



FETAL ALCOHOL SPECTRUM DISORDER ISSUES REVIEW REPORT 2021

A SUBMISSION TO THE ROYAL COMMISSION INTO VIOLENCE, ABUSE, NEGLECT AND EXPLOITATION OF PEOPLE WITH DISABILITY

NOFASD Australia

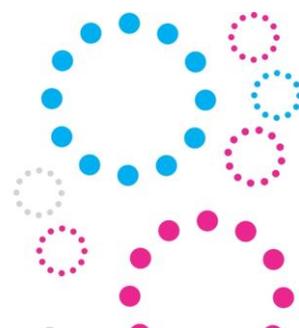
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Fetal Alcohol Spectrum Disorder Issues Review Report 2021

A Submission to the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability

Fetal Alcohol Spectrum Disorder: A Hidden Disability

Fetal Alcohol Spectrum Disorder (FASD) is a diagnostic term used to describe impacts on the brain and body of individuals prenatally exposed to alcohol. FASD is a lifelong disability. Individuals with FASD will experience some degree of challenges in their daily living, and may need support with motor skills, physical health, learning, memory, attention, communication, emotional regulation, and social skills to reach their full potential. Each individual with FASD is unique and has areas of both strengths and challenges.

FASD is a condition that is an outcome of parents either not being aware of the dangers of alcohol use when pregnant or planning a pregnancy, or not being supported to stay healthy and strong during pregnancy. Alcohol can cause damage to the unborn child at any time during pregnancy, even before a pregnancy has been confirmed. The level of harm is dependent on a wide range of factors, making it impossible to predict the outcome of alcohol exposure to any individual pregnancy. Factors include the amount and frequency of alcohol use, parent age, health of the mother (including nutrition, tobacco and other drugs and mental health) and environmental factors such as stress.

NOFASD Australia

NOFASD Australia is the national peak body for parents, carers and individuals impacted by Fetal Alcohol Spectrum Disorder (FASD). Founded by volunteers in 1999 and now funded by the Commonwealth Department of Health, NOFASD provides the essential bridge linking those with lived experience with researchers and clinicians. Our mission is to be a strong and effective voice for individuals and families living with FASD, while supporting initiatives across Australia to promote prevention, diagnosis, intervention and management.

NOFASD Australia operates a helpline for people impacted by FASD. Helpline staff provide information, advice, referrals and support to individuals with FASD and their families. NOFASD maintains an up-to-date comprehensive website with curated resources and shares valuable information to almost 6,000 followers on NOFASD's social media platforms (Facebook, Instagram, Twitter and LinkedIn).

This report provides an overview of how individuals with FASD are impacted by areas of concern raised in The Royal Commission (RC) Issues Papers published between 2019-2020. Included in this report are summaries of empirical research and anecdotal evidence in the form of personal submissions.

Issues Review

Education and Learning

The Education and Learning Issues Paper (Royal Commission [RC], 2019a) listed concerns impacting individuals with a disability as they progress through the education system. Core issues included access to education and the appropriateness and adaptability of education and learning (RC, 2019a). The Issues Paper aimed to consider the extent to which violence, abuse, neglect and exploitation of people with disability occurs within education and learning settings.

Canadian research suggests that there are higher numbers of students with FASD than has been reported, as FASD is likely to be under-diagnosed (Millar et al., 2017). Individuals with FASD may have IQs in the normal domain range and may look not dissimilar from other students, therefore making it difficult to identify students with the disability (Millar et al., 2017). Often, students with FASD may present as ‘naughty’. This is particularly the case when classroom behaviour reflects FASD impairments such as impulsivity, affect regulation, executive functioning, problem solving and cognitive processing (Bower et al., 2018). When these behaviours occur and education staff lack awareness or understanding of FASD, students can be subjected to increased rates of violence, abuse, neglect and exploitation within education settings.

NOFASD Australia recently commissioned an education and learning survey to determine the extent that children with FASD are negatively impacted within the Australian education system (NOFASD, 2020). The survey received 88 responses from parents and carers of children (current and former students) with a diagnosis of FASD or who were likely to have FASD (NOFASD, 2020). The majority of participants (71.4%) reported that their children with FASD experienced discrimination, prejudice or exclusion by teachers and/or education management staff (NOFASD, 2020). Additionally, over half (51.3%) of survey participants reported that their children with FASD were subjected to neglect within an education and/or learning environment, a quarter (25.6%) reported abuse, 17.9% reported violence and 5.1% reported exploitation (NOFASD, 2020). Some responses from the report are provided below:

“Throughout school [my daughter] was often made to feel less than normal due to her learning difficulties and [the] lack of understanding of her condition by teaching staff.”

“We are currently experiencing social exclusion during breaks and exclusion in general as [the] school cannot manage [my child’s] behaviours”.

“[My child] was sent home because he couldn’t self-regulate... Now the teacher along with the therapy service team, who now work with him, use it as a last resort and only after speaking to me.”

“[There was a] refusal to allow a toileting plan or other requested supports to be assessed. The principal did not believe disabilities actually existed and [believed it] was all parental or behavioural issues and things like FASD were made up issues.”

“My child was made to sit in wet, muddy clothes and shoes as a consequence. He was told there were no spare clothes available which wasn’t true. I was not called to pick him up even though the school knew it was my day at home. His behaviour escalated because the wet and muddy clothing were unsettling to his sensory processing needs. He continued to escalate and was removed from class. I was not informed until after school. We are no longer at this school.”

“Toileting is our main issue of neglect. [I was] repeatedly collecting the children in soiled and smelly clothes at the end of a school day [and] constantly trying to have meetings to implement support and strategies around toileting success and hygiene. [My] 12 year old regularly, for years, was suffering numerous [urinary tract infections] from poor hygiene at school and being left to sit in soiled clothing all day.”

Detailed results from this survey are provided in the *NOFASD Australia Education and Learning Paper Response: A Submission to the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability*.

Group Homes

The Group Homes Issues Paper (RC, 2019b) reported that individuals with disability may be at increased risk of violence, abuse, neglect and exploitation if they reside in group homes. Group homes refers to accommodation where services and supports are provided to four to six long-term residents with disability (RC, 2019b). Concerns have been raised about how individuals with disability are treated within group homes.

It is difficult to determine the extent to which people with FASD reside in group homes. Evidence indicates that people with FASD are more likely to be engaged in the foster care system as children and in supported accommodation options as adults, suggesting that people with FASD may be more likely than the general population to reside in group homes (Burnside & Fuchs, 2013). Canadian data shows that approximately 21% of adults and adolescents with FASD reside in assisted or sheltered housing (McLachlan et al., 2020). Australian research has highlighted that children with FASD may be more likely to experience living with an alcoholic parent, child abuse and neglect, being removed from family and being placed in the foster care system (McLean & McDougall, 2014). For adolescents involved in the foster care system, reaching 18 years of age means that they may be prematurely forced to exist the foster care system and find alternative accommodation and living arrangements (Burnside & Fuchs, 2013). For those adolescents with FASD, this transition can be exceptionally difficult. A study by Burnside and Fuchs (2013) detailed how adolescents with FASD can be confused about what to expect when they leave the foster care system, have little chance to plan their living arrangements once they reach 18 years of age and have little to no support to move easily into their new accommodation. Individuals with FASD in foster care may also have little chance to develop their life skills that will support them in independent living arrangements (Burnside & Fuchs, 2013).

It is important to note that many foster parents of children with FASD go above and beyond to support their children as they grow into adolescents and progress to more independent living arrangements. A study by Pepper, Watson and Coons-Harding (2019) found that foster parents of children with FASD expressed a strong desire to support their children to acquire or maintain a stable living environment as they grow to become young adults. However, parents reported a lack of appropriate housing options for their adult children to transition into (Pepper et al., 2019).

Personal Submission 1

“My sister’s grandson Isaac* has been in my care since his removal from hospital at 5 days old, he is now 15. He has been raised as my child, along with his sister. He does not understand what he has done and why he needs to live in a group home. He was diagnosed with Fetal Alcohol Spectrum Disorder (FASD) at 8 years. Other diagnoses include Attention Deficient Hyperactivity Disorder, Sensory Processing Disorder, Oppositional Defiance Disorder, anxiety, significant language disability and mild intellectual disability.

In February 2019, [Isaac] was removed from my care due to his continued aggression and physical and verbal violence. He was placed in a group home. This was not what I wanted, and I knew that he would be in a setting that would have no understanding of his disability or how they need to provide support. This was and continues to be distressing for myself my child and my family.

Group home staff had no understanding FASD; it took 12 months to do a full day training around FASD. Staff seem to think this gives them full understanding and that they are FASD informed. I constantly advocate for them to continue learning about the many complex characteristics of FASD and only then will they be able to comprehend what they see and deal with, with my child and be in a position to support him appropriately. Department of Child Protection indicates that all staff (I am aware of 8) are very exhausted dealing with my child. [They] have asked for him to be transferred elsewhere.

Isaac regularly states he is hungry (he has a number of medications to keep him calm and help him sleep). The group home shop only once a week and food often runs out a couple of days before the next order is delivered. In the past I have purchased food and snacks for him to keep in his room as I know his eating habits that are common FASD traits. He eats very healthy and has not eaten meat in past, so his food choices are limited. I believe they don’t cater for him. We often buy Uber Eats to satisfy him. He does not recognise a breakfast, lunch or dinner times as we do and grazes all day. Staff state he eats all the food at once and they have now begun locking food up.

He has been told that now he receives a study payment through Centrelink he has to purchase his own toiletries. I have often raised the issue of his inability (adaptive behaviour) to care for himself and staff need to understand this and act to assist him in such things as personal hygiene, doing laundry (he does not know when his clothes need washing), helping him to recognise clothes are dirty or need to be thrown out. I have contacted the Social Worker to alert her of these incidents several times to talk to staff. He is unable to pack a bag of clothes to sleepover at my house, he is unable to put the required items together and has often turned up without clothes. I continue to purchase a number of clothes, so he has new items and has change when he has

sleepover at my house. This is a similar circumstance for shoes. His sensory processing causes issues when purchasing new clothes and shoes. That is, he will not wear particular items and just the fact they are new is a hurdle and it takes some time for him to make the change transition to feeling ok about these new items.

Since he has been in the group home his anxiety has increased, he self-harms and threatens suicide. He runs away, he believes the staff don't care or like him. He feels I have abandoned him. He states staff mistreat him regularly and he rings us stating this. Self-harm attempts and my son's suicide ideation have increased significantly since my son has been in the group home environment.

His communication is a huge issue, he has a sense of humour, but it is often inappropriate, and staff react adversely, and this triggers Isaac's aggression. Their responses are constantly inappropriate for a child with FASD who has the significant behavioural challenges and a borderline IQ and significant language disability.

Group home staff believe Isaac is able to behave in line with "traditional social expectation" or learn from consequence. There is constant change in the group home setting with a number of staff; Isaac has never been able to cope with change without the right accommodations for him. Isaac presents to our Women's and Children's Hospital regularly for self-harm or suicide threats, I am very fearful for his mental wellbeing and his life. Mandatory intense training [is needed] for all who have responsibility for working with and supporting children with FASD.

As part of my application to the South Australian Civil and Administrative Tribunal (SACAT) [regarding Isaac's removal from my care], we reached a conciliation agreement to have a FASD Expert Psychologist to assess Isaac and develop a Model of Care Plan that is agreed by all who work with and provide services for Isaac to collaborate, undertake professional development to become FASD Informed:

"A FASD-informed approach recognises that it is the program and /or the practitioners who need to change what they do (i.e., in terms of practice, expectations, program rules, format, etc), rather than the person with FASD, to achieve "a good fit" and positive outcomes." (Gelb & Rutman, 2011; Malbin, 2002, as cited in Centre for Excellence for Women's Health, British Columbia [n.d.]).

However, some elements of this conciliation agreement [are] being blocked by the Department of Child Protection staff.

Relative and carer of Isaac, an adolescent diagnosed with FASD

*Not real name

Personal Submission 2

In our experience the agency managing foster care in our state has not acknowledged the true prevalence and impact of FASD amongst children in state care nor understands the extraordinary care that a child with FASD requires. Through a FASD parent support group I facilitate, I have had contact with many foster carers who have children diagnosed with FASD but who have still not been provided with the support they need to parent their child successfully. This can lead to carer burnout and results in multiple placements and a traumatic life for the child.

Anecdotally, we have also heard stories of many child protection agencies in Australia refusing to explore a FASD diagnosis for a child, despite a history of problematic substance misuse by the birth parents. Carers are struggling to provide appropriate support because the possibility that the child in their care has FASD has not been recognised and hence the need for specialised management plans and interventions, has not been addressed.

I am currently providing emotional support to two carers whose teenage children have been placed into group homes. This was the result of carer burnout caused by the lack of respite for these families. The staff at the group homes have not had the specific training necessary to be able to best support these young people and this had led to a significant deterioration in their health, mental health and wellbeing.

It is inconceivable that FASD is denied, ignored or at the very least “not ruled out” in considering foster placements where parental substance misuse has been the driver for those children coming into the child protection system. If a child does have FASD, diagnosis and targeted specialised supports are critical if there is to be any chance of positive outcomes for that child.

Failure to provide timely diagnosis and appropriate supports for a child with a specific disability is a human rights issue.

Foster parent of an adult with FASD

Health Care for People with Cognitive Disability

The Health Care for People with Cognitive Disability Issues Paper (RC, 2019c) reported that individuals with disability face obstacles and barriers to accessing appropriate health care. Individuals with cognitive disability may experience particular barriers, such as having increased difficulty understanding health information and following instructions from health professionals. The Issues Paper made reference to obstacles such as poor and/or inappropriate training of health professionals, delayed diagnosis or misdiagnosis, inappropriate prescribing processes (including over prescription) and restrictive practices. Individuals with cognitive disability may be negatively impacted by issues within the National Disability Insurance Scheme (NDIS), such as gaps in funding and support options and a lack of coordination between the health system and the NDIS.

Australian online survey data has shown that almost half (44%) of people with disability are unable to access the health care that they need and over half (55%) feel that healthcare workers do not understand their needs (Disabled People’s Organisations

Australia, 2019). These statistics may be higher for people with cognitive disability because of the nature of the impairment. For people with FASD, cognitive functioning is a neurodevelopmental domain that is often impaired, potentially resulting in increased difficulties when accessing health care (Bower et al., 2018). Additionally, because FASD is a lifelong disability, it is likely that people with FASD will have difficulties accessing appropriate health care through the life span (Masotti et al. 2015). Research cites the need for an integrated health system, so that people with FASD can access appropriate healthcare and their families and communities can care for those with FASD adequately (Masotti et al., 2015). For those people with FASD who have impairments in cognitive functioning, particular attention needs to focus on ensuring health information is accessible and understandable.

Personal Submission 3

FASD is a complex disability and varies enormously between individuals. Management and supports need to be specifically tailored towards individuals and their life circumstances. Generic supports and programs are often less successful and sometimes inappropriate when applied to people with FASD. For example, our adult daughter who has FASD is now alcohol dependent herself. Currently in South Australia - and we suspect in most other states - there are no treatment programmes that are appropriate for a person with the wide-ranging cognitive impairments that come with her diagnosis.

Many of the supports and accommodations for people living with the disability are geared towards those with visible physical impairments or those with obvious intellectual disability. The majority of those with FASD have neither of these, however, hidden and significant functional impairments severely affect their ability to conform and survive in the community. Unless health and allied health providers have specific training in FASD, these impairments are not recognised as life-long brain damage that requires specialised management and support services. Instead, their behaviours are misunderstood and blamed on trauma or other environmental factors and affected individuals are not referred for appropriate screening/diagnosis.

Whilst there has been an increase in the number of FASD diagnostic clinics and FASD informed service providers to support children who have FASD, diagnostic and FASD informed services for adults with FASD are virtually non-existent. Adults with FASD will be over-represented in the judicial, mental health and AOD treatment sectors. Appropriate FASD informed treatment and support services would improve outcomes for this cohort and save the public purse millions of dollars.

Foster parents of an adult with FASD

Criminal Justice

The Criminal Justice Issues Paper (RC, 2020d) reported that individuals with disability are more likely to be involved in the criminal justice system, as a victim of a crime, a person accused or suspected of a crime or as a witness to a crime. When people with disability come into contact with the criminal justice system, they are more likely to

experience a heightened risk of violence, abuse, neglect and exploitation within that setting (RC, 2020d).

FASD is largely undiagnosed within the criminal justice system because it is generally unrecognised by professionals at all levels. A recent case describes how a lack of awareness of FASD resulted in unfair treatment and punishment in the Western Australian court process. The case involved a 15-year-old male who was convicted of manslaughter and had his sentence reduced on appeal after a FASD diagnosis was made (Freckelton, 2017). The judge found that impairment because of FASD reduced the individual's moral culpability for the offence, reduced the effectiveness of a period of imprisonment because general and personal deterrence was reduced and explained to an extent the lack of remorse exhibited by the individual (Freckelton, 2017). Although the individual's sentence was reduced after a diagnosis was found, the judge expressed major concerns as to why forensic mental health experts and experienced legal counsel failed to identify a case of FASD or order a FASD assessment during trial or sentencing (Freckelton, 2017). This case demonstrates how FASD as an undiagnosed disability leads to unjust punishment for those involved in the criminal justice system. It also highlights the need for more education and training related to FASD for professionals who work in the sector.

Undiagnosed cases of FASD within the criminal justice system has led to the criminalisation of the disability. Ground-breaking research which occurred at Banksia Hill Juvenile Detention Centre in Western Australia demonstrates the high prevalence of FASD within a youth custodial setting. The study found that 36% of juvenile detainees met criteria for diagnosis of FASD and 89% had at least one domain of severe neurodevelopmental impairment (Bower et al., 2018). Further findings indicate that the majority of young offenders in custody have a lifetime history of engagement with social services without adequate assessment and understanding of the role which prenatal alcohol exposure has played in their lives (Bower et al., 2018). This research highlights how individuals with FASD become entangled in the criminal justice system, with little to no support to direct them away from offending.

Personal Submission 4

It is known that Fetal Alcohol Spectrum Disorder (FASD) is very often present amongst individuals in contact with the justice system. Australian research in 2016 proved that the numbers are likely to be between 36 and 50% of people who are incarcerated based on a WA Juvenile Justice sample.

This case below has been summarised for the Commission because it is a very typical example. It is unacceptable that a young man can reach the age of 30 with an impairment in every domain of brain function and the primary cause has never been addressed or considered, despite a history of involvement with the criminal justice system.

NOFASD was approached in June 2020 by QQ*, a friend of the family of MM*, who she had known for 20 years. MM is in his early thirties [and is an] Aboriginal man. He has been diagnosed with severe and uncontrolled epilepsy and has an extensive drug-related criminal history – he has spent most of his adolescence in juvenile

detention and has spent most of his adult life so far in prison. He has never had any diagnosis, or diagnostic screening for FASD. MM's mother is alcohol dependent and confirmed drinking heavily whilst pregnant. She now lives with terrible shame and regret. MM has been with his now ex-partner for a number of years (living with her whilst not in prison). She is several years older than him and has children ranging in age from about 10 years to adulthood.

In 2020, MM was charged with several sexual offences. His family struggled to get details of the brief from Aboriginal Legal Services (ALS). The family had no information and ALS did not return phone calls from his family or the AOD worker. His family did not know what was in the brief or what was happening.

MM was in an Australian prison and had no contact with his family for a fortnight after being remanded in custody. He has a history of suicide attempts and has been flagged as a suicide risk from QQ, but she did not know if the prison recognised the danger or had taken action to ensure his safety and wellbeing.

QQ provided some information directly from MM who called her immediately when he became aware of the charges. At least one of the charges related to a solo sexual act MM performed on himself, in a communal area of the family home, whilst believing the household was asleep. A minor in the house unfortunately witnessed the act part way through. Overcrowded housing and impulsivity as a result of FASD are significant factors in this case (i.e. MM's exposure was unintentional, his impaired cognitive skills would have impaired his reasoning and ability to think through the potential risks and impacts of someone entering the room). Nine charges were laid, seven of these were later dropped.

MM's lawyer recommended that although he was possibly unfit to plead due to his lack of understanding of the charges, it was advisable for him to plead guilty and provide evidence through the FASD diagnosis – that he did not understand what he was doing was inappropriate and should have stopped when the child came into the room.

FASD diagnosis is costly, not covered by Medicare and no organisations have dedicated funding to provide a diagnosis – despite clients in contact with the justice system displaying obvious symptoms of the disability. Due to a donation received, NOFASD were able to provide financial support for an assessment as a one-off occurrence. An assessment by a Clinical Psychologist was organised to provide a diagnosis. FASD was confirmed with impairment in all 10 domains of the brain – indicating severe, permanent impairment in multiple areas of functioning.

NOFASD staff member

*Not real name

Emergency Planning and Response

The Emergency Planning and Response Issues Paper (RC, 2020e) reported that individuals with disability may be more severely impacted by emergencies and crisis situations than those without a disability. Specifically, the Issues Paper draws attention

to the COVID-19 pandemic and the 2019-2020 Australian bushfires as emergencies that may have resulted in people with disability being 'overlooked' or 'left behind'. Key issues that impact people with disability during emergencies include a lack of provision of accessible information, no or poor access to essential support services and/or health care, housing issues, education issues, a lack of income and food security, increased rates of domestic violence, reduced safeguards and oversight and reduced community participation (RC, 2020e). First Nations people and individuals from a culturally and linguistically diverse (CaLD) background with a disability may be more negatively impacted than non-indigenous and non-CALD people with a disability.

COVID-19 was termed a pandemic in March 2020 by the World Health Organisation (WHO, 2020). Although having a disability does not on its own increase the risk of getting COVID-19, for some people, impairments as a result of their disability may mean a heightened risk of infection (CDC, 2020). For example, individuals who have trouble understanding information about COVID-19 or find it difficult to practice preventative measures may have an increased risk of infection. Individuals with FASD and cognitive impairment may be more likely to have poor comprehension of health information and struggle to follow public health advice, such as social distancing and regular hand washing. Individuals with FASD may come into closer contact with other people as they may have carers and/or support people whom they rely on to assist them with daily tasks.

A secondary concern is the risk of increased prevalence of FASD during COVID-19 as a result of increased isolation and alcohol use. One study found that Australian women increased their rate of alcohol consumption by 22.8% during the COVID-19 lockdown period in May 2020 (Clun & McCauley, 2020). Although it is too early to determine if FASD prevalence has increased as a result of COVID-19 restrictions, when there is a rise in alcohol consumption generally there is a rise in alcohol-exposed pregnancies (Harding, 2020). This is particularly the case when couples spend more time together and when access to contraception is limited (Sher, 2020). Recent research already indicates a 30% increase in pregnancy test sales in 2020 compared to previous years, indicating a potential increase in the number of women who are pregnant (Allen, 2020). It is noted, however, that some authors predict that births will reduce as a result of the uncertainty and socioeconomic scarcity from COVID-19 (Allen, 2020). It is important that the public is made of the risks of consuming alcohol when pregnant and that measures are taken so that people are supported to reduce alcohol consumption during the COVID-19 pandemic.

Personal Submission 5

As a disability, FASD presents many challenges relating to Emergency Planning and Response. Over many years, we have included our son in planning and preparing for known possible events, particularly those relevant to the area in which we live. We have an evacuation plan that is presented in a map of our house, escape routes and a meeting place. We also have a luggage bag packed with essential items and a list of other items we would need to grab in case of an emergency. We have discussed and identified safe places to evacuate to if necessary. All well thought out and well

prepared. However, come to a day of increased risk of an emergency, such as fire danger, and this produces a day of constant anxiety, which often results in problematic behaviours. Everything begins in the lead up to an increased risk day. Whilst we don't have [television] or radio going which constantly reminds us of emergency risks, our newspaper has details of the weather and this begins the rollercoaster. We have an electronic weather station, which has a breakdown of all things relating to weather, which is constantly checked. [Our son] continually perseverates by asking me to check weather, check fire information or whatever the possible emergency is. If the fire alarm goes off in our town, that heightens his anxiety more and he will be demanding to know where the fire is and for me to look up all information on the Emergency App. He will then determine if the truck is likely to pass by our home and will be sure to place himself at our front window to watch it drive by, if it is. Imagine your own anxiety in a situation such as this and multiply it many times. Then imagine the intensity within your home and the additional work a parent/carer must put in, to try to manage through the situation.

As a pandemic, COVID-19 has been something that so many of us have neither witnessed, been a part of or even prepared for, so to say that this has had a significant impact upon our son's life is an understatement. In a year in which we had a long holiday planned, as well as other short trips, the anxiety, frustration and then anger grew as each one was cancelled. The disappointment was immense, as was my husband's and mine, as we had invested a huge amount of time and money to ensure we had set up the best possible outcomes to manage his behaviours during these holidays, which are a result of him living with FASD. Being able to provide answers to him regarding what this pandemic would mean to us in terms of just our daily living was also a cause of anxiety and agitation, as we too were learning and adapting to the results of the pandemic on a daily basis. His sensory system was completely overloaded as he was bombarded with so many new sensory struggles. Things like washing his hands constantly, which has always been a struggle, due to how it makes his hands "feel". Wearing a mask, which he initially refused to do, until we were able to find a soft "gator" in a pattern that made him feel good. As a parent, I encountered many additional difficulties, such as him refusing to enter any shops that I needed to enter for essential items. I cannot leave him at home, because even though he's a teenager, his impulsive behaviours make this too risky. I would need to appoint a designated place for him to stand by our car, so that he could still be safe, but not having to enter any shops. Attending a doctor's appointment was difficult for me, as I could only arrange during working hours and my husband was unable to care for our son during that time. It was the medical clinic's policy, that only the person who the appointment was for, could attend, unless they were a carer for that person. I needed to be firm in explaining that our son needed to be with me, because I had no other options for care for him.

Foster parent of an adolescent with FASD

Rights and Attitudes

The Rights and Attitudes Issues Paper (RC, 2020f) highlighted the need for people with disability to have their rights upheld and to be free from discrimination. Negative or discriminatory attitudes toward people with disability can result in stigma, viewing people with disability as a burden or having their rights removed (RC, 2020c).

Research indicates that people with FASD and their families are subject to negative attitudes and stigma (Corrigan et al., 2019). A recent study involving a focus group and individual sessions with nine stakeholders described negative attitudes ascribed to children with FASD. These attitudes included children with FASD being lazy, violent, unable to learn, brain disordered and unable to learn (Corrigan et al., 2019). Birth mothers of children with FASD were viewed as child abusers, not caring, in denial of how serious or bad their alcohol consumption was during pregnancy, secretive, guilty, ignorant, labelled as ‘addicts’ and perceived as having a history of maltreatment toward children (Corrigan et al., 2019). In another study, research participants viewed mothers of children with FASD as more different, disdained and responsible than women with serious mental health issues, substance use disorder and a history of imprisonment (Corrigan et al., 2017). These studies support the notion that birth mothers of children with FASD are highly stigmatised for their alcohol consumption during pregnancy, indicating that the public may discriminate against this cohort (Corrigan et al., 2017).

Personal Submission 6

I am the birth mother of an individual with FASD – although it took 30 years to understand that this diagnosis is what explained our lived experience. Coming to terms with the enormity of what FASD means has been profoundly painful and made exceptionally challenging due to the prevalent attitudes held in our society: the stigma, blame and shame is something that we have experienced at every step towards seeking better outcomes and has required enormous fortitude to find answers and support.

In our case - as it is with many, exposure to alcohol occurred before pregnancy was confirmed, at a time where guidelines were very different to what they are now. Unfortunately, these ‘older’ guidelines are still quoted today and perpetuate the belief that “a little alcohol is ok”, that exposure early in the pregnancy “isn’t a big deal” and therefore a person with FASD must have been exposed to “large” amounts of alcohol.

This is a dangerous misconception solidifying the stigma that FASD is as a result of an uncaring, uneducated mother, often thought to be in a violent and addicted environment. This was not our experience, nor is it for most, yet I often feel seen through this stigmatising lens, which only served to make seeking out diagnosis and subsequent care exceptionally fraught.

While seeking medical care, support and a way forward, every medical practitioner and clinician that we spoke to about FASD – be it for my child’s care or my own has responded to me (or about me), with the assumption “so... you are a heavy drinker....” writing down this assertion without eye contact or confirmation, then when corrected would scoff at the idea of FASD. This is profoundly upsetting and disempowering. It needs to be said that if in fact I was a “heavy drinker” then it would be indication that I may require help for addiction – a medical condition requiring assistance, not derision. Sadly, when clarifying that I am not a “heavy drinker” and seeking to raise awareness about FASD, both my child and I have been dismissed, patronised or at times, even ridiculed. These experiences have been deeply hurtful and damaging to both my child and myself, and has taken reserves of resilience to move forward, reserves that would not be available to many. There is an unacceptable level of

ignorance about this condition and its prevalence throughout the community which must be addressed.

We sought help for my child's presentation for more than 20 years, trying to find answers and solutions for the many confounding and debilitating symptoms – only for them to be dismissed as a lack of motivation and drive, anxiety and depression. In fact, for a period of roughly 6 years, my child sought medical help almost fortnightly, desperate for answers and suicidal from being unable to move forward in life. At any time, [health professionals could have] confirmed exposure to alcohol in utero, [but] the question was never asked. Despite regular and numerous medical visits my child was told to “just get on with it”, and “to stop procrastinating”. This was profoundly damaging to my child's mental health and put their life at serious risk.

Investigations for the lifelong, consistent, and sometimes unusual symptoms were never made. It needs to be said that my child's symptoms clearly indicated FASD, yet despite years of seeking help not one teacher, GP, specialist or clinician identified the problem. As a parent, I was told that my person would “grow out of it”...evidently not. When my child was 29, I finally realised that we were dealing with FASD upon watching an investigation on Four Corners. Then came the very uphill climb to find practitioners willing to listen and able to perform the investigations. My child could not have done this without my help and advocacy. Had it not been for my intervention, my child would be DEAD.

How can this happen? How can an Australian live a lifetime with a brain-based disability, consistently seek help and yet be ignored? Because of the stigma and discrimination attached to FASD. This is what prevented early diagnosis and intervention, this is what caused immeasurable suffering and hindered the development of strengths through the support of weaknesses. It is exceptionally painful to think of what my child could have achieved had early intervention and supports been available, but it is clear that even after 30 years without help, awareness, intervention and support has significantly improved outcomes.

My child, now an adult, is an intelligent, charming, well spoken, well groomed, thoughtful, caring, and talented individual who also happens to be significantly and clearly affected by FASD, requiring support. Stigma around how a person with FASD presents contributed to hiding the disorder and is what prevented better outcomes sooner and what caused the secondary issues of anxiety and depression and for many others addiction and involvement in the judicial system. There is clearly an imperative to raise awareness of FASD, its prevalence and presentation and to provide education and training to those in positions to ask the difficult questions that would identify FASD.

Birth mother of an adult with FASD

Personal Submission 7

Because FASD has not yet been recognised for the disability it is, the services and support that can be accessed is often discriminatory. The first barrier is the intense advocacy that parents/carers need to undertake to ensure that services and support can be obtained. This is not only draining, but often still leaves huge gaps that need to be filled. The second barrier is obtaining the supports and services that have FASD training, because through my experiences, this is essential for any program to have a

chance at a positive outcome. The third barrier is working through the often, inevitable scenarios of the person affected by FASD as appearing “normal” to an outside carer and therefore being given freedoms that will be problematic. The end result from these situations, is additional behavioural problems that not only affect the individual with FASD, but their family as well. Those who live with FASD, have the right to services and supports not only in line with other disabilities, but also specific to FASD and their needs.

Attitudes from the public can be very hurtful for anyone living with FASD and their loved ones. A recent article that appeared in many leading Australian newspapers and had the heading “Booze Babies”, was particularly hurtful to our son. The heading itself was derogatory, but it was the content of the article, particularly the statement about how much money each person with FASD who is accessing the NDIS, costs the taxpayer each year, that made our son feel unvalued. He felt angered with the attitude of being considered as a burden to Australia. The truth for those individuals with FASD who are accessing the NDIS, is that having the opportunity to receive the benefit of supports and services specific to their needs, will in fact reduce the likelihood of being incarcerated, which is far more expensive than an NDIS package.

Foster mother of an adolescent with FASD

Employment

The Employment Issues Paper (RC, 2020g) reported that people with disability experience poorer employment outcomes than people without disability, including reduced access to employment, lower income, underemployment, and unemployment. The paper suggested that first nations people with disability and people from culturally and linguistically diverse (CaLD) backgrounds experience even poorer employment outcomes than non-indigenous people with disability (RC, 2020g).

There is no identified Australian data to determine the rates of people with FASD engaged in employment and/or experiencing employment issues. Canadian data, however, provides a useful guide. Data indicates that 37% of adolescents and adults with confirmed prenatal alcohol exposure (PAE) were found to have employment problems (McLachlan et al., 2020). Some research has found that individuals with prenatal alcohol exposure face a host of other issues which is likely to impact on a person’s ability to obtain and maintain employment (McLachlan et al., 2020). These issues include support to live independently (63%), alcohol misuse (38%), other substance misuse (46%), legal problems with offending and victimisation (34%), housing issues (21%) and incarceration (3%) (McLachlan et al., 2020). Other research indicates that contextual factors play a role, such as negative stereotypes and stigma toward people with FASD from employers and the community and a lack of understanding of FASD by employers and colleagues (leading to unattainable expectations) (Makela et al., 2018). Despite these findings, it is important to note that individuals with FASD can thrive within the workplace when provided with the right job fit and relational supports (Kapasi et al., 2019).

Personal Submission 8

My son is about to turn 15 years of age and was diagnosed with FASD in 2020. He also has ADHD and a specific language disorder. I have needed to continually advocate for him within the education system to raise awareness of the learning challenges he experiences. My son wants to succeed in the classroom but for this to happen, provisions and accommodations need to be made to ensure his strengths are fostered in the school environment. Frequent engagements with my son's teachers and support staff are required to ensure his needs are met and he and his peers can achieve the intended outcomes.

Whilst school is a daily struggle, he is in a somewhat protected environment where he is identified as a child. The expectations of his ability to attain in class are not realistic for his developmental age, however, they are for his chronological age.

My son's disability cannot be seen, his brain-based disability is hidden. He presents as a neuro-typical teenager, an individual who wants to be treated the same as any other teenager. He does not want to be singled out as an individual with special needs or a disability. When conversing in and around adults in retail, health, and service environments, it becomes clear quite quickly that his use of language and his adherence to expected social norms are not developed at a level that is expected of a young adult. This usually results in anecdotal feedback, comments, or an unappreciative look in his direction.

I have great concern for the lack of mainstream knowledge, understanding and compassion for individuals with a hidden neurological disability. FASD is a stigmatised diagnosis, due to the lack of awareness and understanding of this disability and because it can only occur when a fetus is prenatally exposed to alcohol.

The majority of employment services and disability employment services I have engaged with to date, know very little about FASD. When there is knowledge, this is usually centred around the incorrect belief of low prevalence rates, particular members of society being impacted and the requirement for the mother to have alcohol dependency issues.

My son has good expressive language skills but his receptive language, working memory, auditory processing skills and reasoning abilities are developmentally several years below his chronological age. When engaging with employment services to discuss my son's needs, there has been little understanding around the functional impairments impacting my son's daily life and the supports he will require to be able to access meaningful employment and to sustain this.

Funding for individuals through the NDIS is possible, however this process is complex and fraught with barriers in relation to language and the burden of proof for the functional impairments sustained by an individual with FASD.

For children such as my adolescent son to be successful in the workplace, the provision and accessibility of services and supports available within Australia need to be investigated. My son is currently experiencing discrimination due to a lack of knowledge and understanding within a system which must know how to advocate and support individuals with FASD. The advocacy for individuals needs to include systemic advocacy to educate and raise awareness.

Birth mother of an adolescent with FASD

Restrictive Practices

Restrictive practices is a term used to refer to an action, approach or intervention that has the effect of limiting the rights or freedoms of movement of a person (Commonwealth, State and Territory Disability Ministers [CSTDM], 2013). Restrictive practices may include seclusion and/or the use of restraints (physical, chemical, mechanical, environmental or psychosocial) (CSTDM, 2013). Restrictive practices may occur in any setting, but may be more common in homes, community settings such as day programs or disability service settings, in detention settings, mental health settings, workplaces or within the health and education systems (RC, 2020h). The Royal Commission Restrictive Practices Issues Paper (2020h) included restrictive practices in its definition of violence and abuse.

There is minimal research available exploring the use of restrictive practices in relation to people with FASD. A recent submission to The Royal Commission by the Royal Australian College of General Practitioners (RACGP) identified that people with FASD may be increased risk of being subject to restrictive practices given that they are likely to present with impulsive behaviour (RACGP, 2020). The use of restrictive practices for people with FASD could lead to an increased risk of engagement with the criminal justice system and subsequent incarceration (RACGP, 2020). Restrictive practices appear to be used to 'manage' children with FASD within the education system (NOFASD, 2020). The *NOFASD Education and Learning Paper Response: A Submission to the Royal Commission Report* indicates that 75% of children with FASD were subject to inappropriate and/or ineffective behaviour management practices within education settings, including being put into isolation (seclusion), being grabbed by the arm by school staff and being restrained (NOFASD, 2020).

Personal Submission 9

Due to their cognitive and neurological deficits, there are sometimes “restrictive practices” that may be necessary to help the person with FASD achieve the goals they have for themselves. For example, our daughter has her money managed by the Public Trustee and only has discretionary funding of \$10 put into her account three times a week. She does not have access to larger amounts unless [she is] supervised or supported to spend it. When she was younger, she was most unhappy about this restriction, but it was necessary to protect her from behaviour that was placing her at extreme risk of physical/emotional harm. Now she is 40, she accepts this restriction because over the years she has finally managed to develop the insight to realise that she has a far better life than others on the Disability Support Pension. She is thankful now that she always has money available to support her goals and for the material things she desires.

One size does not always fit all when it comes to restrictive practices. When thinking about restrictive practices it is also important to think about rights and responsibilities. Is a right really a right if one is unable to understand and take on the responsibility that must go hand in hand with that right? If the answer is no, then that right can become a set up for failure. Is that a fair outcome for that person?

We have no doubt that our daughter may not be alive today if it were not for some of “the restrictions” that have been placed on her so called “rights”.

Foster parents of an adult with FASD

First Nations People with Disability

The First Nations People with Disability Issues Paper (RC, 2020i) reported that there are a disproportionate number of First Nations people with disability in Australia. First Nations people with a disability are referred to as having a ‘dual status’, meaning that this population compounded levels of discrimination (RC, 2020i).

Research indicates that non-indigenous Australians and First Nations Australians consume alcohol at similar rates, with 79.8% and 78.3% Australians and First Nations Australians having consumed alcohol within a certain time period, respectively (Lee et al., 2019; Colvin et al., 2007). Due to similar alcohol consumption levels, prevalence of FASD within non-indigenous people and First Nations people is likely to be similar, however, prevalence studies have only been carried out in First Nations populations (Fitzpatrick et al., 2017). A recent 2017 study found a high FASD prevalence rate of 314.8 per 1000 in the Western Australian Fitzroy Valley (Fitzpatrick et al., 2017). It is likely that First Nations people experience more negative outcomes as a result of FASD than non-indigenous people, due to compounding levels of discrimination and minority group involvement.

It is important to note that First Nations people have led the way in developing prevention and awareness campaigns to address FASD in Australia. In 2006, alcohol overuse and supply became a critical issue within the Western Australian Fitzroy Valley, reflected in a spate of 13 suicides and the identification of serious learning and behavioural difficulties, abnormal facial features and poor child growth (Fitzpatrick et al., 2017). These critical incidents led to community leaders calling on local paediatricians and experts for advice and assistance, leading to the creation of The Marulu Strategy (Fitzpatrick et al., 2017). Research has found that the Strategy has resulted in a significant reduction of alcohol use from 2010 (61.0%) to 2015 (31.9%), demonstrating the effectiveness of community-led strategies for First Nations across Australia (Symons et al., 2020).

Personal Submission 10

I think it is fair to say we live in a very discreet area and our children are well shielded and protected from discrimination that most of these children would experience in many locations. We have certainly experienced many occasions where discrimination has reared its ugly head, but we are in a different situation as we are not also the ones suffering from that discrimination and are more than capable of jumping onto it before it gets out of hand.

The kids have suffered some different forms of discrimination at school, but the teaching staff have been very quick to deal with it and this is possible because they attend a very small school and the kids have a fantastic support base that assists us

all in combating any issues that arise, quickly and effectively. The school staff have been very supportive of the kids' indigeneity and their disability and this we believe has resonated through the school community.

We see and feel the discrimination amongst the community but also receive great support and protection particularly by those people who have come to know the children and have learnt the value of the kids contribution to the community and are often more effective in dealing with any discrimination that may occur long before we need to intervene. The worst experiences we have suffered have occurred in the hospital, but in fairness to the hospital considering the amount of time we spend there, the issues represent a very small percent of our interactions at the hospital and the hospital have been very effective in dealing with these and ensuring there are no repeats or continued issues. It must be said we have a very good support base at the hospital and we have been able to effectively use this to ensure issues are adequately dealt with.

There are always occasions where you wonder how discrimination has a part to play within services and interaction particularly with therapy and how much is determined by incompetency and apathy. We are burdened with three areas of discrimination, the aboriginality, their disability, and the fact we are foster parents, these three are often a negative, but also at times a great asset and so you are required to foster the good and just try and move on from the negative. I am happy to say for us the positive far outweighs the negative and certainly makes it easier to deal with.

Foster father of two First Nations children with FASD

Safeguards and Quality

In November 2020, The Royal Commission released their Safeguards and Quality Issues Paper (RC, 2020j). This Issues Paper seeks to understand how safeguards and quality services work to prevent and reduce violence and abuse toward people with disability (RC, 2020j). Safeguards can be informal (such as building skills, providing cultural support and enabling self-advocacy) or formal (laws, policies and regulations) (RC, 2020j). Some examples of formal safeguards include the NDIS Quality and Safeguarding Framework and the Australian Commission on Safety and Quality in Health Care (RC, 2020j).

There is limited research regarding the role that safeguards and quality services play to support people with FASD. NOFASD Australia's recent education survey report provides some insight, however. Findings from this report suggest that not enough is being done to safeguard children with FASD within the Australian education system, leading to substandard provision of education and the occurrence of neglect, abuse, violence and exploitation within the system (NOFASD, 2020). The below comments provide some insight into the consequences of poor safeguards within Australia's education sector:

"My child was made to sit in wet, muddy clothes and shoes as a consequence. He was told there were no spare clothes available which wasn't true. I was not called to pick him up even though the school knew it was my day at home. His behaviour escalated because the wet and muddy clothing were unsettling to his

sensory processing needs. He continued to escalate and was removed from class. I was not informed until after school. We are no longer at this school.”

“We are currently experiencing social exclusion during breaks and exclusion in general as [the] school cannot manage [my child’s] behaviours.”

“When we were finally able to gain funding [for my son], every conversation with the school was about how they weren’t legally required to spend that money to help him and that maybe he would do better in a ‘more supported environment”.

Detailed results from this survey are provided in the *NOFASD Australia Education and Learning Paper Response: A Submission to the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability*.

Violence and Abuse of People with Disability at Home

The Royal Commission released their Issues Paper on Violence and Abuse of People with Disability at Home in December 2020. The paper reported that the Commission sought to investigate all forms of violence and abuse which occurs within the home including but not limited to physical violence, neglect, emotional or psychological abuse, sexual abuse, financial abuse, exploitation, restraint, coercive control, deprivation of liberty, intimidation and threat (RC, 2020k). The Royal Commission considers violence and abuse inflicted by intimate partners, other family members and First Nations kinship networks (RC, 2020k). For the purpose of the Issues Paper, ‘home’ is described as private or family homes; group homes, large residential centres or other forms of specialist accommodation; out-of-home care, boarding and rooming houses and hostels; and domestic and family violence shelters and refuges (RC, 2020k).

The Issues Paper reported that people with disability are more likely to feel unsafe in their home than people without disability (Australian Bureau of Statistics, 2020, as cited in RC, 2020k). People with disability may be subjected to distinct forms of violence including withholding of food, water, medication or personal care such as toileting; restrictive practices; reproductive control; seclusion; discrimination and limiting or controlling communication, activities, relationships with others and a lack of autonomy (RC, 2020k). Individuals with FASD have impairments that put them at risk of increased victimisation of abuse and violence within the family home (Thiel et al., 2011). Yet, individuals with FASD are less likely to report victimisation (Fogden et al., 2016). There are many reasons why individuals with FASD may not report abuse or violence committed against them. Individuals with FASD may not be able to comprehend that an act constitutes abuse or violence, or they may not know how to report it or to whom (Thiel et al., 2011). Impairments in cognitive functioning, intellectual impairment and memory could all lead to decreased reporting of abuse and violence within the home.

In cases of abuse and violence at home, individuals with FASD may rely on the perpetrator for their care (Thiel et al., 2011). In cases such as this, individuals with FASD may feel less able to report victimisation because the perpetrator is in a greater

position of power. Additionally, people with FASD may not be able to report an offence because they have little to no time away from the perpetrator, they lack opportunities to report and/or are isolated from support people. Disempowering and manipulative behaviour from the perpetrator could easily persuade an individual with FASD not to report an offence, and threats or more violence may be used to prevent reporting. Given that individuals with FASD likely rely on their perpetrator for their care, it is probable that abuse and violence at home is grossly underreported in this population.

Promoting Inclusion

The Royal Commission's Issues Paper on Promoting Inclusion reported that people with disability experience barriers to inclusion which can result in exclusion and/or prevention from equal societal participation (RC, 2020I). When people with disability are excluded, they may experience an increased risk of violence, abuse, neglect and/or exploitation (RC, 2020I). Barriers to inclusion may include negative attitudes toward people with disability; discrimination or prejudice; poor recognition and respect for autonomy, independence and interdependence; inaccessible environments, public spaces, transportation, facilities, information and communication; a lack of culturally appropriate supports; or supports that are only provided in closed or segregated settings (RC, 2020I). The Royal Commission aims to achieve an inclusive society, which is described as a society which values difference and where dignity and equality of people with disability is upheld (RC, 2020I).

People with FASD may be likely to be excluded in various settings, such as education and employment. NOFASD Australia's recent education report highlighted that, in their sample of 88 Australian parents, 61% of children with FASD had been suspended or expelled from an education setting for reasons associated with their disability (NOFASD Australia, 2020). Additionally, over half (51.28%) reported that children with FASD had experienced neglect within Australian education settings. Survey participants reported overwhelmingly that more training was needed to improve awareness and understanding of FASD within education settings. Whilst most parents and carers wanted their children to be part of an inclusive education system, some reported that children with FASD are better suited to a specialised environment to meet their needs.

People with FASD may be excluded from participating in employment. Unfortunately, little to no research has been conducted on this issue, making it difficult to determine the extent to which people with FASD are impacted. It is likely that negative attitudes toward people with FASD, exclusion from education and the neurological impairments that is a result of the disability, reduces the likelihood that people with FASD are employed. These issues may influence how long individuals remain employed. Ultimately, reduced employment can have significant flow-on effects for individuals, including reduced income earning potential; reduced social interaction and social capital; reduced autonomy and independence; and reduced ability to engage in meaningful and/or purposeful activity. These outcomes may be experienced at high rates by people with FASD.

Personal Submission 11

Inclusion is such a different experience for so many people but for someone with a disability it is something that they battle against constantly on a day-to-day basis; be it at school, in employment, amongst the community or on a sports or social experience. Just for someone with a disability to experience day-to-day occurrences without the constant battle to partake or enjoy the opportunity, without the thought of other people's prejudice and the physical barriers that are constantly encountered, is still not much more than a dream for so many. Inclusion to me, for a person with a disability is the ability or opportunity to be able to do or partake in an experience without insurmountable obstacles encountered, that inhibit the positive experience for that person and the knowledge that they can undertake that experience without the thought of other people's views or prejudices.

Australia has become a far more inclusive community but, unfortunately, still has a long, long way to go before, I believe, it is anywhere near acceptable. We still have so far to go with education of people as towards the ability to understand the needs and requirements of the persons disability. I think the meme "why do we spend all our time and efforts teaching people with a disability to fit in, but no effort to teach people without a disability to understand and be able to assist and accommodate a person with a disability" is just so apt to our current community view. While people aren't exposed or educated in all areas of disability, there will always be a fear of the unknown with uneducated prejudicial views, and this miseducation, a lack of understanding, along with the financial burden often required for inclusion means that there is still a huge gap in the availability of inclusion for all people. My belief is, that it will take a brave, innovative, passionate and caring government to change the course of disability inclusion through education, advertising and legislation to ensure that inclusion for all people forges ahead and strives for an acceptable level of understanding and availability within this country. We need a strong push in education, to allow the community the opportunity to experience the joy, positivity and reward [and] inclusion of people with a disability can bring to all aspects of community life and engagement, and without these positive experiences, it continues to be difficult to overcome the lack of understanding and prejudicial views.

We have been extremely lucky to have been able to experience the joy and success of inclusion for our children and are always amazed by the positivity, enjoyment and satisfaction others have been able to derive from the success of inclusion for our disabled children, however, unfortunately we have also experienced the frustration that a lack of inclusion that has fronted our children and the sadness and disappointment this creates. I hope and pray that in the future, all people will get the opportunity to experience the positivity that comes from inclusion for disabled people and get to experience the great joy and satisfaction that is gained, from all aspects of the community, least of all from the person with the disability themselves. If we were able to ensure positive inclusion was available to all people, the world would be a much better place for the experience, and I hope one day a government will have a leader with enough compassion and vision to lead the community in ensuring that inclusion encompasses all people regardless of their situation.

Foster father of two children with FASD

Personal Submission 12

During [my son's] 5 terms at his last school he experienced exclusion to many school activities. His whole special needs class were told they couldn't come to the swimming carnival. When teachers were struggling with managing his class during lunch times, they were excluded from having lunch play times with the general population of students altogether every day for over a term. When activities like the dance and fitness group that came in to work with general population students, he was excluded, even when it had been paid for.

Toileting has been an ongoing struggle for [my son] and common with FASD. When bringing clean clothes back into the school office after an accident, the office ladies noted they didn't have clothes big enough for him because normally students his age don't have that problem - this was said in front of [my son].

[My son] was suspended many, many times for behaviours that directly related to his disability.

Adoptive mother of a child with FASD

Closing Statement

This report provides an overview of evidence (empirically and anecdotally) which shows that individuals with FASD are impacted by various issues within Australia. People with FASD experience unfair treatment and discrimination in relation to group home involvement, the criminal justice system, education, employment, health care and victimisation. People with FASD are more likely to be excluded from activities and have difficulty coping with emergencies and crises compared to the general population. This report suggests that more needs to be done to provide fair, equitable and just treatment to people with FASD in Australia. NOFASD Australia hopes that this report will provide an important source of information from which recommendations can be made to the Australian government, to ensure that people with FASD and their families are afforded the human rights they deserve.

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