13 August 2010

Productivity Commission Submission: Disability Care and Support
Personal Submission: Kate Evans & Frank Beard

To Whom It May Concern,

Our daughter is only three years old, but she is unlikely to live to see a National Disability Insurance Scheme put into place. She may not even live to see the results of this inquiry. Adania was born full term after an unremarkable pregnancy, with a severe level of disability that means she cannot walk, talk or sit unsupported. She has a gastrostomy button for assistance with feeding, and has had occasional seizures. Adania has Hypotonic Quadriplegic Cerebral Palsy, but this does not explain all of her symptoms – and so she is also described as having an unknown neurological disorder. She's an affectionate, happy, child, with no sense as yet of any limitations on her life. It's in this context, with a very young child and uncertain diagnosis, that this submission has been written.

It is impossible to separate the economic, access, health and educational issues from the cultural questions of rights, discrimination, support and emotional impact on her extended family. This submission will address a range of these points, from a highly personal and particular perspective. It's about what we've experienced, and our anxieties and concerns for the future. Having said that, we do support the idea of a National Disability Insurance Scheme.

The impact on our family of our daughter's disabilities has been immense, and her needs are complex. The care she has received through the public health system has been exceptional, and allied health services have also been very good, but also ad hoc, difficult to access, inconsistent and – when it comes to equipment – expensive. Looking into her future, it's also alarming that many of the crucial services she receives are aimed at "children", and will cease when she's older, even though her need for them will remain for her whole life.

Diagnosis and the early days: Eligibility issues

From when our daughter was about six weeks old, it became clear that something was "not right". She was very floppy; she couldn't hold her head up. This began a long round of tests, which were inconclusive. What it did show, rather definitely, were the gaps in a system that left us floundering, and which did not "speak" to each other. At a community level, for example, Queensland's Child Health Centres are the base referral points for any new baby, who is weighed and checked and assessed for growth, feeding and other developments. These nurses are warm and compassionate and knowledgeable, and quickly showed their concern. They, too, felt something was not right. Once it became clear, however, that we had a child with an (unnamed/ unknown) disability, and we asked where we should go for support, advice, allied health services – we were told, unequivocally, that they “didn’t know”, because they dealt with (yes, this is a quote) “well children”.

Neurologists and other specialists through the Queensland Children’s Hospital were also very good medically, but did not seem to be linked into any wider systems of support outside the hospital, particularly when there was no clear “box” to tick, diagnostically. We were told, very early on, that it was unlikely our daughter would walk. Here, then, is the almost clichéd image of a child with a disability: a small person with a wheelchair. Even so, the question “what do I do if my child will never walk” is one it’s very difficult to get an answer to.

Approaching various organisations as individuals, we were also struck by the insensitivity of initial “gatekeepers” to these services, who acted as if we needed the secret password to a club whose membership we were still uncertain of. The lack of a clear diagnosis, in particular, bothered them.

> **Implications for a NDIS: Who’s eligible?** So in addressing any structural support for people with disability, as well as acknowledging the confusing and emotional wallop of discovering that your child has a disability, the system needs to deal with the fact many conditions do not fit into any neat box or category. That is, there needs to be a functional assessment, rather than a simply medical one. Categories need to be flexible.
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> In addition, and this is harder to deal with in many ways, there needs to be a major investment into the knowledge and communication economy in this sector. This may not be about finances at all, but about ensuring that knowledge of the system is spread widely, between all the disparate parts and services, so that proper referrals, advice, access and so on is possible. At the moment, it’s not at all clear who’s responsible for what, and who provides what, across systems that encompass local, state, federal systems; medical, educational, and private organisations; government, charitable and NGO bodies. Not even the relevant websites point to each other’s existence, leading to an awful lot of reinventing of the wheel.

Who provides the support?

Once it was clear that the Community Health Centres, and even GPs, did not have the requisite specialist knowledge to help us make sure our daughter lived the very best possible life, the challenge then was to tap into existing specialist disability networks and services. Some of this came via Brisbane’s Royal Children’s Hospital and, after a year, came through a specialist disability organisation with expertise in rare disorders – Montrose Access. That first year, before things started to “work”, was very distressing and bewildering, even for people with the cultural capital to access information. Once we began to receive good support, however, there were still confusing aspects of the system: should we register with Centrelink, to receive the Carer’s Payment? (Yes, on advice of a hospital neonatologist.) Should we register with Disability Services Queensland? (No, we were told by an administrator with Montrose, although quite possibly we should have.)

Then, when our daughter was two-and-a-half we received a new diagnosis, and with it came the possibility of moving to a different organisation (the CP League). . . and it was not at all clear whose responsibility this was, whether we were obliged to move from an organisation providing us with services we were happy with to one where we'd have to begin all over again, whether it was a good idea, and indeed whether the levels of therapeutic and other support would be matched.

This lack of clarity, and indeed lack of knowledge and advice between organisations, is a major problem. Why didn't Community Health know what was available? How is it that GPs are central to the health system, but are not equipped to properly refer or integrate care for children with disabilities? Why are the hospital doctors so very good in their area of specialisation, but incapable of pointing patients in the right direction for allied or external services? And at what point does, or should, the state's disability organisation provide an overview?

> **Implications for a NDIS**: More than just what services are available needs to be assessed. Systems of referral, relationships between sectors, knowledge of what's available, and how that knowledge can and must be made available to those "outside" the disability sector, must also be a part of any transformation. GPs and others must be part of the system, not separated from it.

What it costs

Our daughter is unable to sit unsupported. She cannot crawl or shuffle or walk. If she spent her days lying on her back, as well as having a very dull life, she would not be able to engage with other people, develop the use of her hands and arms, play with objects, or develop a good spatial sense or use of her eyes. She needed proper supportive seating, which needs to be fitted and adjusted by specialist Occupational Therapists and Physiotherapists. This is not an optional extra, but a necessity. Supportive seating is not in itself covered by Queensland's Medical Aid Subsidy Scheme. We were able to find a system that doubled as a mobility device, which meant it was partly subsidised. (Seating system: $10 000 – for which we paid $5000.)

We have also bought a shower chair ($1500 – to which we paid $700); a standing frame, which is both developmentally and physically essential, to allow for bone density development etc (not subsidised: $5000); special needs car seat ($2300 – and not tested properly under ANZ Standards).

Depending on the length of her life, we will need to buy a new wheelchair in a year or two (many thousands); a high-low bed ($2500-$3000); a hoist; and a new car. Car modifications for wheelchair access are $20 000 or more, and are currently unsubsidised.

Once in a conventional wheelchair, and too heavy to carry up and down stairs, we would have to move house. The house has been professionally assessed for modification – and was deemed unmodifiable, although some changes could be made to a cost of $100 000 or more.

> **Implications for NDIS:** Ideally, the Commission should look to extend the categories of special needs equipment that can be subsidised; or look to a system in which such equipment is entirely provided by the state (as, eg, happens under the NHS in the UK). This needs to be done carefully so that individuals are not, for example, left in a situation where they have to choose between (say) a standing frame and extra therapy, when in fact both are essential. Car and house modification also need to be included as a necessity not a luxury.

Systems of Funding: NDIS

Given the age of our daughter, the debates about funding and disability are rather new to us. Many lobbyists and activists argue for individualised funding, that is then controlled by that person (as an adult), or their carers (when children). The situation for independent adults making decisions about their own lives is obviously quite different, and we cannot comment on that. They must, of course, have full rights and independence.

Our concern about individualised funding, concerns its impact on service providers, and what it expects of us as parents. That is, any new system needs to increase the knowledge and communications economy, as well as acknowledging that this is or can be an emotional process as well. It is not just a question of cost and access to services. When you don't know who to turn to or what questions to ask, living across the road from a brilliant service provider would not help.

We are not necessarily the best "experts" on our child's health and needs, much as we know we are the people with her best interests at heart. We would not have known, for example, about the positive role a supine standing frame would have for our daughter, without being told by a good physiotherapist; would not understand the ways in which the work of a speech pathologist and occupational therapist complement each other without seeing them work as a team. Not only that, we have attended group classes on (eg) the Hanen Communication method via Montrose, that no amount of independent funding would have occurred to us.

So how, then, can a funding system support the needs for some people to be independent and find the therapists etc they need, without undermining the good service providers, who need overheads and a broad base, rather than a simple one-on-one client model? Not only that, it's fair to say that not all the NGOs are the same, and some provide inadequate levels of support for their funding.

That is, while the philosophy of individualised funding is a good one, that should address equity and access issues, and also acknowledge the ongoing needs of people with disabilities, it needs to be developed in a sophisticated way that does not place too much pressure on individual decision makers to be their own "experts". This is a confusing and difficult area, where the needs of the person with a disability might change over time.

This is also part of a much wider challenge for the whole disabilities sector – and for this inquiry. Too much of it comes straight out of a nineteenth-century charity model, which posits the person with disability as a deserving (or undeserving) object of pity, and which undermines independence, true social inclusion, and citizen rights. In developing a funding model, the commission surely has to grapple with the fact that too many organisations in this field have to raise money by using heartbreak and victimhood as a marketing tool, and by acting as mendicants appealing to the state or "the public". An individualised funding model must not lead to individuals competing with each other over who's more "deserving".

Moreover, in any assessment of the role of service providers, the political questions of transparency, accountability and representation also needs to be addressed. Surely, as a matter of course, organisations that provide care for people with disabilities need to have people with disabilities on their boards or other management structures (ideally paid or recompensed in some ways, to counter exploitation), and need to include family-centred care or representation when working with families of children with disabilities.

Comparative Systems

Adania's development is considerably delayed, and her progress is slow. Even so, she is communicative and responsive. She gets pleasure from interaction and music and play. She is learning. Another way of looking at it is, if we weren't doing all these things, both her physical and developmental situation would be a lot worse, she would be missing out, she could too easily be "beanbagged" in a corner. And so we are of course delighted with the input she gets from the therapists at Montrose, and from her time at the Red Hill Special School, where she spends one day a week in their ECDP class. But is it enough?

In an ideal world, we would also support our daughter to the very fullest level of her abilities – with more of all these types of therapies, active play, communication skills. It would be instructive for the Commission to compare educational and community outcomes for children like her with, for example, the UK, where therapies like this are supplied by the state, weekly, rather than via NGOs, monthly.

The Future

Our daughter is entirely dependant on us for every aspect of her daily life – even more than any other three year old is. She cannot feed herself, she cannot move on her own, she cannot speak and ask for help. She is, in other words, extremely vulnerable. She has a brother who is only eighteen months younger than her, and she has parents who are "old" (44 and 50): we won't be around forever, and we cannot expect her brother to take responsibility for her.

What will happen to her, should she live anything like a normal life span? Her daily life and needs are high, but more than that, surely she has the right to a quality of life, to stimulation, to education, to interaction with other people, to love and laughter? When we are not here, what possible place is there for her? What expertise, input, money, care, responsibility and protection can she expect?

What do these questions of an uncertain future mean for a NDIS? As well as the issue of supported accommodation and specialist care for an adult who is entirely vulnerable and – sadly – will not be able to participate in the workforce, the situation of a child like Adania points to a range of other issues. Ideally, a system that addresses the life-long needs of a person like her would assuage our fears and anxieties as parents. Ideally, it would also address the mismatch of services that seems to have arisen through the (admirable) attention to early intervention and the increased role of the education sector. The services our daughter needs as a child, with intensive interaction and input to keep her physically as well as she can be, and to keep her as socially and intellectually as engaged as she can be and as she has a right to be, are likely to cease when she's no longer a child. And yet she will need them for as long as she lives, however long, or however short, that life will be.

She has the right to a life that is as full and engaged as it can be.

Sincerely

Kate Evans & Frank Beard

Cc Montrose Access, Qld
Cc Red Hill Special School, Qld
Cc Fed Govt, Parliamentary Secretary for Disability Services
Cc Qld State Ministor for for Disability Services and Multicultural Affairs, Annastacia Palaszczuk, Minister
Cc Fed Member for Brisbane, Arch Bevis, ALP
CC State Member, Brisbane Central, Grace Grace