Disengaged Services and Disempowered Rural Consumers: Implications for NDIS (Disability Care) in the Bush?

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Vulnerability and Rurality: Parental perceptions of quality of life for families and children with disabilities

Project Aims

Understand the perceptions of parents in rural northern NSW regarding quality of life (QoL) issues for families with child/children with ID.

In particular,

- Service provision
- Schooling
- Respite and Accommodation options
- Impact of inadequate services on QoL issues for families
Methodology

Mixed-methods study with postal survey and in-depth face-to-face interviews with parents of children with disability across rural and regional parts of the state of NSW.

This presentation focuses only on findings from the qualitative component of the study only.
Research setting

[Map of New South Wales, Australia]
Findings
Experience with service providers

- Problematic
- Confrontational / Adversarial

Lack of:
- Information
- Training
- Experience
- Empathy

Fear of:
- Withdrawal of Support
- Fear of Retribution
Service Provision

“There is no support in rural areas”.

Yeah, there was the physio and the speech and the OT.

The OT we always had trouble getting, [even though] for her it was essential. Couldn’t hold a pencil, could barely draw with a pencil because she just had no strength in her hands or anything.

But she didn’t get regular therapy through OT, and I think we missed all the playgroup and stuff like that, so maybe that was a point. I don’t know. Anyway, we didn’t get it.
Service Provision

When I wanted to get a frame for the toilet so she could be more independent with toileting, we had to get the OT to come out and measure our toilet. So, I was furious, because I rang up and they said, ‘right, we’ll put her on the waiting list’.

‘OK. How long’s the waiting list?’ ‘Well, we can’t tell you because there are all these other children who have got real needs’. So the whole implication, this wasn’t from the OT herself, it was from someone administrative….that I was trying to jump the queue, thinking that my child was of more value than all the other poor kids with really severe disabilities. And I’m like, ‘up to a year!’ It’s going to take her five minutes to measure the toilet. I can measure the toilet and send the measurements in. ‘No, no, we can’t do that’.

… took several months to get that done and get the funding to get the toilet frame made up and it changed her life. She can now go to the toilet almost independently without falling off ….. So, the impact on her life is just tremendous and the struggle you have to get something and it cost them… three hundred bucks or something. Like, it’s not a lot of money, is it?
Service Provision

I think we were one of the lucky ones. I’ve heard some bad stories but I think we were one of the lucky ones that got the good end of the stick really.

...we’ve had access to everything that we’ve needed.

He’s had physio, he’s had OT, he’s had speech, he’s had that basically from the time he was about 10 months old when we first knew what we were looking at and he’s had that right up until he went to school and they touch base ... 6-12 months just to check how things are going. I mean we’ve had guide dogs as well for mobility issues, because he’s nearly blind in his left eye. So basically anything we’ve needed we’ve had... we haven’t had to stress too much about anything.
Service Provision

For a rural family, sometimes I think you have better access in terms of perhaps you are not on waiting lists of six months like you are in Sydney because there are so many people trying to access.

But then at other times, well at least they have someone … *we don’t even have anyone*. So it kind of depends on what it is you are trying to access and what time it is that you are trying to access it.

You are disadvantaged as someone else can drive home and stay at home every night [in Sydney] whereas I don’t have that option, or rural people don’t have that option.
Attitude of Health Professionals

With some of them I’m treated really good and they really do listen to me …

The majority of them *I’m treated like I’m stupid* and they’re the better ones ‘cause they’ve got that degree or whatever – they’ve studied it, …. we know, you don’t’!

But they haven’t studied my child. I feel like they’re calling the shots, I’m not. They’re deciding for my son, I’m not.
Financial Support

The carer’s pension... yeah goodo! Seriously, it does nothing, I appreciate it ...because if it wasn’t I would be screwed.

But it could be a lot more. When you think about it you’re trying to live on about $500, that’s just ridiculous. That’s not even minimum wage. ...They throw all these bonuses at you which don’t get me wrong I appreciate …they’ve gotten me out of some sticky spots but ...

They’ve got to think long term not just these quick fixes of we’ll throw a thousand dollars at them and that will keep them happy.

And I’m worth more than that. I’m a person…

Everyone has the right to a life. You can say well why should the government support you? I say well if I was to put my son in an institution, not that I ever would, but if I was to put him in an institution it would cost you bucket loads more. Absolutely.
The multimillion dollar question is:

*What will NDIS (Disability Care) change in relation to empowering individuals and their families??*

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**Choice & Control**

The introduction of individualised and self-directed funding will require a major shift for many service providers

**Choice:** Maximise opportunities for PwD to plan and design their support arrangements.

**Control:** Each person should be able to choose how much control they want over their funding, supports and service providers, and be able to change this control over time.
What will NDIS (Disability Care) change in relation to empowering individuals and their families?

What about rural and remote areas?

To exercise choice and control people need access to a supply of support and service options, which may *not* be the case in rural and remote areas.

The NDIS will need to consider options to increase choice by encouraging services and developing the sector.

- Carers Australia has completed a survey [late March]
- NRHA position statement
- Service Providers