



STRENGTHENING PARENT/WHAANAU CAPABILITY

Improving outcomes for blind, deafblind, low vision and vision impaired
children and young people



DR REBEKAH GRAHAM
WINSTON CHURCHILL FELLOW 2023
PARENTS OF VISION IMPAIRED NZ
MARCH 1, 2024

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Acknowledgements

Thank you so much to those who have supported and encouraged me on this learning journey. Firstly, to my family, who both encouraged me to apply and were supportive of me being away. Next, thank you to Parents of Vision Impaired for being a supportive employer, for cheering me on, and for making sure there have been plenty of opportunities to share my learning. Thank to Blind Low Vision NZ for your ongoing support of consumer groups, such as Parents of Vision Impaired.

Lastly, and most importantly, thank you to the Board of the Winston Churchill Memorial Trust, for believing in me and what I wanted to do, and for funding me to undertake this research. Your support was instrumental and deeply appreciated.

Introduction

Parents of Vision Impaired NZ (PVI) is a nation-wide parent-led group, driven by parents, for parents. PVI has strong connections within the group and with local providers. As a national group, with members across the country, PVI is in an ideal place to disseminate information and work with our partners to create and deliver parent programs which build capacity and capability, strengthen whānau networks, and enable parents/whānau to support their young person into employment.

My research project was to understand the exciting things happening in the UK and Scotland; and use that knowledge to inform PVI's programmes and share with the community. I travelled to London and Edinburgh and met with:

- Karen Hirst, CYPF Early Support, Education and Training Manager, RNIB
- Katrina Thompson, Family Support Officer, RNIB Children, Young People and Families
- Chris Kelly, RNIB Edinburgh
- Rachael McMurchy, Policy Officer Haggeye, Edinburgh
- Luke Wakefield, VICTA Parent Network, London

Key learnings

Online programmes for parents: Being able to draw on an already developed parent programme designed for online use. This is a useful resource to discuss with our parents and tailor it to a New Zealand context.

Accessibility: Seeing access requirements enacted in thoughtful ways opened my thinking to what is possible here in New Zealand. This ties into employment and training opportunities in a very practical way; if the work building is not accessible, how will our young person think that this is a career for them?

Continual engagement with government agencies: Keeping the needs of our families and children in front of government agencies is essential. Keeping needs front of mind ensures decisions are made both short and long term to benefit our children.

Developing youth activism: This is intentionally developed in Scotland through the Youth Parliament. Regular Zooms are held with young blind and low vision people who discuss the matters important to them. This process supports self-determination, develops political capability and capacity, and scaffolds interest in the process of enabling change.

Dissemination activities

Activities that have been done:

2023 PVI Annual Conference: presentation and workshop: I presented a summary of my overseas engagements and key learnings as part of the full conference programme. This was well received and there was interest from parents in hearing more about the Winston Churchill Fellowship.



Figure 1: 2023 PVI Conference

A key learning has been provision of an online programme for parents. The people I connected with at the RNIB generously shared their programme resources with me. I

drew on these for a workshop at the PVI 2023 Conference where we co-designed a parent programme for new parents (to be rolled out in 2024). This was a highly interactive session, with parents very enthusiastic about the possibility of a bespoke online programme for new parents.

2023 Biennial Hui Taumata for Kāpō Māori Aotearoa: I presented at the Kāpō Māori Aotearoa Biennial Conference and contributed into the workshops and discussion regarding whānau engagement and support.



Figure 2: Presenting at KMA 2023 Hui Taumata

Written articles: I collaborated with Rebekah Corlett MNZM to produce a presentation for the South Pacific Educators in Vision Impairment (SPEVI) 2023 biennial conference and to write a subsequent paper for their 2024 journal (J-SPEVI)¹. This collaboration brings awareness to parent experiences for educators across the South Pacific. Vision Australia subsequently invited me to present to their Community of Practice group², and there has been interest from colleagues in Australia to set up a parent advocacy and peer-support group similar to PVI.

¹ <https://www.spevi.net/jspevi/>

² <https://s-cloudfront.cdn.au.panopto.com/sessions/0aa4b7c2-e1d1-402a-9bd7-b12200b164bf/bb257730-b111-4bf6-a039-b12200b164d2-9615027b-b4b1-49ac-a47a-b123003320a9.mp4?invocationId=12a1c34f-1dd5-ee11-82ae-06aed105158a>

Social media: This was useful to share interesting snippets and information across the time of the Fellowship. This generated interest and was useful when more formally presenting. There is ongoing need to promote inclusion for disabled children here in Aotearoa New Zealand. Post-fellowship has seen regular inclusion of posts regarding disability inclusion on my personal social media, PVI social media³, eVision⁴, and my Substack newsletter⁵.

Key conversations: Post Fellowship I met one-on-one with the incoming CEO for Blind Low Vision NZ, Andrea Midgen. One of our discussion topics was transition from school into employment or further training. We will have ongoing conversations around how to improve this for young people and their families.

Accessibility: Working with local council. Access to public transport, cycle lanes, and pedestrian spaces is notably behind here in Aotearoa New Zealand when compared to the cities I visited during my Fellowship. There is a need for local parents to have access to resources and templates to assist them in making submissions. Since my Fellowship I have worked alongside my local council (Hamilton City Council) to raise awareness of access needs of low vision children⁶.



Figure 3: Screenshot from the Hamilton City Council campaign

³ <https://www.facebook.com/pvinz>

⁴ Available on our website <https://pvi.org.nz/>

⁵ <https://drbex.substack.com/>

⁶ See for example, the video embedded some way down on this site: <https://hamilton.govt.nz/strategies-plans-and-projects/projects/cerf/>

Accessibility: National Advocacy: Drawing on my Fellowship experiences I contributed into a **Child Poverty Action Group (CPAG)** policy piece on disability and poverty, and how this intersection contributes to adverse outcomes for disabled children. I have increased my involvement with **Access Matters Aotearoa (AMA)**⁷, a Trust focused on accessibility for all. Travelling overseas and seeing firsthand how accessibility is (and isn't!) provided gave insight into key barriers young people face when transitioning from school. Seeing the integration of simple things, such as braille on bathroom doors, made me realise that we have some way to go here in Aotearoa New Zealand.

Government Agencies: Drawing on the conversations had with people in England and Scotland, it became clear that there is need to continually engage with government agencies. Keeping the needs of parents/whānau alongside that of the disabled person front of mind for government agencies is important and necessary. Subsequent to the Fellowship, I have prioritised contributing into these spaces to challenge and support as needed. Key spaces include meeting with Whaikaha – Ministry of Disabled People on relevant topics such as respite and support, ensuring that parent/whānau voice is included in the review of the HDC Code of Rights, and Access Matters Aotearoa.

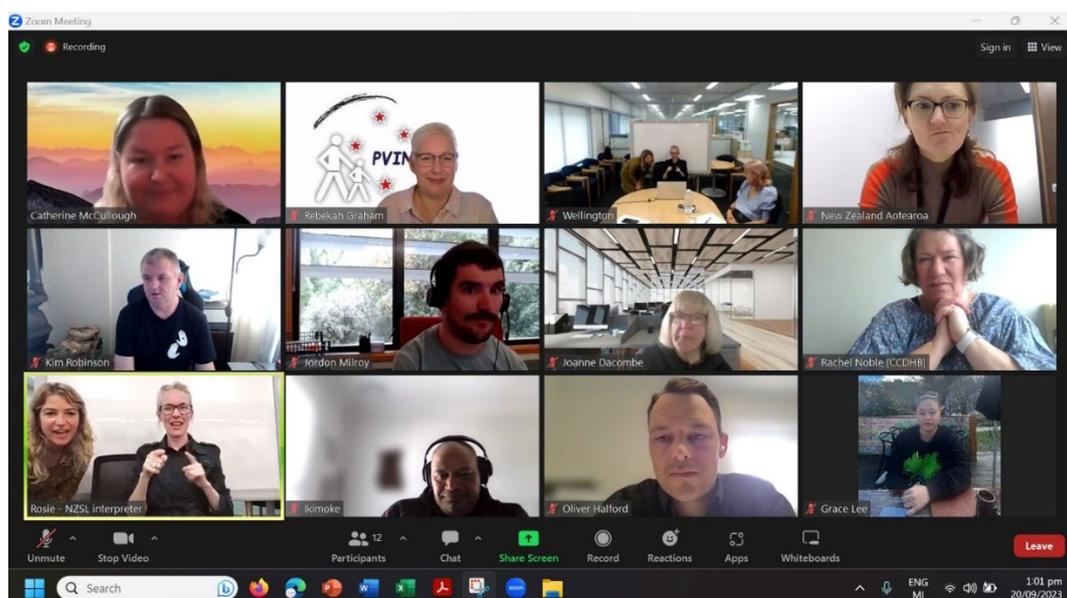


Figure 4: HDC Code of Rights Zoom, September 2023

⁷ <https://www.accessmatters.org.nz/>

Activities planned for 2024

New parent orientation programme: Families across the UK face the same challenges that parents here do; they are scattered across the country, often isolated, and have many questions. Holding a new parent orientation over Zoom has been quite successful and I am hoping to replicate that success here. At the co-design workshop at the 2023 PVI Conference there was strong support for online mechanisms and being able to connect with parents across the country. The next step, currently in progress, is to finalise the programme and then roll it out over two weeks. This is planned for Term 2 (as Term 1 is already a busy time for many parents).

Noho-based wānanga for whānau: The inclusion of parents and whānau in England and Scotland was well in advance of offerings here in Aotearoa. Post-fellowship I secured additional external funding for a noho-based wānanga for tāngata whānau Māori within PVI. The inaugural wānanga was held in Taupō in July 2023, and a second is scheduled for Auckland in May 2024. These are intentionally oriented differently to the PVI Annual Conference. Drawing on international learnings as well as findings from the Royal Commission, these wānanga provide spaces for capacity building alongside respite and care in a culturally supportive way.



Figure 5: Attendees at the inaugural PVI whānau wānanga.

Accessibility toolkit: I am aiming to draw on this to develop a toolkit for parents to use when looking to raise accessibility awareness in their own communities. This toolkit will contain templates, topics, and key information and phrases to support parents to engage with decision making bodies in their local area.

Conclusions

Overall, the Fellowship has encouraged me to keep advocating for parents and whānau. Seeing the high level of inclusion and support provided overseas has shown me what is possible. The areas of focus have been accessibility, parent/whānau involvement, and transition from school into education, employment, or training. Each of these areas has specific outcomes; overall the common theme is partnership and collaboration. That is, finding ways to partner with others who are interested in achieving particular outcomes so that it is not all reliant on myself or on PVI. This is healthier for me and more sustainable long-term.

Appendix 1: Travel diary

Travel details:

- Arrive London, England on 30 June 2023
- Train to Edinburgh, Scotland on 4 July 2023
- Return to London - visit Paris (annual leave)
- Return to London 13 July 2023
- Leave London 16 July 2023

While in London I familiarised myself with the Tube and public transport systems as well as making connections with relevant staff/persons from the Royal National Institute of the Blind (RNIB), and our PVI equivalent in England.

In Scotland the core connections were with the Youth Engagement team who run the Haggeye program for blind and low vision young people. This included learning about the Scottish Youth Parliament, and the ways in which blind and low vision young people are actively encouraged to develop in their political activism.

Core connections made:

- Katrina Thomson, Youth Engagement, Haggeye, Scotland
- Rachel McMurchy, Policy Officer, RNIB Scotland
- Karen Hirst, CYPF Early Support, Education and Training Manager, RNIB England
- Chris Kelly, RNIB Edinburgh
- Luke Wakefield, VICTA Parent Network, London

Zoom and online tools such as email were excellent for facilitating initial meetings and conversation, and for sharing of resources and information post-travel.

Appendix 2: Publications and presentations

- Graham, R. & Corlett, R. Parent Perspectives on Engaging with Educators and Specialist Staff. Presentation to *South Pacific Educators on Vision Impairment (SPEVI) Annual Conference 2023*. Online, January 17-20, 2023. Link to presentation recording on YouTube: <https://youtu.be/t5ROdyGbThE>
- Graham, R. (2023). *Aotearoa New Zealand failing to meet human rights obligations to disabled people according to 2023 Human Rights Tracking data*. Substack. 23 June 2023.
- Graham, R. (2023). *Schools keep excluding our vision impaired kids and it's not good enough*. Substack. Online. 23 August 2023.
- Graham, R. (2024). *Assistive technology is inclusion*. Substack. Online. 7 March 2023.
- Graham, R. Social inclusion for children/young people with blindness and low vision. *SPEVI Community of Practice for Parents and Carers*, Online workshop, 26 February, 2024. Facilitated by Melissa Fanshawe, SPEVI co-president and Melinda Whipp, parent volunteer facilitator for Vision Australia Parent Community. Link: <https://s-cloudfront.cdn.au.panopto.com/sessions/0aa4b7c2-e1d1-402a-9bd7-b12200b164bf/bb257730-b111-4bf6-a039-b12200b164d2-9615027b-b4b1-49ac-a47a-b123003320a9.mp4?invocationId=12a1c34f-1dd5-ee11-82ae-06aed105158a>
- Graham, R. Supporting parent involvement. *PVI Annual Conference*. Movenpick Hotel, Wellington. 3-5 November, 2023.
- Graham, R. Workshop 2: Co-designing an induction for new parents. *PVI Annual Conference*. Movenpick Hotel, Wellington. 3-5 November, 2023.
- Graham, R., & Corlett, R. (2024). Parent perspectives on engaging with educators and specialist staff. *Journal of South Pacific Educators on Vision Impairment (JSPEVI)* 16(1), 38-44. Link: <https://www.spevi.net/jspevi/>
- Masters-Awatere, B., Graham, R., & Cowan, C. "Ahakoa kāhore mātou, i te kite kei te kite - We may be blind but we have vision". *Kāpō Māori Aotearoa New Zealand Hui Taumata 2023*. Millenium Queenstown. 16-18 November, 2023.
- McKenzie, R., Graham, R., d'Apice, T., & Godfery, J. Partnerships and Collaboration Plenary Panel. *South Pacific Educators on Vision Impairment (SPEVI) Annual Conference 2023*. Online, January 17-20, 2023.
- Brown, C., Graham, R., Wallace, A., & Hogan, A. (2023, June). *Child Poverty Action Group 2023 Policy Brief on disability support: Stop driving disabled children into poverty*. Child Poverty Action Group, Auckland, NZ Link: <https://www.cpag.org.nz/policy-briefs/disability-support>
- Hogan, A., & Graham, R. (2023, 15 May). Why people with disability get caught in a poverty trap. *The Spinoff*, Online. 15 May 2023 Online. Link: <https://thespinoff.co.nz/society/15-05-2023/why-people-with-disability-get-caught-in-a-poverty-trap>