice- or near-justice involved, and who have been, or who ought to have been, diagnosed with ASD.

Positive Youth Incorporated is a not-for-profit organisation that works with justice- and near-justice involved young people aged between 11 and 26 years old exclusively on the basis of PYD.

The submission addresses several of the terms of reference, and outlines the following proposals for change:

- That families and significant others ought to be included in wraparound service teams that are designed to support young people with ASD.
- That schools ought to design programs based on PYD theory and practice to provide individualised support to young people with ASD, and that these programs ought to include families and significant others, and be designed to improve school engagement.
- That programs and services based on PYD ought to be designed and implemented specifically for young people with autism.

Introduction

Positive Youth Incorporated

Positive Youth Incorporated (Positive Youth) is a Canberra-based not-for-profit organisation. Incorporated in 2019, Positive Youth aims to work with justice- and near-justice involved young people aged between 11 and 26 years old. Positive Youth's programs and services are based on positive youth development (PYD) theory and practice. As such, Positive Youth's programs and services are strengths-based and aim to support young people to identify their strengths and make deep and lasting personal change. Positive Youth's focus goes beyond interventions that aim to exclusively address risk. Rather, Positive Youth focuses on prioritising young people's individual attributes, skills and competencies. Positive Youth is committed to the idea that community is vital to enabling personal change to occur, and that young people should be supported to participate in decisions that affect them.

This submission was co-authored by Talyor Heslington while undertaking an ANU College of Law internship with Positive Youth Incorporated.

Focus of the submission

The focus of the submission is justice- or near-justice involved young people aged between 10 and 16 years old who have been, or who ought to have been, diagnosed with ASD. When we say 'ought to have been', we are referring to young people who demonstrate behaviours consistent with an ASD diagnosis, but who have not completed an ASD assessment that has led to a diagnosis. Reasons why young people with certain challenging behaviours may not have completed an ASD assessment include misinterpretation of challenging behaviours ('she's just a naughty kid'), limited access to information about ASD, limited access to resources, long wait times for publicly-funded psychologists, poor past experiences with the public health system, and inattentive adults who ought to be making referrals, such as GPs and teachers. We define 'justice-involved' to mean young people under a juvenile justice order in a State or Territory of Australia. We define 'near-justice involved' to mean young people at risk of involvement with the juvenile justice system.

Positive youth development

PYD focuses on strengths that enable young people to succeed in life, rather than on risk-taking behaviours (Benson et al. 2006). This strengths-based approach envisions young people as resources, rather than problems (Damon 2004). PYD recognises that young people are embedded in developmental contexts, which include their peer group, school and family (Benson et al. 2006). PYD acknowledges that young people actively engage with these contexts, which have the potential to guide their development (Benson et al. 2006). Thus, young people can be active partners with their communities, giving them a set of rights and responsibilities therein (Damon 2004). Positive development occurs when young people are given the opportunity to participate in communities that enable their development (Benson et al. 2006).

Positive Youth exists because of a belief that young people who have done harm, and to whom harm has been done, can positively transform through discovery of their strengths and connection to their community.

Noting that young people with autism – diagnosed or otherwise – are overrepresented in the juvenile justice system, Positive Youth suggests that PYD programs and services ought to be designed and implemented specifically for young people with autism. Positive Youth also suggests that any such programs and services must enable young people to discover and leverage their strengths, and must emphasise young peoples' relationships with their families and communities, which must be strengthened.

Terms of Reference

(a) Current approaches and barriers to consistent, timely and best practice autism diagnosis

Early diagnosis of ASD is essential, as it enables children to receive effective help at an early age. The earlier that children are diagnosed with ASD, the earlier they are able to access early intervention programs, which have the best opportunity of providing developmental benefits

when children are young and have a higher degree of brain plasticity (Bent, Dissanayake & Barbaro 2015). The age of diagnosis can impact outcomes as children reach school age. In fact, research has demonstrated that children diagnosed before three years of age have better cognitive abilities at school age, when compared to children who are diagnosed between 3 and 5 years of age (Clark et al. 2018).

Despite the positive outcomes that early intervention can have, studies have found that ASD diagnosis is often delayed until children are at least three years old (Bent, Dissanayake & Barbaro 2015; Clark et al. 2018). However, as the Committee will no doubt hear, it is the experience of many parents of children with autism that such diagnosis does not come until the early primary school years at least. For families with children who are at risk of coming into contact with the juvenile justice system, sometimes diagnosis does not come at all.

Diagnosis is influenced by individual and social factors that exist at the family and community level (Fountain, King & Bearman 2011). One of the social factors that can impact the age of diagnosis is the socioeconomic status of the family seeking a diagnosis. A number of studies have highlighted that delayed diagnosis often occurs among low SES families, in under-resourced areas, and among families with lower levels of parental education (Daniels & Mandell 2014; Fountain, King & Bearman 2011). Information about child development and ASD is often passed on to families through contact with health services. If families do not have the resources to access these services, they may not obtain the information necessary to alert them to the fact that their child's behaviours may point to ASD (Fountain, King & Bearman 2011).

Once signs of ASD have been identified by families, the significant costs of the process to obtain a diagnosis can impact the time it takes for their child to receive a diagnosis. Best practice for ASD diagnosis involves several health professionals, including at minimum a speech therapist, a paediatrician or child psychiatrist, and a psychologist (Parliament of Victoria 2017). The need for a multidisciplinary diagnosis can create significant barriers for families trying to source a diagnosis, including long wait lists through the public system, and the high costs of obtaining a private diagnosis if families do not want to wait for a public diagnosis (Parliament of Victoria 2017).

In summary, a significant barrier to early diagnosis is socioeconomic status. Our interest in the relevance of socioeconomic status to diagnosis of ASD is that low socioeconomic status is a risk factor among some justice- and near-justice involved young people. This means that a lot of children and young people either end up involved with the justice system because their ASD is undiagnosed, or end up not receiving useful, high quality interventions for their ASD after they become involved with the justice system, thus potentially exacerbating – and in some cases, deepening – their engagement with that system, as discussed below. **Targeted resources ought to be directed at low SES families to support early diagnosis of ASD.**

(f) The interaction between services provided by the Commonwealth, state and local governments, including: health and mental health; education; employment; justice; and housing

The interaction between services is of serious importance for justice- and near-justice involved young people with ASD because of the consequences when these services fail to support them. As the United Kingdom's Joint Committee on Human Rights (2019, p. 14) stated, the detention of young people 'is usually the result of a long and predictable series of failures to appropriately support them and their family'.

ASD is one of the most commonly diagnosed conditions among young people in juvenile detention in Australia (Australian Government, 2017). Complex issues that can influence the likelihood of contact with the juvenile justice system include a poor experience in the education system, poor housing circumstances, limited family resources and a lack of access to disability services (Dowse et al. 2014). Reports have also shown that a late diagnosis is associated with a higher risk of offending (Rutten, Vermeiren & Nieuwenhuizen 2017).

There is a lack of integration of services across all levels of government, both for people with ASD and families supporting children with ASD (Parliament of Victoria 2017). Individual services may be able to respond to particular needs of a child with ASD, but a lack of coordination between these services can mean that complex issues that require a multidisciplinary approach will not be effectively addressed (Dowse et al. 2014). When there is poor coordination across education, welfare and justice systems, responsibility for addressing these problems often ends up falling to the juvenile justice system (Dowse et al. 2014). Juvenile detention is far from beneficial for young people, and does not address the issues that led them to offend in the first place (Australian Government 2017). Improving the interaction between services is necessary to prevent involvement with the juvenile justice system, and to address the complex issues of disadvantage that justice- and near-justice involved young people with ASD experience.

To improve the interaction between services, the implementation of wraparound services designed on the basis of PYD principles could be established in selected pilot sites across Australia.

Typically, a wraparound service involves a team-based approach that provides care for young people with complex needs (Strnadova, Cumming & Lee 2019). Individuals are brought together from different organisations, including from the education, health, housing and justice sectors, to collaborate in a way that meets the young person's needs (Dowse et al. 2014). Such services ought to be individualised and focused on the young person's strengths and what the young person and their family need (Strnadova, Cumming & Lee 2019).

A 2019 report from the Gonski Institute for Education examined the state of wraparound services in New South Wales. Generally, wraparound services were only vaguely described, and education providers were not reported to engage in interagency collaboration as a matter of course (Strnadova, Cumming & Lee 2019). Wraparound models were found to be used in some schools, but they were typically used by not-for-profit organisations (Strnadova, Cumming & Lee 2019).

In fact, what the report reveals is that wraparound services need better articulation when they are used to support children and young people.

On the basis that they bring different people and services together, we suggest that the application of wraparound services to support children and young people with autism merits consideration, especially if they are designed and implemented on the basis of PYD principles and practice.

(g) The social and economic cost of failing to provide adequate and appropriate services, including to support key life stage transitions of autistic people

A key life stage transition for young people with ASD is the transition from primary school to secondary school. Support during this transition is crucial because disengagement from school is a factor that can lead to involvement with the juvenile justice system (Dowse et al. 2014). Research highlights that young people who participate in school have an increased sense of school belonging, and the formation of peer bonds can decrease the likelihood of offending (Curran & Wexler 2017).

Failure to engage justice- and near-justice involved young people with ASD in school transitions, especially young people who experience risk factors such as low socioeconomic status, or who have not yet received a diagnosis, will place them at higher risk of involvement with the juvenile justice system.

Entering secondary school is a significant challenge for young people with ASD (Mandy et al. 2016). There are many changes in the environment, including changes in peer culture, relationships with adults, and expectations for social success (Carter et al. 2014). The success of this transition depends on a student's ability to change their behaviour to align with the expectations of both their teachers and peers (Carter et al. 2014). This can be difficult for young people with ASD, as they may have difficulties with skills such as socialising, regulation of emotions, and flexibility (Mandy et al. 2016).

There is evidence to suggest that Australian schools are currently not equipped to ensure that the needs of students with ASD are being met. The Parliament of Victoria's *Inquiry into Services for People with Autism Spectrum Disorder* (2017, p. 185) noted that 'mainstream schools are not commonly providing an inclusive model of education that would encourage parents of ASD to enrol their child'. Also, a survey by Autism CRC of parents of school-aged children with ASD indicated that parents did not highly rate the approaches taken by schools in relation to their children, and only slightly agreed that schools were responsive to the needs of their children (Saggers et al. 2018).

Maintaining school connection for justice- or near-justice involved young people with ASD is a challenge. Autism CRC's survey revealed that students with autism had low levels of connection to their schools, and that mechanisms such as peer education, school community education and curriculum adjustments should be utilised to enhance school connectedness (Saggers et al. 2018).

The transition from primary to secondary school is just one example of a critical point at which young people with ASD need to receive improved support. Other transitions that will not be explored in this submission, but that should be considered in this context, include the transition between living arrangements for young people who live in out-of-home care and the transition from juvenile detention back to the community.

(k) The social inclusion and participation of autistic people within the economy and community

Both young people and adults with ASD face challenges that prevent them from participating in the economy and community. The Parliament of Victoria's *Inquiry into Services for People with Autism Spectrum Disorder* (2017, p. 332) noted that 'people with ASD and their families have frequently been isolated, marginalised and excluded from the community'.

Research has shown that fifty percent of adults with ASD have poor participation outcomes for friendship (Krieger et al. 2018). Focusing on the participation of young people in the community may lead to more successful participation outcomes in adulthood, as patterns of action for participation are learnt in adolescence (Krieger et al. 2018).

Regarding employment, a low number of adults with ASD are in paid work (Gray et al. 2014). A longitudinal study of 119 individuals in New South Wales and Victoria revealed that although 99 percent of the participants were engaged in a daytime activity, only 18 percent were in paid employment (Gray et al. 2014).

Socially and economically, people with ASD are often excluded from the community.

PYD emphasises the importance of community because communities can have a positive influence on guiding the development of young people.

PYD-based initiatives for justice- and near-justice involved young people diagnosed with ASD may promote the formation of valuable connections that strengthen neighbourhood support (Bazemore & Terry 1997), thus leading to better outcomes for individuals with ASD when they reach adulthood.

Harnessing positive youth development

This section addresses how PYD theory and practice may be harnessed for the benefit of justice- and near-justice involved young people diagnosed with (or who ought to be diagnosed with) autism. It sets out how some of the issues noted above can be addressed, and provides several ideas for further consideration.

Proposal for change: Incorporating both formal and informal supports into wraparound services

Integrating the PYD principle of connecting young people to their communities into wraparound services (Benson et al. 2006) could provide more effective support for justice- and near-justice involved young people with ASD. This could be achieved by involving families and significant

others in wraparound teams. For example, when it comes to ensuring the needs of students with ASD are being identified and met, education research has demonstrated the importance of incorporating different perspectives from parents, specialists and educators (Saggers et al. 2019). This suggests that teams that incorporate formal supports (education, health, housing and the juvenile justice system), and informal supports (family and influential members of the community), has the potential to create a holistic wraparound approach that more effectively addresses the needs of young people with ASD.

This community wraparound model could address some of the issues with diagnoses highlighted above by improving communication between the people involved in assessing the developmental needs of young people. A wraparound model that brings in families and important community figures has the potential to establish a partnership between a young person and their community. Thus, incorporating community supports into wraparound teams could create stronger, more connected, and more relevant supports for justice- and near-justice involved young people with ASD, preventing them from falling through the cracks and becoming involved with the juvenile justice system.

Proposal for change: Focusing on engagement in schools

As highlighted above, schools provide a crucial point at which support should be provided to justice- and near-justice involved young people with ASD. Support can be provided through the implementation of programs that aim to improve engagement with school and prevent contact with the juvenile justice system. In some places, PYD underpins a broad range of school-based programs that support young people by improving protective factors, including interaction with caring adults and pro-social peer networks (Curran & Wexler 2017). Research into existing programs has revealed the elements of the most effective PYD programs (Schulman & Davies 2007). Such programs must:

- be universally applicable to the health progression of all young people through adolescence, and be strengths-based;
- be structured, through both the program itself, and the extent to which the program is informed by the developmental trajectory of adolescents; and
- ensure the process of the program is linked to its environment and outcomes by interacting with other aspects of young peoples' lives (e.g. improving relationships, opportunities and supports) (Schulman & Davies 2007).

Incorporating these elements into school programs aimed at supporting justice- and near-justice involved young people with ASD has the potential to improve engagement with school. Indeed, studies have suggested that a whole-of-school approach can improve outcomes for students with ASD (Webster & Roberts 2014; Saggers et al. 2019).

Positive Youth suggests that PYD provides an ideal framework for a whole-of-school approach. Schools should be supported to develop their own whole-of-school approaches that are tailored to support individual students through PYD programs that are designed on the basis of the research-supported elements outlined above.

Conclusion

Positive Youth suggests that services and programs underpinned by PYD theory and practice will improve ongoing support for justice- and near-justice involved young people who have been diagnosed with, or who ought to be diagnosed with, ASD.

Young people with ASD who are exposed to social, emotional, developmental and financial risk factors, including low socioeconomic status, are at heightened risk of engagement with the juvenile justice system.

On the basis of the defining elements of positive youth development theory and practice, Positive Youth recommends the following proposals to the Committee:

- That families and significant others ought to be included in wraparound service teams that are designed to support young people with ASD.
- That schools ought to design programs based on PYD theory and practice to provide individualised support to young people with ASD, and that these programs ought to include families and significant others, and be designed to improve school engagement.
- That programs and services based on PYD ought to be designed and implemented specifically for young people with autism.

We must do better by these young people, and addressing the issues highlighted in this submission is a place to start.

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