

We are not doing enough for children with neuro-disabilities

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I recently made a submission to the Abuse in Care: Royal Commission of Inquiry on behalf of a young whānau-member survivor who is autistic and lives with Foetal Alcohol Spectrum Disorder (FASD), Attention Deficit Hyperactivity Disorder (ADHD) and mental health issues. I made that submission also because I am a social worker and a staunch advocate for those who live with neuro-disabilities; many of them have experienced early removal from birth families, as well as lifelong rejection and misunderstanding by systems of education, health, care and justice. In my submission, I discussed how today's current care and justice systems cause as much harm to children and whānau as historic ones. In my recent Reimagining Social Work blog (Gibbs, 2022), I highlighted the harm to children caused specifically by current, residence-based interventions in youth justice, but in this piece, I also want to highlight how multiple aspects of both current care and protection, and youth justice provision harm our children with neuro-disabilities. In a future, research-based article, I will highlight specific findings on best practices for working in the justice space for youth living with FASD (in preparation).

My motivation to discuss this topic is the current under identification of these children in the care and justice spaces; there are thought to be up to 50% of potential children in care (and even more in justice) living with neuro-disabilities, yet absolutely hardly any identification efforts are being made to find out what specific neuro-challenges these children are facing in the areas of communication, executive function, memory, emotional regulation and adaptive or social skills. Too many excuses are made by both health and child protection services

that we cannot afford the complex neuro-assessments required to understand what is going on for our children in care, yet when we fill our youth justice system up with these kids a few years later, they start costing us tens and hundreds of thousands of dollars per year. If expense is really the services' greatest concern, it's cheaper by far to assess them early so we can intervene early. What is \$9,000 for an assessment compared to \$250,000+ to place them in residences or \$500,000+ for bespoke one-child-only bail, or support homes, a few years later when they go off the rails? We waste *so much money* by not acting earlier, and we harm children by denying them the right to be assessed, and for disabled children especially, the right to live a good life. My submission to the Royal Commission was forward thinking, as well as backward looking, and it contained many suggestions of how we can implement better practice as social workers and helping professionals because I simply do not want to be attending another historic abuse in care inquiry in 20 years' time. Children and whānau in the neuro-disability space have suffered enough and we need to address the failings of our healthcare, care and justice systems now. Below I will consider some of the harms caused to children and youth with neuro-disabilities and their whānau when care and justice systems engage with them, and what needs to be done to address the issues explored.

We harm children with neuro-disabilities by failing to have the infrastructure and competence to screen, assess and diagnose early. While some services for autism and ADHD are offered before the age of five, most children with FASD and co-occurring conditions are not helped

AOTEAROA
NEW ZEALAND SOCIAL
WORK 34(2), 90–93.

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until it is almost too late. When children come into formalised care, few come with any formal diagnoses and few are thoroughly assessed with neuro-cognitive assessments, i.e., rarely are sensory, occupational, communication or cognitive assessments undertaken, even attachment and trauma-assessments can be “light” or missing. Caregivers inform me often that it then takes years of harm and chaos and multiple placements before these areas might be explored. Unfortunately, most social workers and others within health and care systems are still not trained in the nuances of what a neuro-disability looks like, across what experts call the 10 brain domains (FASD Coalition, n.d.). Often it is the caregivers or parents or other whānau who train themselves up with knowledge and skills and they then try and pass this knowledge on to those working with the child, with varying degrees of success, as whānau are often not believed. Ignorance is not an excuse when whānau are telling you the child is dealing with FASD, or another suspected neuro-disability. In reality, few social workers have been trained in disability frameworks, models or strategies (Badry & Choate, 2015; Gilbert et al., 2021). We need social workers who are curious and want to find out the underlying cause of worrying behaviour. In order for this to happen, however, we need good quality baseline and specialist training for social workers and all those working in care and justice settings. My own whānau member had to wait until 14 years of age to benefit from a detailed diagnosis report for FASD, and until 17 for autism, and it only happened via a youth justice pathway when requests had been made going back years for assessments via health, mental health and care and protection. For many children in care, this experience of delay is mirrored because general and mental health services have little neuro-disability expertise, or willingness to engage with conditions like FASD in particular. Care and protection resources are stretched and provision of help is often limited until a

child starts getting into minor offending. Children and young people in our care and youth justice systems are our most complex and vulnerable children and if we can find ways to do a better job for them *earlier*, we will benefit thousands of whānau. The social work profession needs a much deeper awareness of what neuro-disability is. By failing to consider (or know about) the basics, social workers tend to view children with neuro-disabilities as engaging in deliberate and wilful misconduct, and children with neuro-disabilities tend to get labelled as “naughty”. Fortunately, new training initiatives to help social workers and allied health professionals address their gaps in knowledge and skills are beginning to emerge (Lewis, 2022).

Of major concern is that children in care get fast-tracked to involvement with the justice system. We know that the majority of children involved in justice have some care and protection history (Reil et al., 2022). With that in mind, social workers may benefit from returning to advocacy principles and practices to attempt, as far as is practicable, to apply the United Nations Convention on the Rights of Children, most notably the following recent comment on justice and neuro-disabilities:

Children with developmental delays or neurodevelopmental disorders or disabilities (for example, autism spectrum disorders, fetal alcohol spectrum disorders or acquired brain injuries) should not be in the child justice system at all, even if they have reached the minimum age of criminal responsibility. If not automatically excluded, such children should be individually assessed. (United Nations Committee on the Rights of the Child. GC no. 24., 2019, para 28)

Unfortunately, when children with neuro-disabilities become involved in justice, they are viewed through a lens that is unforgiving and operates primarily on reasoning and behaviour-based models—not disability models (Gibbs, 2022; Wartnik et al., 2021).

These behaviour-based models fail to take account of the developmental age of the child, the child's dysmaturity, the child's susceptibility to grooming and victimisation, or the child's inability to fully understand or follow rules, conditions, neurotypical systems and adult expectations (even when these impairments are known, or previously diagnosed). Our youth justice system exemplifies ableism by setting our children up to fail because, instead of identifying and accommodating brain-domain differences and injuries, we punish those who offend (Reil et al., 2022). Our youth justice practice punishes those who do not learn from repeated mistakes even when this lack of learning is a strong indicator of neuro-disability alongside communication, impulsivity, executive and adaptive functioning difficulties. These same children who come from care backgrounds, who are both victims and offenders, are often those with a lifelong, fixed disabilities and they need accommodations, not negative judgments.

The best approach, therefore, is to introduce disability rights-based practices in care and protection and justice as early as possible. This is likely to include disability-focused specialist teams with specialist practitioners who can be called on early to assist a child and their whānau to get the wraparound supports they need. Disability teams and disability specialist social workers, of which there are only a few in Aotearoa New Zealand, can advocate for the specialist assessment and diagnosis of neuro-disabilities alongside brokering supports and opportunities for participation. If a disability-rights approach is taken specifically for neuro-disabilities then social work teams, including justice teams, can be better positioned to help children and young people flourish. Too many young people in our current care and justice systems experience failure rather than flourishing. I can truly say that from deep, personal experience, that my whānau member has been on the receiving end of a lot of "you are a failure" messages from a vast

range of helping professionals and justice officials who had little idea about disability or neuro-disability generally. I asked a group of caregivers recently to describe what neuro-typical good practice might look like and they talked of:

...person-centred practice; listening to families as experts; showing compassion; stop trying to fix people; being educated and understanding of how the brain works, understand that behaviours are often a sign of brain injury and diversity and not "badness" as such; and that neuro-typical people are not superior to neuro-divergent people.

For those children and youth living with neuro-disabilities who still find themselves in contact with youth justice processes there are practices that can be implemented to reduce the harm. Drawing on submissions from whānau members and the literature, the following can be helpful:

- Regularly normalise the use of diversion or alternative action plans rather than formal justice procedures.
- Ensure plans are focused on supporting whānau first rather than child-only, and focus on strengths, skills and positive interventions.
- If FGCs occur, then these need to be run by neuro-informed facilitators who facilitate plans that are simple and supportive and are not overlain with negative consequences should they not be followed—*less is more* in terms of conditions and punishment.
- Ensure all staff are neuro-disability trained and highly knowledgeable, including knowing how to access neuro-disability support services.
- At all stages of justice, use communication assistants and specialist neuro-disability services.
- Ensure neuro-informed policing and specialist neuro-informed justice social workers and legal advisors are employed.

Back in 2016, after much campaigning by whānau of children living with FASD, the Aotearoa New Zealand government created the FASD action plan, which ran until 2019 (FASD Working Group, 2016). This plan supposedly offered a chance for health and welfare services to become much more neuro-informed, but the plan received little core funding and ultimately failed to deliver, thus leaving the vast majority of children and youth with FASD in particular with few assessments, services or supports (Human Rights Commission, 2021). Both the children's and disability commissioners have campaigned hard for core funding, yet none has been approved (Human Rights Commission, 2021). We have so far to go before we can offer rights-based neuro-informed care or social work to our most vulnerable children.

Fundamentally, no child born with permanent brain differences and assessed as having a serious disability should be in our youth justice system where they continuously get punished for being born the way they are. Rather, they need to be acknowledged, assessed and cared for by specialist disability care teams. We will know these children have well-being and equity when we have kept them out of formalised care and justice processes, and enabled them to flourish and participate without punishment, as others who are regarded as neuro-typical are enabled to: we are all neuro-diverse after all.

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