



PARENTS OF VISION IMPAIRED (NZ) INC

National Office: 59 Commerce Street, Frankton, Hamilton

Postal address: PO Box 5629, Frankton, Hamilton 3242

www.pvi.org.nz

Providing a community to support parents of children with vision impairments

5 November 2020

Tēnā koutou,

Please find attached PVI's feedback on the next steps for transformation of the disability support system.

Ngaa mihi,

Rebekah Graham
National Executive Officer
Parents of Vision Impaired (NZ) Inc
Mobile: 0226215740
Email: rgraham@pvi.org.nz



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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 292 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.

Feedback on next steps for transformation of the disability support system

1. In relation to the story and proposed next steps...

- **what do you like?**
- **what's missing?**
- **what needs to be changed?**

The proposed ideas sound thoughtful and indicate positive progress. PVI families have appreciated being involved in the various EGL trials and have predominantly found it to be positive and a major improvement on previous services. PVI is predominantly very supportive of this approach and keen to see it rolled out across the motu.

However, on closer reading, the story tends to brush over key pain points for vision-impaired persons and their families – namely the slowness of larger services to respond agilely and in a timely manner, the paternalistic and inflexible attitude of existing services, an embedded medical model without health systems, and a tendency of government/state-funded systems to return towards one-size-fits-all solutions and regimented rules and regulations.



PVI observes that we are being asked to provide feedback on a document that is missing detail with regards to background information and are concerned that the Ministry of Health is “reinventing the wheel” and going over ground already covered by the Ministry of Social Development and the Ministry of Education with regards to engaging with disabled persons and their families. We are concerned that this process will take another three years, leaving families without sufficient supports and enduring difficulty accessing services year on year.

The story as it currently is written misses how obstruction by people in positions of power will be addressed. The story mentions equal partnership with tāngata whaikata but unless those who are already in a position of power are prepared to de-power themselves, learn to practice in anti-racist ways, and learn to work in true partnership, it is just the same old model just with newer, nicer words. How will this provided story actually create change on the ground, specifically with those organisations and decision-makers who have been doing this work for a long time and have not yet been able to change their approach? How will this story result in anti-racist practice on the ground? How will this story shift and streamline arduous administrative processes?



Within the current health and disability system, there are very few recourses or levers for holding people and service providers to account. Many parents self-silence out of fear of retribution against themselves or their young person. Others simply don't have the time or energy or resources to engage in long, protracted battles or Tribunal hearings. For example, a recent NZ Herald article found it took 2 years from the initial complaint to the Tribunal finding. In this case, a blind young person was abandoned and left alone at a bus stop without sufficient care due to the disability service failing to



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provide a scheduled caregiver. Not every family has the capacity or energy to write a complaint, let alone wait two years for a nominal apology.



Lastly, the story seems to be missing connections with related Ministry's, namely the Ministry for Social Development and Ministry of Education, both of whom have been involved in the disability space for some time, and who are also actively consulting and progressing change with regards to working with disabled persons and their families.

2. As we bring this work together what do you think success will look ...

- **for disabled people and tāngata whaikaha**
- **their families and whanau,**
- **the wider community**
- **the system as a whole**

For PVI families, success will look like a wider community that has a basic understanding on the nature of vision impairments and which easily and seamlessly engages with families in a positive and supportive manner. Success will look like professionals understanding the nature of vision impairments and how best to provide accessible services.



Families are often incredibly stretched and are dealing with multiple agencies and ministries. PVI is enthusiastic about a systems change that will be less exhausting for families. Success will look like families that have time and resources to enjoy spending

time with each other and engaging in activities that the whole family can enjoy and participate in. Success will also look like the Ministry of Health working alongside the Ministry of Education and the Ministry of Social Development, learning from each other, and providing integrated services for families.



PVI families with older vision-impaired adults have multiple stories of trauma. Success will look like future PVI families not having to endure being treated poorly or having to fight and to argue for basic human rights for their young person. Success will be positive stories of their young person living a good life.

3. What would a genuine and equal partnership approach to progress the proposed next steps look like and need to consider?

It will need to consider where the power sits. Currently power sits primarily with CEO's, managers, DHB's and suchlike. Few persons willingly concede power and less so to those they deem "unqualified" or "incapable" such as family members or to intellectually disabled persons.

It will need to consider who controls the money and how rules get navigated. For example, disability services currently "clip the ticket" from individualised funding – this is funding meant for the disabled person, but it gets clawed back into larger service providers to pay for their bureaucratic systems. Others aim to maximise profit and have closed less profitable services, despite disabled persons enjoyment of or need for such services (seen most recently with IHC).

It will need to consider paternalism, medicalisation, and racism and how these are enacted in everyday life by people in positions of decision-making power. How will anti-racism be embedded into disability support systems? How will the Ministry of Health use the levers available to it to shift paternalistic thinking and change systems already in place? How will this story shift the medical model thinking embedded into DHB-funded services and the perverse outcomes associated with having to quantify success in medical terms?

Vision impairments appear to be poorly understood by many, including disability services (except of course by persons responsible for providing specialist vision services). Parents often feel dismissed by professionals when attempting to explain or advocate for their child or young person's vision needs. There seems to be a strong



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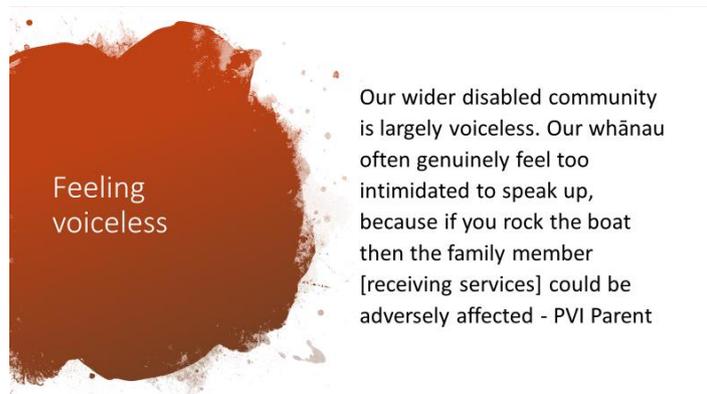
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need for ongoing training for disability services and associated professionals in this regard. A genuine and equal partnership would see parental knowledge and understanding of their child's condition(s) valued and welcomed and would leave parents feeling treated with dignity and respect.



Vision needs are always overlooked and staff desperately need more education around this area - PVI Parent

It will need to consider how those persons already in positions of power and who control funding co-opt the language of EGL but fail to actually engage in meaningful change with regards to their provision of services. IDEA Services and IHC are excellent case studies of how, despite multiple complaints and reports and reviews, an organisation can still receive millions from the MOH for a service that continues to fail families.



Our wider disabled community is largely voiceless. Our whānau often genuinely feel too intimidated to speak up, because if you rock the boat then the family member [receiving services] could be adversely affected - PVI Parent

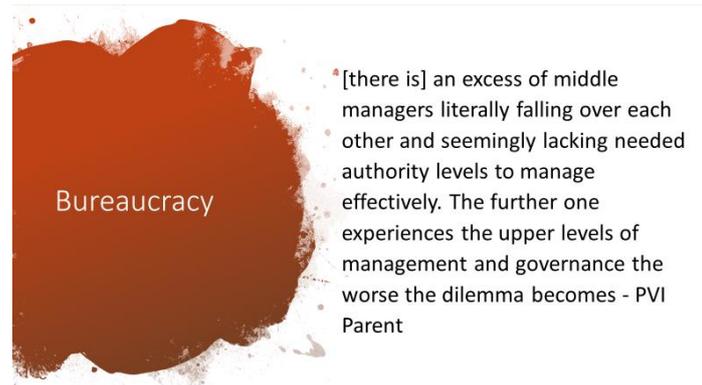
Lastly, it will involve learning from the previous EGL trials in Christchurch, Waikato and mid-Central. It is worth noting that PVI has already responded to and engaged with community feedback with the relevant MSD-associated sessions on these. To be perfectly frank, it is getting exhausting being constantly consulted by various government departments, who seem a little unable to talk with each other and share findings from their respective community consultations.

4. How could a mechanism to enable and support this partnership approach work and what skills and capabilities are needed?

I am not entirely sure what this question is asking.

5. Other suggestions about the story you want the advice to Ministers and the Cabinet Paper to tell?

PVI families note the need an agile and flexible disability support system that can appropriately meet the social, emotional, and physical needs of disabled persons and their families. Within vision impairments, for example, there is a wide range of eye conditions with a range of abilities and requirements. Even people with the same eye condition may have very different capabilities for vision, and vision ability itself varies according to various conditions (e.g. time of day, lighting, stress levels, noise, sensory capacity). Any system must be capable of responding agilely in a manner that is relevant for each family and that does not place additional burdensome administrative requirements on families.



PVI families want a “one stop shop”. The current system is fractured and piecemeal. The Ministry of Education, Ministry of Health, and Ministry for Social Development are difficult, time-consuming agencies for families to navigate. It is eternally exhausting jumping through each of their respective hoops! Each system is designed from the perspective of clinicians and administrators, with the time and cost to families not included in reporting structures, goal-setting, targets, or financials. These costs are invisible in the current reporting structures but are borne by family members of the disabled child. How might we better report on the cost to families of engaging with services?

6. Anything else?

Other key frustrations for PVI families include:

- (a) getting appropriate and timely medical appointments with paediatricians and ophthalmologists who are only located at tertiary facilities in major urban centres
- (b) insufficient medical and disability services in rural areas, requiring long travel times which places additional stress on families
- (c) professionals who engage with their vision-impaired child but who are not vision specialists (e.g. teachers, nurses, caregivers) do not always receive appropriate support and training regarding best practice when engaging with a vision impaired person. Every new person that enters the child’s life must be trained afresh on these matters, often by the parent. Parents find this tiring, especially when their concerns or attempts to explain are treated dismissively.
- (d) Sometimes familial support means it might not be ‘mum’ who is attending meetings. Nevertheless, having positive and supportive familial relationships is vital to positive long-term outcomes for all.