

Best practices for justice: Practitioner views on understanding and helping youth living with fetal alcohol spectrum disorder (FASD)

Anita Gibbs, University of Otago, Aotearoa New Zealand

ABSTRACT

INTRODUCTION: International studies and New Zealand publications note that care groups, as well as youth and adult justice populations, have high rates of fetal alcohol spectrum disorder (FASD) and other neuro-disabilities, alongside mental health problems and adverse childhood experiences. This research explores justice practitioner views of helping young people living with FASD, especially when they come into contact with the youth justice system in Aotearoa New Zealand.

METHODS: Semi-structured interviews were undertaken with 11 practitioners that included social workers, disability advocates, police, legal professionals, and others working in the justice space with youth living with FASD. Stakeholders were asked what practices might help youth do well in the justice space, but also what changes need to happen in systems of health, care, justice or disability in order to ensure those living with FASD have wellbeing.

FINDINGS: Practitioners noted widespread ignorance about FASD, resulting in delays in getting appropriate supports for youth living with FASD. Practitioners spoke of the importance of early diagnosis leading to early intervention but how rare that was. Wellbeing of youth was vital but there were too many barriers to fair and equal participation for youth living with FASD in all aspects of society. All systems needed to understand FASD and provide specialist FASD services and supports.

PRACTICE IMPLICATIONS: Urgent training and practice guidance is required for all professionals working in the youth justice space. Practice needs to ensure disability rights are upheld to enable flourishing and participation by young people often on the margins of society.

KEYWORDS: Youth justice; fetal alcohol spectrum disorder; FASD; wellbeing; disability

Fetal Alcohol Spectrum Disorder (FASD) and the justice system

International studies and national reports note that care groups, as well as youth and adult justice populations, have high rates of FASD and other neuro-disabilities, alongside multiple other issues including mental health problems and adverse childhood experiences (Flannigan et al., 2021; Lambie, 2020). The

research reported in this article explores justice stakeholder views of helping young people living with FASD, especially when they come into contact with the youth justice system in Aotearoa New Zealand. Social workers and other helping professions lack training, knowledge and skills in dealing with FASD because rarely does basic training cover material on FASD

AOTEAROA
NEW ZEALAND SOCIAL
WORK 34(4), 6–18.

CORRESPONDENCE TO:
Anita Gibbs
anita.gibbs@otago.ac.nz

or other neuro-conditions (Gibbs et al., 2020; Gilbert et al., 2021). Practitioners appear unaware of the full extent of FASD, how to identify the characteristics of it, how to access assessment and diagnosis, and what strategies or interventions might be helpful. This article seeks to fill some of these gaps.

Unfortunately, New Zealand has very high alcohol-drinking rates with 71% of women reporting using alcohol prior to pregnancy or becoming aware of their pregnancy. And 23% of women reported drinking during the first trimester, reducing to 13% after the first trimester (Rossen et al., 2018). It is thought that around half of all pregnancies could have been exposed to alcohol. It is widely known that alcohol is a major social problem yet the conversations we need to have as a broader society are not happening sufficiently when it comes to harm reduction and prevention of harm (Alcohol Healthwatch, 2021; Penfold & Cleave, 2022).

FASD is a brain-based disability affecting all parts of the individual, including impacts on physical, emotional, cognitive, mental, spiritual and behavioural wellbeing. It is a physical disability that people are born with as a result of pre-natal alcohol exposure, and it is lifelong, which means it is not behavioural issue that can be 'cured' with 'reasoning' treatments, such as those commonly used in justice settings. However, rights-based disability accommodations can be made, and targeted therapy can assist in growth and skill development (Gibbs et al., 2020; Pei et al., 2019; Rutman, 2016). In the general population, FASD prevalence is noted to be between 2–5% (up to 3,000 births every year in New Zealand) but for vulnerable populations, like those in care or justice, the prevalence rates are much higher (Gibbs, 2021; Lambie, 2020). The most detailed study, in a youth justice setting from Australia, noted a 36% prevalence rate for FASD, and that 89–93% of the study population had at least one severe neuro-cognitive impairment (Lambie, 2020). In New Zealand, we have not yet seen a funded

prevalence study for FASD in either care or justice settings, but Oranga Tamariki (drawing on international evidence), estimates up to 50% of children in care may live with FASD (Gibbs, 2021; Gibbs et al., 2020; Lambie, 2020; Oranga Tamariki Practice Centre, n.d.).

Sadly, it is common for the phrase *care to prison* pipeline to be used to recognise that children involved in care systems end up in trouble with the law (Reil et al., 2022). Others have noted that youth living with FASD are simply primed for encounters with the justice system (Gibbs, 2021; Oatley & Gibbs, 2020). This is because the primary impairments of FASD make youth vulnerable to easily becoming victimised, being led astray, making repeated mistakes, seeking excitement and not being able to understand cause and effect. The main brain impairments of FASD (poor reasoning, struggles with communication, impulsivity, dysmaturity, suggestibility, poor adaptive and social skills, and struggles with self-regulation and memory issues), are impairments which can see young people fast track to offending (Gibbs, 2021; Oatley & Gibbs, 2020; Reil et al., 2022). Children living in care are invariably involved with multiple systems, yet their neuro-disabilities are not picked up early by screening or thorough assessment processes.

Research is very clear that early identification, alongside lifelong supports and joined-up working, as well as the use of the social model of disability can lead to healthy outcomes (Gibbs et al., 2020; Oatley & Gibbs, 2020; Pei et al., 2019; Rutman, 2016). Being truly FASD-informed ensures that youth are screened for neuro-disability, and that children and youth, in the context of stable and loving whānau (family, extended-family) support, have individualised strengths-based plans designed to help them live the best lives they can live. Rutman (2016) identified that a FASD-informed approach will recognise that children and youth find it hard to follow

rules or expectations unless environmental adaptations are made. Rutman argued that accommodations can be made in all environments when services focus on flexible and individualised supports, as well as ensuring key family members are involved where appropriate, and that a non-judgemental and non-stigmatising relationship is built between workers and the person living with FASD.

Pei et al. (2019), approached FASD from a systems' perspective and note that healthy outcomes for people can only come "when we have a shared roadmap" which is used to support a positive pathway that is the right fit for each person. The goal must be wellbeing and efforts directed at individual success. Yet, multiple improvements in systems working with those living with FASD are required before the thousands of people living with FASD in New Zealand can imagine a truly good life. Healthy outcomes for those youth living with FASD are more likely if systems, supports and interventions are life-course focused, and flexible enough to respond to the specific needs and exact developmental challenges and capacities of the individual (Pei et al., 2019). That is why in-depth assessment and reassessment are so vital. New Zealand's unfortunate position of great need and few services need never have occurred had robust efforts been made to fully implement New Zealand's initial and only FASD Action Plan 2016–2019, which was created after much concerted effort from key stakeholders, like Alcohol Healthwatch, judges, FASD champions, and families of those living with FASD (FASD-CAN, n.d.; Gibbs & Sherwood, 2017; Penfold & Cleave, 2022). The plan laid out a roadmap and goals for change, but received so little funding that the disability and children's commissioners, in collaboration with disability advocates, pointed out in several submissions to government that individuals and whānau will continue to be denied assessments and services until FASD is recognised and funded as an official disability (Human

Rights Commission, 2021; Penfold & Cleave, 2022).

Unlike Alberta in Canada, which does have a "shared roadmap" (Flannigan et al., 2022), New Zealand has a dearth of funding and no FASD infrastructure which has likely led to most children with FASD never being diagnosed or supported, and therefore much more likely to be misunderstood, and not accommodated for their neuro-challenges.

Methods

The research reported on in this article is part of a larger Aotearoa New Zealand wide study entitled "Building Ramps Instead of Walls" which involves interviews with 41 stakeholders working in the field of FASD. Out of 41 stakeholders, 11 professionals talked extensively about their involvement with FASD and the justice system. The main research questions focused on what wellbeing looks like for someone living with FASD and what needs to change in all systems, including the justice system, to ensure wellbeing? Semi-structured interviews were undertaken with the 11 justice professionals who included: two social workers, a prison chaplain, two police officers, one specialist psychologist, two legal professionals, one youth worker, and two other professionals working in the justice space with youth living with FASD. There were six females and five males, and two practitioners identified as Māori. The practitioners who participated in the study were all highly experienced in the FASD field, and in the justice sector. They were recruited purposively via social media posts, word of mouth, at training events and via email invitation.

Interviews lasted 30 minutes to 90 minutes and were recorded, transcribed and then checked by participants before being anonymised and analysed. Ethics approval from the University of Otago was obtained. During interviews, practitioners were asked what best practices might help youth

do well in the justice space but also what changes need to happen in systems of health, care, education, justice or disability in order to ensure those living with FASD have wellbeing and live good lives. Three of the 11 practitioners also had had family members with FASD who had been through the youth justice system and drew on their lived experience when answering questions. The interview material was analysed thematically using thematic analysis and general inductive analysis methods outlined by Thomas (2006). In the findings sections, I use extensive quotes to illustrate five broad emergent themes and to ensure the voice of the practitioners is emphasised.

While this study is based on a small number of interviews focused on aspects of the justice system, it does allow some exploration of the gaps in justice professionals' understandings and practices towards disabled youth living with FASD. The limitations of this study are that this study misses the views from inexperienced practitioners and a more diverse group of professionals that would have been obtained from a larger group of volunteers. The findings are, however, consistent with major themes from the ongoing analysis of the other 30 stakeholder interviews.

Findings: Key themes

Ignorance, intolerance and incompetence

Practitioners discussed the major concerns they had about the levels of ignorance, intolerance and incompetence, not only amongst the general population but significantly amongst their own justice professions and from other justice workers currently involved in the lives of youth living with FASD. Typical comments included:

They're the ones who are blamed for it and they're the ones who are imprisoned and are excluded from school and considered failures and not respected in society.

The system failed him time and time again. Nobody recognised his disability, they just went no, he doesn't have this, he doesn't have that, so there was just no proper support for him.

The word *punishment* was used by three participants, as well as noting the deep levels of stigma and oppression that youth living with FASD face as they have contact with the justice system. And youth were blamed for failing to keep to the expectations of justice.

They end up being penalized and further punished and then more rules get put on and everybody thinks they're just being naughty. They're not being naughty.

I don't think we're a very tolerant or a very empathetic society in New Zealand because people don't want to accept that the people who are offending are the people who need the most help and we're not able to provide that help in the appropriate way, and so we send them to prison.

Six justice professionals noted that the justice system was full of young people who had not been picked up earlier for support and that the current systems missed the real issues, harmed young people or made them worse.

[I]t's just a catalogue of missed opportunities ... You think why did nobody think then to do something or whatever? So, when it comes to prioritising where we put our energies first, I would strongly urge for it to be miles before they could ever [get to Court] because if we get it right earlier, they won't be coming into the court world.

It's the systems that are wrong and to see them all facing such terrible adversity on top of their disability, which makes life hard by being misunderstood and mistreated by the very people who are meant to be helping them makes life hard.

Three justice professionals who had worked to support young adults in justice over 20 years and had family members with FASD had seen a great cost over the years of lost lives, broken families, entrenched victimisation and mental health problems, as well as incarceration.

[W]hat I see is individuals that because of who they are, they're easily misled, predators themselves will pick up on their behaviours and see them as an easy Tom. As a result, because of their inability to know what's appropriate behaviour, they do stuff and they get themselves into a lot of trouble over it.

Journey to knowledge and skills

A number of the professionals talked of the importance their own journey to knowledge and skills in the field of FASD. They highlighted *lightbulb* moments when others had come alongside them to train or educate them on the issues, which they had previously not known about. They realised that they had been misunderstanding the symptoms of FASD as those of *bad behaviour*, rather than as symptoms of brain damage.

[W]orked in the youth services field for the last 20 years within [Justice], and I became aware through staff training of FASD, and I was fascinated because I had no clear understanding of it prior to that, and so that was an extra 13-14 years in the service that I had worked, saying "oh, you are just bad", without fully understanding.

[T]he lights went on for me and changed my life because I suddenly realised that we had been completely missing a more viable explanation for the behaviour that was bringing these young people in. So, by missing it, we were either not responding at all or misdiagnosing it, we were not addressing the real issues.

Most of the justice professionals undertook their own significant research and attended

conferences and international or national training, in order to upskill themselves once they realised how significant an issue FASD was, or when they met their first diagnosed client or, in the case of the three caregiver-professionals, when they started looking after a child with FASD.

Through experience, talking to people, own research. Probably for me, probably the biggest thing was my research surprisingly. Because that was the part that actually started making me click, understand a lot better... All of a sudden, I clicked as to why these individuals are like they are, and why we're never going to fix them.

Wellbeing

Participants were asked to consider what wellbeing looks like for youth living with FASD and some took a very specific angle, e.g., the absence of being arrested or not ending up in youth court, and others took a more life-course and active participation in society approach.

Not coming back to Court or Police—avoiding justice because of other service provision.

Well, I guess I would want to see people thriving, doing the things that they love doing, feeling good about themselves, knowing where they fit.

Wellbeing for those with FASD looks like being who they are meant to be... being accepted ... being valued ... being tolerated ... being supported ... having the chance to fully participate in all aspects of life.

Wellbeing for caregivers was considered important too, especially in relation to adequate support and respite to be able to cope with the high and complex needs of those living with FASD. Practitioners were extremely passionate about wellbeing being focused on supports for caregivers, knowing

full well that core relationship stability and a solid home life were linked to better outcomes.

Well, we have to support the caregivers ... we have to start believing caregivers when they come and ask for help and we have to provide regular ongoing support in a multitude of areas that they may request help for.

Part of the focus on wellbeing included upholding human and disability rights. That they should be able to have the same life and enjoyment out of life and so on, that somebody who does not have a disability has.

If people's rights were respected, then they would be provided with what they need to live a healthy and successful life.

One police officer noted how important it was to always ask young people regarding decisions about their welfare because, too often in justice, this did not occur—he noted that: “we must consult with them and take account of their views as much as possible.” The police officer explained that if the core principles of the OT Act were implemented correctly then young people in justice would be well served.

Another justice professional who worked regularly in the youth court mentioned the vast numbers of children coming into court with a current care and protection history who are then abandoned to the full excesses of the justice system: “the care and protection people walk away.” This often led to a criminalisation process and eventual lock-up in a youth justice residence. This legal professional was adamant that youth living with FASD rights' were being trampled over. His aim in his work with youth was to ensure fair and equitable and inclusive responses.

Best practices

All 11 practitioners were able to describe in detail what best practice looked like, both

in general terms around what needed to happen to ensure youth are enabled to live their best possible lives but also specifically, in terms of the accommodations and strategies required of the justice system to ensure a young person gets treated fairly when in trouble with the law.

General best practices. Overwhelmingly, practitioners noted that getting an early diagnosis and early interventions would offer children with FASD the best start:

[E]arly identification, early diagnosis and then obviously like a plan from that diagnosis for supports, that could be speech and language, that could be occupational therapy, that could be buddies, could be supports in home for the caregivers in their jobs of looking after these children; it could be so many more things than we actually see available currently in Aotearoa.

Professionals working in care, justice and education also needed to understand, in depth, what was going on for children in trouble and getting good training was a key part of this.

[Y]ou need educated people working with them so that they have got a basis of understanding ... look beyond the behaviour and not see them as naughty but also have a few techniques, understanding that they really need structure, they need to be well supervised and feel safe.

I would like to see FASD knowledgeable practitioners, that means they get training before they qualify; that they get a chance to know about good strategies and practices that will support families and individuals.

A number of practitioners mentioned the need for wraparound teams with specialist FASD navigators—FASD-informed practitioners who case-manage, or co-ordinate teams around the young person.

In New Zealand, currently there are only a handful of these people, primarily working in specialised FASD roles.

[H]ave individual wraparound teams around the child and plans focused on supporting whānau first for the child, a focus on strengths, skills and alternatives, alternative education is especially important.

We need core services with FASD navigators. These navigators can come alongside families and individuals and help identify what their needs are and where to access the bespoke education, health, welfare, employment and so on supports that they need to succeed.

Practitioners mentioned using specific models and strategies in their everyday practice; for example, the *5S model* (Oranga Tamariki, n.d.), and the *8 magic keys model* (FASD Outreach, n.d.). Both models emphasise the importance of structure, supervision, supports, keeping things simple and building on strengths. A couple of practitioners talked about the importance of using catch phrases to help understand and work with youth, for example, “*can’t not won’t*” “*brain not blame*” and “*less is more.*” One practitioner, also a caregiver, noted how vital it was for all practitioners to know about the *Ten brain domains* (FASD Coalition, n.d.). For practitioners, it was vital that those working in all areas of the justice system had a good understanding and grounding in FASD knowledge.

A few Māori-focused models and approaches were mentioned by practitioners as being useful. Justice practitioners noted the need for Māori-centred practices or kaupapa in the justice space, the need for Māori practitioners to support one another and share information, and the use of helpful models like *Te Whare Tapa Wha* (Durie, 1998) and the *Meihana model* (Pitama et al., 2007), when working with both Māori and non-Māori youth. Both Māori practitioners

and several non-Māori ones talked of using core Māori concepts of *manaakitanga* (expression of respect and generosity), and *whakawhānaungatanga* (actively pursuing positive relationships), to establish supportive and helpful relationships. One police officer working in a remote coastal area described how he worked to divert youth from criminal activity by spending quality time with them and their whānau, by chatting through issues, doing fun activities and “having kai [food] and a cuppa.” He talked of the importance of believing in young people, having hope and offering creative plans to support rather than enforce unworkable plans and conditions. He discussed how vital it was for police to gain understanding and knowledge specific to FASD and to use that to respond better to young people at the time of engagement with them (i.e., potential arrest).

Best practices for justice specifically. Apart from early screening and assessment of FASD, practitioners emphasised the need for diversion from justice altogether by help offered before children get into trouble and then the use of police discretion to avoid prosecution.

For disabled children, ultimately, we need them to not enter any justice involvement and if they have contact with the police for the police to immediately try and work out alternatives to formalized justice involvement.

Once youth became involved in more formalised justice processes, practitioners spoke of the need to provide specialised FASD services and supports.

In the Criminal Justice System, at all stages, we need communication assistants and specialist services e.g., Courts that are mental health and neuro-diversity focused. Without this specialist knowledge and skill set our children continue to be treated as neuro-

typical and they are highly stigmatized ... If we have more problem-solving justice process or court process[es] as well as police who are FASD informed or specialist lawyers and justice social workers and corrections officers we're bound to find that our justice system in particular will be more tolerant.

A few practitioners noted the importance of central support people as young people navigated the justice system. This could include the support person helping them get to appointments or court on time, as well as connecting all the different agencies to the one young person.

[A] lot of people who come into contact with the justice system who could benefit from I think possibly the role of a social worker for a young person but basically a central support person who is their go-to for pretty much everything.

One of two lawyers who contributed to this research outlined a range of ways in which the justice system could be improved for youth. This included having lawyers trained in FASD, using the specialist problem-solving court model already in operation in a few courts in Aotearoa New Zealand to enable courts to offer a suite of support and welfare and advice services on the day of court appearances. This might include requests for communication assistants more often, requests for specialist neuro-psychologist reports and FASD assessments, ensuring court flexibility in that alternatives to sentencing to court orders are used for those with FASD, and ensuring disability rights are considered and upheld by referring to sentencing decisions in previous court cases.

A practitioner with a particular focus on communication and language skills noted how vital it was to employ speech language therapists in multiple settings, including justice and multidisciplinary assessment teams, to ensure young people could

both understand what was happening for them and actively participate in justice proceedings. Other professionals agreed that it was important for everyone to use simple, concrete language in justice and call on the use of communication assistants and use visuals or easily read materials to help young people understand legal processes, Family Group Conferences and court-ordered bail or supervision plans.

Change to systems

All participants noted the need for FASD to be included in the Disability Support Services for funding, as currently FASD, in its own right, is not accepted as a funded disability. Participants were adamant this needed to change, and that Aotearoa New Zealand as a nation and its government needed to accept FASD as it would any other disability. This would then normalise the disability for support and development and have a knock-on effect of the development of national plans, training, and strategies and interventions across all systems.

We need resourcing on every front to alleviate the difficulties and that's not even that expensive. It's way cheaper than imprisoning them all.

It [FASD] can be classed as a disability but it's got to have the lifelong funding to go with it and that it's recognised and so allowances are made.

But I guess I think what people with FASD need is they need for the government, or all the systems across education, health, justice, social development, to understand that FASD is a real disability.

The application and enhancement of disability rights were vital for youth living with FASD to be able to live a good life.

Enable them to be the people that they can be and don't judge them for their problems, because it's just terrible to see

all these children growing up feeling bad about themselves because they've got a disability.

I just would like to see people with FASD able to be themselves and to flourish with the set of problems that they've been born with and do the very best they can and be happy.

Education system change was noted as significant—several practitioners noted the need to pick up FASD through education screening and assessment as part of the early diagnosis and intervention systems-wide change.

You could be picking up kids so that before they even get to school...But once they are in school, let's actually make sure that the teachers and the other professionals around are equipped to give them the best help that they can and let's put that with a lot more intensity than ever anyone does at the moment.

Training for everyone involved in the care of at-risk-of-justice involvement children was considered a necessary system change.

We're always gonna need well trained and highly knowledgeable professionals and support staff so we need to ensure that anyone working with children and youth with FASD has had base training and advanced training in understanding a managing those living with FASD so that is a systems issue, and all professional groupings and training institutions need to create FASD informed pathways of training.

For social workers and other justice professionals in particular changed practice was recommended:

[You] need to think about neuro-disability and ableism, and think about what their assumptions are around expectations because they're in their own neuro-typical world, so to speak, what

does that look like? What are the rules? What are the layers of expectations that they're placing on these young people? Is it too much? We talk about things like little messages, "brain not blame." Think about the brain. If you understand the brain, then you'll be less likely to blame.

A number of participants noted that substantial system change could only come from significant government intervention and effort by those in power.

But I really think change has got to come from the top. It's got to be a national project or program that just looks at the whole thing.

And several practitioners linked system change to challenging the acceptance of harm from alcohol in New Zealand culture which led to the ignoring of FASD as a lifelong disability as well as harsh judgement of those living with FASD. Practitioners felt the need to challenge all of this at a societal level and at the systems level.

It's something to do with our alcohol problem in New Zealand. It's the denial around the harm that drinking causes... But there's something about society that won't face it.

But, actually, to reduce the harm of alcohol, which reduces the number of people born with FASD, you actually have to as a society look at your drinking.

Professionals talked about the need to deal with our intolerance and stigma and rejection of youth living with FASD, and that we could not do that until Aotearoa New Zealand faces the denial of alcohol harm and seeks to lower the large numbers of children born every year with FASD.

Discussion

Social workers and other professionals working with vulnerable children and young people, who are at risk of, or currently in

contact with the justice system need to “get on the journey.” There is widespread ignorance and misunderstanding about what FASD is and how to incorporate best practices when working with this disability across multiple systems (Pei et al., 2019). Nowhere is this more harmful than in the criminal justice system which upholds reasoning, accountability and learning from one’s mistakes as pillars of dealing with those who offend (Wartnik et al., 2021). But when the child is disabled and unable to do any of these things well because of their serious brain injury, the justice system “gets angry,” and punishes youth for their inability to follow rules, keep appointments, work out alternative strategies, understand what the complicated conditions are, and communicate well with neuro-typical adults who have not been trained in managing or helping clients with severe neuro-impairments (Gibbs, 2021). The expectations are too high, and the gaps in training and skills from practitioners are obvious. Practitioners need to “get in the game” and, to do this, we need baseline FASD training at both introductory and specialist levels. There are several great courses already available for practitioners to access (see for example: <https://www.tepou.co.nz/initiatives/fetal-alcohol-spectrum-disorder-fasd>, and Lewis, 2022), as well as excellent online guidance specifically for social and justice workers (Oranga Tamariki Practice Centre, n.d.; Saskfasdnetwork, n.d.). In-house disability advisors for Oranga Tamariki can also provide workshops for staff who request them and FASD-CAN members and other NGOs throughout the country are more than willing to provide good local training bespoke to specific clients (FASD-CAN, n.d.).

One participant noted that a national FASD training strategy would be helpful across all systems involved in the lives of youth living with FASD. In Australia and Alberta, we have excellent examples of strategy plans with associated funding that include training (Department of Health, 2018; Flannigan et al., 2022). These would be good models to work

from in Aotearoa. In order to improve how youth are dealt with in the criminal justice system, we need to ensure a raft of best practices that include supporting caregivers and focusing on the wellbeing of the whole whānau (Lambie, 2020; Oatley & Gibbs, 2020; Reil et al., 2022; Rutman, 2016). Best practices begin well before youth start getting into trouble and include early screening, assessment, diagnosis and a clear plan of supports which stretch into education, speech and occupational therapy, family respite and other assistance. Children are unlikely to either end up in justice because of their neuro-disabilities if an infrastructure to address FASD is in place but alas in spite of significant efforts there currently is no FASD national strategy in Aotearoa New Zealand (Human Rights Commission, 2021). Aotearoa New Zealand does have a well written FASD action plan, but the absence of funding has seen little improvement since the plan was published in 2016 (Human Rights Commission, 2021; Penfold & Cleave, 2022).

A priority for action would be to implement the UN convention general comment on children’s rights in juvenile justice which states strongly that children (under 18 years) with FASD should not be in criminal justice; in other words, they should be funnelled out through diversion and prevention efforts (Lambie, 2020; United Nations Committee on the Rights of the Child, 2019). But if children still end up being processed within the justice system, then they need to be fully accommodated for their disabilities; these accommodations would include: FASD-informed police, lawyers, judges, social workers, allied health workers, psychiatrists and psychologists to name a few professions; justice processes that accommodate diverse learning and communication abilities; the use of specialist FASD court hearings; the implementation of individualised plans; the use of the least restrictive penalties; and ensuring the best interests of children are always upheld even when resources are limited (Gibbs, 2021, 2022). Many of these practices are enshrined in our current

Oranga Tamariki Act 1989 but are not upheld in the practices towards our youth who get enmeshed in the youth justice system.

Participants in our study emphasised the need for both human and disability rights to be upheld and that wellbeing was about neuro-divergent youth being able to participate and enjoy the same rights and privileges as neuro-typical youth. Justice professionals need to develop what Chapman and Carel (2022) called *neuro-typical humility*. The use of neuro-typical humility when working with neuro-divergent people would include: moving away from deficit views of neuro-difference; embracing a neuro-diversity paradigm which focuses on the rights, strengths and flourishing capacities of neuro-divergent people; the recognition that those living with neuro-disabilities are not doomed to lower wellbeing; and recognition that their thriving and interests can look very different from neuro-typical thriving and interests. Participants in this study emphasised person-centred practice; listening to families as experts; showing compassion; stop trying to fix people; being educated in how the brain works, and that behaviours are often a sign of brain injury and diversity and not *badness* as such; and that neurotypical people are not superior to neurodivergent people.

The knowledge and skill-base amongst social workers and other professionals working in the justice space with youth who have FASD has been neglected through lack of infrastructure, base-training and allocation of funding to resource proper assessments and interventions. Social workers have on occasions joined with others to advocate for change at individual, organisational and structural levels (Gibbs, 2022; Gibbs et al., 2020). FASD-CAN (n.d.), the peak Aotearoa New Zealand support body for caregivers and professionals, specifically encourages professionals to collaborate with whānau

to undertake joint training, joint awareness and knowledge building, as well as encouraging ongoing submissions to MPs, politicians with disability responsibilities and senior managers within their own organisations. As a social worker and well-known disability advocate, I have continued to advocate for change in multiple media outlets, recognising that nothing will change unless the voices of all interested stakeholders are heard. There are also other social workers and allied professionals in Aotearoa participating in strategic initiatives to push for more focus on neuro-disability and FASD, in particular throughout Oranga Tamariki, Corrections and NGOs working in the justice sector.

Conclusion

Currently, FASD is not funded as a disability in Aotearoa even though it is two or three times more prevalent than autism, which is funded. This is a government issue that not only impacts individuals who are denied all manner of assistance, but it affects the services who want to help but cannot because of limited funding to work with this group of disabled youth. This, in turn, hampers the work of helping professionals, whether in the justice system or elsewhere, as they have few places to find the right kind of help for their clients. Hence, the call for this disability to be fully funded is urgent (Human Rights Commission, 2021; Penfold & Cleave, 2022). Urgent training and practice guidance are also required for all professionals working in the youth justice space. A fully funded national FASD strategy would also ensure disability rights are upheld to enable flourishing and participation by young people living with FASD who are, too often, left on the margins of society.

Submitted: 25 May 2022

Accepted: 2 December 2022

Published: 15 December 2022

References

- Alcohol Healthwatch. (2021). Prenatal alcohol exposure and lifelong impact of Fetal Alcohol Spectrum Disorder [Fact sheet]. Auckland: Alcohol Healthwatch. <https://www.ahw.org.nz/Portals/5/Resources/Fact%20Sheet/2021/Factsheet%20-%20Prenatal%20alcohol%20exposure%20and%20lifelong%20impact%20of%20FASD%20Sept%202021%201.pdf>
- Chapman, R., & Carel, H. (2021). Neurodiversity, epistemic injustice, and the good human life. *Journal of Social Philosophy*. <https://doi.org/10.1111/josp.12456>
- Department of Health. (2018). *National FASD strategic plan*. Commonwealth of Australia. <https://www.health.gov.au/sites/default/files/national-fasd-strategic-action-plan-2018-2028.pdf>
- Durie, M. (1998). *Whaioira: Maori Health Development*. Oxford University Press.
- FASD-CAN. (n.d.). Fetal Alcohol Spectrum Disorder Care Action Network. <https://www.fasd-can.org.nz>
- FASD Coalition. (n.d.). *Ten brain domains (functions) affected by FASD* [Fact sheet]. Canada: FASD Coalition. <https://www.fasdcollection.ca/wp-content/uploads/2016/10/Ten-Brain-Domains.pdf>
- FASD Outreach. (n.d.). *8 magic keys* [Fact sheet]. Canada: FASD Outreach. <https://www.fasduitreach.ca/resources/all/0-9/8-magic-keys>
- Flannigan, K., Kapasi, A., Pei, J., Murdoch, I., Andrew, G., & Rasmussen, C. (2021). Characterizing adverse childhood experiences among children and adolescents with prenatal alcohol exposure and fetal alcohol spectrum disorder. *Child Abuse & Neglect*, *112*(2021), 104888. <https://doi.org/10.1016/j.chiabu.2020.104888>
- Flannigan, K., Wrath, A., Mcfarlane, A., Murphy, L., & Rogozinsky, L. (2022). Integrated service delivery in fetal alcohol spectrum disorder (FASD): A review of the Alberta FASD service network model. *Journal on Developmental Disabilities*, *26*(2). <https://doi.org/10.5281/zenodo.5711239>
- Gibbs, A. (2021). Neuro-disabilities and criminal justice: Time for a radical re-think. In E. Stanley, T. Bradley, & S. Froideville de Monod (Eds.), *The Aotearoa handbook of criminology* (pp. 358–369). Auckland University Press.
- Gibbs, A. (2022). I am not a bystander ... abuse in care still continues: It's not just in the past. *Reimagining Social Work in Aotearoa*, The RSW Collective Blog. <https://reimaginingsocialwork.nz/2022/03/15/i-am-not-a-bystander-abuse-in-care-still-continues-its-not-just-in-the-past>
- Gibbs, A., Bagley, K., Badry, D., & Gollner, V. (2020). Foetal alcohol spectrum disorder: Effective helping responses from social workers. *International Social Work*, *63*(4), 496–509. <https://journals.sagepub.com/doi/pdf/10.1177/0020872818804032>
- Gibbs, A., & Sherwood, K. (2017). Putting fetal alcohol spectrum disorder on the map in New Zealand. *Psychiatry, Psychology and Law*, *24*(6), 825–842. <https://doi.org/10.1080/13218719.2017.1315784>
- Gilbert, D., Mukerherjee, R., Kassam, N., & Cook, P. (2021). Exploring the experiences of social workers in working with children suspected to have fetal alcohol spectrum disorders. *Adoption & Fostering*, *45*(2), 155–172. <https://journals.sagepub.com/doi/full/10.1177/03085759211011735>
- Human Rights Commission. (2021). *Report of the disability rights commissioner and children's commissioner to the prime minister, FASD: A call to action*. https://www.hrc.co.nz/files/6516/3815/0843/FASD_Report.pdf
- Lambie, I. (2020). *What were they thinking? A discussion paper on brain and behaviour in relation to the justice system in New Zealand*. Office of the Prime Minister's Chief Science Advisor. <https://cpb-ap-se2.wpmucdn.com/blogs.auckland.ac.nz/dist/f/688/files/2020/02/What-were-they-thinking-A-discussion-paper-on-brain-and-behaviour-in-relation-to-the-justice-system-in-New-Zealand-updated.pdf>
- Lewis, J. (2022, March 16). Course covering children's neuro-disabilities. *Otago Daily Times*. <https://www.odt.co.nz/news/dunedin/health/course-covering-children-s-neuro-disabilities>
- Oatley, V., & Gibbs, A. (2020). Improving treatment and outcomes for young people with fetal alcohol spectrum disorder in the youth justice system: A social work led response and practice framework. *Aotearoa New Zealand Social Work*, *32*(2), 5–16.
- Oranga Tamariki. (n.d.). *5S model* [Fact sheet]. <https://practice.orangatamariki.govt.nz/assets/legacy/documents/knowledge-base-practice-frameworks/fetal-alcohol-spectrum-disorder/fasd-5s-template.pdf>
- Oranga Tamariki Practice Centre. (n.d.). *Fetal alcohol spectrum disorder (FASD)* [Fact sheets]. <https://practice.orangatamariki.govt.nz/previous-practice-centre/knowledge-base-practice-frameworks/fetal-alcohol-spectrum-disorder/>
- Penfold, P., & Cleave, L. (2022, March 10). Government plan to tackle fetal alcohol spectrum disorder has failed. *Stuff*. <https://www.stuff.co.nz/national/stuff-circuit/300536280/government-plan-to-tackle-fetal-alcohol-spectrum-disorder-has-failed>
- Pei, J., Kapasi, A., Kennedy, K. E., & Joly, V. (2019). *Towards healthy outcomes for individuals with fetal alcohol spectrum disorder*. Canada FASD Research Network in collaboration with the University of Alberta. <https://canfasd.ca/wp-content/uploads/publications/Final-Towards-Healthy-Outcomes-Documents-with-links.pdf>
- Pitama, S., Robertson, P., Cram, F., Gillies, M., Huria, T., & Dallas-Katoa, W. (2007). Meihana model: A clinical assessment framework. *New Zealand Journal of Psychology*, *36*(3), 118–125.
- Reil, J., Lambie, I., Becroft, A., & Allen, R. (2022). *How we fail children who offend and what to do about it: "A breakdown across the whole system"*. The Michael and Suzanne Borrin Foundation, the New Zealand Law Foundation & the University of Auckland. <https://www.lawfoundation.org.nz/wp-content/uploads/2022/04/2018-45-28.Children-Who-Offend.Final-research-report-March2022.pdf>
- Rossen, F., Newcombe, D., Parag, V., Underwood, L., Marsh, S., Berry, S., Grant, C., Morton, S., & Bullen, C. (2018). Alcohol consumption in New Zealand women before and during pregnancy: Findings from the Growing Up in New Zealand study. *The New Zealand Medical Journal*, *131*(1479), 24–34.
- Rutman, D. (2016). Becoming FASD informed: Strengthening practice and programs working with women with FASD. *Substance Abuse: Research and Treatment*, *10*(S1), 13–20. <https://doi.org/10.4137/SART.S34543>

- Saskfasdnetwork. (n.d.). *Tips for justice workers FASD* [Fact sheet]. https://ac965253-06fe-4ffb-8eb5-c38685bfd030.filesusr.com/ugd/6eb9fe_bd462e3cf2fd4240a8b12f793c73f346.pdf
- Thomas, D. (2006). A general inductive approach for analysing qualitative evaluation data. *American Journal of Evaluation*, 27(2), 237–346. <https://journals.sagepub.com/doi/pdf/10.1177/1098214005283748>
- United Nations Committee on the Rights of the Child. (2019). *General comment No. 24 on children's rights in juvenile justice. Para 28. CRC/C/GC/24* https://tbinternet.ohchr.org/Treaties/CRC/Shared%20Documents/1_Global/CRC_C_GC_24_8968_E.docx
- Wartnik, A. P., Anderson, L. G., & FitzGerald, A. J. (2021). Views from the bench: Fetal alcohol spectrum disorder in the courtroom. In N. Novick Brown (Ed.), *Evaluating fetal alcohol spectrum disorders in the forensic context*. Springer. https://doi.org/10.1007/978-3-030-73628-6_18