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Parents of disabled adults demand better support - research suggests

Most parents want their children to outlive them. Hoping your child dies before you is a strong sign of how distraught some parents feel, as the University of Auckland graduate Hemant Thakkar found out during the research for his PhD.

His thesis confronts the concerns of the parents of disabled adults about what will happen to their children when they die and he hopes his research will play a role in improving outcomes for people in this situation.

The North Shore resident was born and bred in Mumbai, India, shifting to New Zealand in 2002 to pursue further studies in the field of disability. His thesis: *"When I am no longer alive: Understanding what the parents want for the future of their disabled adult children with high and complex needs"* examines some of the issues parents of disabled children face in both countries.

It was a highly emotional topic, one that he prepared himself for by reading literature around dealing with delicate subjects and supporting participants.

"I knew that I was dealing with a very sensitive topic, so was mentally prepared for some emotional responses from the parents. But nothing prepares you for responses such as – 'I hope that my child dies before me'," he admits.

Hemant said that some of the parents he spoke to were completely at the end of their tether and couldn't bear the thought of leaving their children behind vulnerable to State care. They were the ones who often told him that they would rather see their children "move on in front of their own eyes".

His conclusion at the end of the study was that the formal support systems in both New Zealand and India are falling short in providing adequate support for disabled adults.

"Despite having a reasonably well-established disability support system in New Zealand, it became clear that our system is failing in adequately supporting the adults with high and complex needs and their families," he says.

"In India, there is minimal formal support from the State for disabled people. Traditionally, informal support of family and friends has been the backbone of support for most families. But, as family size reduces (as it has in recent years in India), the informal support from extended family is less available.

"This puts these families in a very vulnerable situation; many Indian parents are concerned that their children could end up on the streets or placed in 'mental institutions' if something happened to them."

Hemant's study highlighted an urgent need for better partnership between the parents of adults with high and complex needs and the professionals at both practice and policy level to ensure a better future for these children beyond their parents' lifetime. To that effect, the study recommends a unique model of partnership called 'Parents as Partners in Policy and Research (PPPR)'.

Hemant currently works as Acting Community Lifestyle Manager for Te Roopu Taurima, a kaupapa Māori disability service provider, assisting people to live independently and participate in community. Hemant's ongoing engagement in the field has made him increasingly aware of the need for more trained empathetic people in the disability sector.

"The sector needs people with the right skills and a good heart to make a positive difference in the lives of some of the most vulnerable people in our society."

To read the full thesis, visit ResearchSpace@auckland

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