If only Teina Pora had a MedicAlert bracelet

Anita Gibbs

Teina Pora was an 18-year-old Māori male who was convicted in 1994 of the rape and murder of Susan Burdett in 1992.1 Pora did not commit these crimes but he spent 21 years in prison before his case was heard by the UK Privy Council in London and his convictions were quashed.1 Crucial to his release and acquittal was the discovery that Pora had Fetal Alcohol Spectrum Disorder (FASD), a neuro-disability arising from prenatal alcohol exposure with lifelong impacts, most noticeably impairments of executive functioning leading to impulsiveness, poor reasoning, problem-solving skills and memory deficits. The primary impairments of FASD include physical and neurological impacts and they often co-occur with conduct and language disorders, and mental health issues, and lead many with FASD to poor educational outcomes, school exclusion, relationship problems, addictions and arrests.2–4 Teina Pora admitted to crimes he did not commit and he had a disability that made him vulnerable to doing this.5 I wonder if his story would have been different had he been diagnosed with FASD as a child and offered the protection of early intervention as well as a raft of other supports, for example, wearing a MedicAlert bracelet as young adults with FASD in Canada now do.5 By being diagnosed and wearing a MedicAlert device, perhaps Pora might have received a more appropriate response from arresting police officers and medical professionals involved with his case.

A study just out from Western Australia confirms that up to 90% of young people incarcerated have a severe neuroimpairment, many of whom will have FASD, but more often not than most of these will be undiagnosed.6 In New Zealand, we currently have no prevalence data for FASD but robust international evidence tells us that up to 5% of the general population will have FASD, and a much greater proportion of vulnerable groups—children in care, adopted children, offenders, indigenous populations and those with other disorders or mental health issues.2,7 FASD rates are higher than rates of autism or ADHD.3,7 The productivity losses due to FASD in New Zealand are estimated to range from $49 million to $200 million and the social and emotional burden on families supporting those with FASD is immense.6 Given these wide ranging costs, surely it is time to pay more attention to the scale of FASD as both a health issue and social problem.9

In the last 10 years, New Zealand has begun to implement measures to assess and diagnose FASD, as well as develop action for intervention, but this is currently happening in only a few places.5 FASD assessments need to be conducted by a multidisciplinary team and due to their complexity can cost up to $8,000. The medical and allied health professions are in need of training and upskilling to screen, understand and help individuals and families where FASD is an issue as well as organisational support that enables them to sustain these important services. The New Zealand FASD Action Plan9 has led to a few initiatives to pilot training materials and hopefully increase clinical diagnostic and assessment capacity. The action plan, while detailed and positive, has only $12 million from the public purse allocated to its implementation over four years, compared for example to Alberta, Canada (population similar to New Zealand), which spends around $18 million per annum on FASD services and research to cost-effectively prevent and treat FASD. Also sobering is the fact that the New Zealand Treasury levied almost one billion dollars in alcohol excise duties last year,10 and this has not been used to fund action to increase training, services or research in this now well-established area of neuro-disability.
In a recent UK *Lancet* publication, philosopher Havi Carel points out the extensive everyday struggle that children with FASD have and that we all need to understand this experience and accommodate the ‘virtue in deficit’ that having this disability entails. Each year New Zealand has up to 2,000 children born with likely FASD, and with 1,000s of other undiagnosed children, youth and adults, it is time to offer more support. Even a small intervention like MedicAlert bracelets can offset some of the negative impacts of school exclusion or arrest. The evidence-based research, mostly out of North America, highlights the importance of early diagnosis and intervention, having a stable home life and ensuring that a range of appropriate accommodations and targeted interventions that help build self-control are implemented. Medical and allied health professionals can play an important role in both the prevention of FASD and intervention when FASD is suspected. There are guidelines available for a range of health professionals and under the New Zealand FASD Plan more training is coming.

People with FASD can flourish with targeted help and support. We need to at the very least ensure that their rights as disabled citizens are upheld. They should have access to good-quality health provision, especially early screening and assessment, but they should also be acknowledged as having a neuro-disability that warrants life-course provision of support, and the right to be the definers of what that support might entail to enable them to live good lives in the same way as people with other impairments can live good lives. Teina Pora lost 21 years of his life in prison, yet he showed great ‘virtue in deficit’ and was poorly compensated, but his story compels us to intervene and ensure the next generation of Pora’s are treated better and helped before the damage is done.

**Competing interests:**
Nil.

**Author information:**
Anita Gibbs, Associate Professor, Department of Sociology, Gender and Social Work, University of Otago, Dunedin.

**Corresponding author:**
Anita Gibbs, Department of Sociology, Gender and Social Work, PO Box 56, University of Otago, Dunedin 9054.
anita.gibbs@otago.ac.nz

**URL:**

**REFERENCES:**


5. Malone, G. How a bracelet is helping first responders understand fetal alcohol spectrum disorder. TVO,


