REQUEST NAME BE WITHHELD

I am a mother, a carer, to two children aged 4 and 2. Both of my children have a rare genetic condition, which qualifies them for the disability label.

I would like to reiterate that carers often do not have a voice. That our time is consumed with our child's daily needs, with therapy, appointments, paperwork. Time to research services and lobby for support is an unimaginable luxury, and I thank those people and organisations that are working on our behalf. If you truly want to know what life is like for carers, and what they need, find the ones who haven't written to you, bring someone to help them for the day and enable them the time and opportunity to talk.

>> Who should be the key focus of a new scheme and how they may be practically and reliably identified?

I believe that there should not be discrimination between disabilities, eg where it is dependent on which genetic condition, or which type of impairment an individual has. Too many people are slipping through the cracks because they have an undiagnosable condition, a rare condition, or have aged out of qualifying. If categories need to be created, perhaps they could be based on whether there is a single or multiple areas of impairment/disability, whether there it is only of a therapeutic nature, or also requires medical intervention, and whether the individual is under or over 18 years of age.

>> Which groups are most in need of additional support and help?

I don't think it is necessarily about more, but about improving the way support and help is offered. I'm sure everyone is in need of more, but it needs to be effective. There may be services out there, but in my case at least, I can not access them through lack of awareness, lack of time to research and follow through, having the wrong disability or living in the wrong area.

>> The kinds of services that particularly need to be increased or created?

I would like to see flexible respite funding packages that allow families to find their own respite worker. This would enable us to find someone who suits the needs of our children, and best fits into our schedule.

>> Ways of achieving early intervention?

I think there needs to be some education to the doctors, nurses and other professionals that are the first people who see children suspected of having additional needs. In our case, it was this lack of awareness that delayed my elder child accessing available ECDP services. It can be hard with developmental disabilities to identify which children are lagging behind, and which will have ongoing problems. And I think in these situations it is better to be giving more support to children who on review no longer require it, than to realise in hindsight that a child should have received that support. Perhaps more playgroups (for the under 3s) could be established based on the ECDP model, for children who are in that grey area.

I would also like there to be an option to have support workers that can do in home therapy. I believe the best way to do this is through a flexible funding package generally, where carers can allocate funding towards the therapy, respite, other services as needed. However, if the goverment prefers to set up services, then I think one way of achieving this would be to establish programs for university students (in the appropriate field) to work for university credit, or a subsidised fee. The idea being that they help the carer to practise at home the therapy goals set out in their official therapy appointments. As an example for you, I find that regardless of the type of therapy, it is much more effective with two people than with one. Often one person is needed to engage the child, while the other one supports them physically, or with hand over hand guidance. This may not be something every child needs, but it is an option that would be helpful for many. Even more so for those of us who have more than one child with a disability.

>> How a new scheme could encourage the full participation by people with disability and their carers in the community and work?

I don't believe the current system provides adequate full time support for children under school age, and I am not sure if or how a new system could (or should) do so. At the least a full time person (or two) would be needed to replace me in caring for my children and taking them to all their appointments.

However, I do believe that once my children reach school age, there would be a potential for me to return to work. Potential only at this stage, however a new scheme could make it so. Basically it would be supporting children to access existing before/after school care services. This could be through inclusion support workers. Another option would be through families accessing flexible respite funding, that can be used to hire someone to assist with this role. Giving families the control of hiring their own worker also enables them to supplement the funding to have their neurotypical children cared for at the same time. I believe with most respite services, only the child with the disability can be cared for. As I have two children with a disability I haven't had to worry about this. I believe it should be a choice for carers to return to work, as it still may be in the best interests of the child to have their familial carer as their primary carer.

My children are not yet school aged, so I haven't given much thought to their future in the workforce. Perhaps there could be support for them to access further career training after leaving school through the tafe system or similar. I believe my children have the potential to perform a job, but would need focussed training, and a small group setting would be ideal.

>> How to improve service delivery — including coordination, costs, timeliness and innovation

I think there needs to be a consistent entry point for carers to get established. As most people would start with applying for and receiving Carer Allowance, I would suggest this as a starting point for identifying carers. I think they should then be allocated a case worker [not from Centrelink though!!!]. A first point of contact for the newly diagnosed, where you get to chat to someone on the phone. They advise you about Centrelink and other funding options. They direct you to established agencies where relevant, such as DSQ, CP League, DSA, Autism Qld, or if there is not an appropriate major established organisation to take over your case, they keep you on as your caseworker. They could send some basic information, with generic literature about benefits of early intervention, the Centrelink information, and outline the general types of services to look into, like private/public therapy, respite, medical supplies, equipment funding, counselling. It could also include a leaflet listing service providers in your area. Then if they continue as your case provider, you would have a face to face meeting where they can meet your child to get a better understanding of their needs, the family dynamics and living situation, and brainstorm initial ideas. Perhaps a review at 6 months once the initial arrangements have been made, to start looking into the secondary issues. After that available by phone/email if you need, and perhaps annual face to face follow ups.

>> The factors that affect how much support people get and who decides this?

As I proposed in the first question, based on single or multiple impairments/disabilities, whether they require medical intervention, and whether they are under or over 18.

>> Reducing unfairness, so that people with similar levels of need get similar support?

Don't have a finite list of disabilities that have canvassed to be included to the exclusion of all others. Instead allow any individual with a disability, provided their needs meet the criteria.

>> Getting rid of wasteful paper burdens, overlapping assessments (the ‘run around’) and reducing duplication in the system?

Have a central body that carers apply to initially to prove eligibility, and allow all other services and organisations to refer to that. It would be good to see a pension style card, that all individuals with a disability are eligible for, that they can then show as evidence. Disability doesn't stop just because your carer doesn't meet the income test.

... General Comments

I do not believe eligibility should be based on having a diagnosed condition. From my own experience I am aware that it is not always possible to reach a diagnosis and medical professionals do not always consider this a priority. We are one of the lucky ones, and it was not possible until this year. As therapists and other services providers treat individuals based on their symptoms, not on their label, it is not prioritised there either. I understand that a line must be drawn for eligibility sake, then I suggest creating a label for "suspected permanent condition" to allow these individuals to receive support without delay.

As a parent and carer, I feel that I have been thrown in the deep end. I now "work" in the disability field, yet I was not trained for it. I think it is important to provide early support in the form of guidance and information to help set us on the right path. I find that I am starting to get the idea of how things work and what's available, only in time for my elder child to no longer need that type of service, and I have to start researching the next issue.

I feel that a case worker allocated to guide us through this process, would also bridge the communication gap between carers and service providers. I find that it can be hard to find the right type of support when as a parent I do not know what to ask for, while service providers do not know what we need. If we had a caseworker to interpret us through the process, it could be more effective for all involved.

I believe it is important that any new scheme does allow for flexibility, because what I need may not help someone else, and what someone else needs may not help me. In our case, even when both of my children qualify for services, they still have to share me as their primary carer and miss out on the extra support they could access if not for eachother.