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I am an occupational therapist who works with a small NGO in Brisbane supporting families who have children with very high support needs arising from a multiplicity of physical, intellectual and sensory impairments. There are approximately 200 children on our caseload. I see the futile struggle that every single one of these families goes through to secure essential equipment that will minimize the impact of their child's disability on the quality of their family life. I regularly assist families to 'beg' for money from Disability Services & from a variety of charities. I see families begin to crash and burn by the time their child is around 8 – 9 years old. By this time, parents are physically exhausted; they all have chronic back injuries; their family income has never returned to the levels it would have it they didn't have a child with a disability; the relationship between parents has generally cracked beyond repair. Of the 82 families I work with specifically, 28 parents are 'single' parents. 10% of the families I work who have disclosed this information to me are or have been living with partners who are physically abusive. By the time these children are around 10 years of age, every single family I work with is consumed by the thought of how they are going to manage as their child enters adulthood. In particular, how are their care needs going to be met once they are no longer going to school. I have worked with parents who contemplate relinquishing their child in the hope that it will secure a more 'secure' future for their child than the one they know they can physically and financially provide.

What sickens me is that a good portion of this heartache, stress and financial strain could actually be avoided if this country acknowledged its responsibilities.

I will focus on the equipment side of things because this is what I am employed to handle:

Every family on my caseload basically has the very similar equipment needs related to the manual handling component of care that could benefit greatly from a national insurance scheme. Each family needs a wheelchair accessible vehicle; every family on my caseload needs accessible housing, an accessible bathroom; lifting equipment (ceiling hoist in the longer term once stable housing is secured); electric bed to manage their child's positioning needs. Whilst some equipment in equipment is subsidized in Queensland, much of it isn't. This week, for instance, 5 families rang me to ask for advice about wheelchair accessible vehicles. I can provide a heap of information on that; what I can't provide is the financial resources to make it actually happen.

As a strong supporter of a national disability insurance scheme, I am keen to see access to disability specific equipment become much easier, and less of a lottery. I would be proposing that the Medical Aids Subsidy Scheme, one arm of Queensland Health (and the equivalent in other states) is funded through a National Scheme to fund essential pieces of equipment, based on the assessment of a registered therapist in consultation with the client or client's family they are working with. This would ensure that due processes are followed; that prescribers are accountable and the framework already exists to provide the necessary checks and balances.

I am keen to see all Aids & Equipment programs in each state develop a framework that is consistent across the board. There is enough experience here to do that without reinventing the wheel. In terms of implications for staffing, it would undoubtedly mean that staff levels for these programs is expanded to administer it. I would also envisage that Information Officers who are able to provide clients with detailed information about equipment options are employed so that clients without a regular service provider (or without a very good one) are also able to receive the information they need.

Although it is outside my scope of practice, another issue that families raise with me is that of care arrangements or day respite programs suitable for their children with very high support needs once they finish school. As an 'easy' solution, I have offered wondered whether the age of leaving for children with complex special needs could be raised to 21 across all states, given that these school environments have the equipment, staff and experience of working with these young adults to meet some of their needs. Yes, it is a stop gap solution, but in the absence of real alternatives, it would at least provide parents with a few more years of assistance. Implications, here, of course, relate to increases in staffing numbers & classrooms for special education schools.

Finally, as a therapist employed by a government funded organisation, I would love to see the focus turning to actual provision of service to clients. Too often, the ambiguity of ‘case management’ services translates into very little that is meaningful to a family at all. Clients want and need service (whether it be respite, in-home support; accommodation alternatives; equipment). I see millions of dollars being poured into the disability sector and so much of it going to fund salaries of people who are quite content to do as little as possible.

I remain excited by the possibility that Australia will follow best practice in terms of this new direction; and hopeful that rather than bog the process of introduction down, will learn from other countries where these systems are already in place.

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