



PARENTS OF VISION IMPAIRED (NZ) INC

National Office: 59 Commerce Street, Frankton, Hamilton

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www.pvi.org.nz

Providing a community to support parents of children with vision impairments

Parents of Vision Impaired

Parents of Vision Impaired (PVI) is a registered charity which supports parents who have blind, low vision, or vision-impaired children. There is no cost to enrol and we provide a supportive community of parents who are overcoming challenges every day. Our current membership is at just over 1300 active members, with close to 800 email subscribers.

PVI offers parents advice, information, and opportunities to meet other parents. We publish a quarterly newsletter (eVision) and have a members-only Facebook page (currently at 282 members) for families and whānau to share information and to network. PVI also runs an annual conference and AGM which allows parents and whānau to get together face to face for a longer time to talk, listen and learn in a social setting.

Additionally, PVI takes an active part in the disability sector through making sure that the voice of visually impaired children and their parents is heard in consultations with government, schools, local councils, and other organisations.

Submission on the Oranga Tamariki (Youth Justice Demerit Points) Amendment Bill: Summary

PVI does not support the addition/inclusion of a youth demerit system. Youth with visual impairments are more likely to have challenging behaviours; cognitive visual impairments are correlated with intellectual disability; and accessing support from our health and social support systems is difficult. These effects are compounded for Māori.

The proposed Youth Justice Demerit Points Amendment Bill fails to address these underlying drivers of offending, does not give the best possible chance for growth and rehabilitation, does not effectively address recidivism, and moves towards a more punitive approach for youth which disproportionately affects Māori and those living with disability. Given the disproportionate impact of such a Bill on disabled youth, PVI feels that a different approach is needed to address youth offending.

Rationale for our position

Visual impairments (VI) are underdiagnosed in Aotearoa New Zealand, meaning that young people who have a VI often don't receive the support that they need in their learning and social environments. Without diagnosis and without support, the visual fatigue and challenging behaviours associated with VI can be misinterpreted and misread.

More specifically, Keratoconus and Cerebral Visual Impairment are both common but underdiagnosed in Aotearoa New Zealand. Keratoconus is a progressive visual condition that predominantly affects Māori youth: generally Keratoconus affects 1 in 191 adolescents BUT 1 in 45 Maori adolescents¹. Keratoconus is associated with Maori ethnicity, atopy, lower school decile, visual impairment, and the underutilization of visual aids. There is currently no nationwide screening program or efforts to reduce the burden of disease associated with Keratoconus. Cerebral Visual Impairment (CVI) is a congenital condition, and the underdiagnosis of CVI contributes to insufficiency of vision services for children². While support is available, the variable nature of CVI along with difficulties in accessing ophthalmology services which are located only within certain tertiary health facilities, makes it challenging for families to get their child diagnosed.

International research has found that various forms of maladaptive behaviours occur at higher rates in children and adolescents with visual impairments, with self-injurious, aggressive and/or destructive behaviours in youths occurring more frequently the more severe the visual impairment³. The underdiagnosis of visual impairments means such behaviours are more likely to be misread and such youth to experience the youth justice system rather than ophthalmologist assessments and provision of services.

For children with congenital vision impairments, there can be an associated diagnosis of Intellectual Disability. Rates of offending by people with ID are unclear. However, it is suggested that a person with ID may be more likely to get "caught" than peers who can better talk their way out of trouble, understand risks and consequences, complex legal language or rights to silence or a lawyer⁴. Again, a demerit point system does little to address any of these issues.

All of the above issues are compounded for rangatahi Māori. The **Māori Health Disability Statistical Report (2019) Wai 2575, #B24**⁵ described difficulties found in attempting to locate robust, comparable data for vision-impaired tamariki Māori. That is, we don't know how many Māori whānau and their children have poor vision. Additionally, ophthalmology appointments for Māori children were poorly attended by families, irrespective of whether these were referrals from B4 school checks or regular

¹ (Owens & Gamble, 2003; Papali'i-Curtin et al., 2019)

² (McDowell, 2020a, 2020b)

³ (Lang & Sarimski, 2018)

⁴ (Lambie, 2020)

⁵ (Ministry of Justice, 2019)



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appointment rounds. Māori non-attenders were not routinely followed up by ophthalmology departments. The experiences of Māori in hospitals are that hospitals have consistently been alien and inhospitable environments for whānau⁶. Ophthalmology appointments through the publicly available health system are only available upon referral from a medical specialist such as a GP, with only certain urban centres having ophthalmology services. This makes transport and travel a major barrier when accessing ophthalmology services.

Addressing youth offending means addressing underlying drivers. As noted above, VI youth can exhibit challenging behaviours. Effectively addressing youth offending in VI youth will require thinking beyond the demerit point system which is at its core a punitive approach and will disproportionately impact on Māori and youth with disabilities.

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⁶ (Graham & Masters-Awatere, 2020)