Inquiry into Disability Care and Support

Personal Response

Background Information

- This response is based on experience with Disability care and support firstly as a parent of a 33 year old who has Prader- Willi Syndrome. This is an omnipresent disability that not only impacts on every aspect of his daily life but also that of his parents and siblings. My son's daily battle is with food and my battle is reducing calorie collateral damage in a society which seems to flaunt food where ever we turn, be it on TV, shopping or indeed any social gathering seems to focus on food. Throw in a complex health profile of diabetes, sleep apnea, osteoporosis, an intellectual disability, visual and hearing problems.
- Secondly, this response is based on my 10 years experience as an Integration/Special Needs Coordinator in a mainstream Victorian primary school in the outer eastern suburbs. Its student profile is diverse with an increasing number of students coming from a lower socio- economic background, with complex welfare issues. As well as writing submissions to access funds for disability support and supporting students on a regular basis, the most important aspect of my role involves supporting the parents to access the different agencies and medical facilities to enable them to support the needs of their disabled /special needs child. Time and time again I question why children with disabilities are starting school with little or no early intervention. Often it is the school that has to initiate the conversation with the parent to the fact that their child has a disability. Systematic failure at several levels of preschool intervention has a serious implication for the child's future educational, social and emotional wellbeing.

My response is based on the following premises

- Anyone can be affected by a disability through no fault of their own. At some point each family will be touched by the affects of a disability in their immediate or extended family.
- Families should not have to face a lifetime of disadvantage or hardship because they care for a disabled child.
- It is the community's responsibility to help support those who have a disability, to ensure they are able to access education, health care and community life to a standard appropriate to that expected by the general Australian community.
- It is the community's responsibility to help to support those parents who do accept the responsibility to care for their disabled children.
- It must be accepted that the community will have to accept responsibility for the care of some of our disabled in some instances –
    1. Those who require high level of care above and beyond what a family can be reasonably be expected to provide
    2. Disabled children whose parents are unable to care for them due to their own disability, mental health problems or old age

- The present system which pits agency against agency results in a lot of administration, costly tendering and a pitifully low level of service delivery to the disabled.
- Those with similar needs should get similar levels of support - at present a percentage get a lot and the majority get little. The present system is a very unfair system. Under the present system you are disadvantaged if you are born disabled rather than acquired the disability such as in an accident.
- The system tends to focus on crisis management and stopgap solutions rather than long term planning and management. The families who get on with the business of trying to ensure that their child achieves his/her potential get minimal support.
- Early intervention programs are absolutely essential for the management and care of the disabled child.
- There will continue to be a need to review the diagnosis of some disabilities. There will also be a need to reassess the guidelines for the diagnosis of some disabilities. There are some very liberal interpretations of the guidelines for diagnosis of many of our behavioral disordered disabilities such as ADD, ADHD and Autism Spectrum Disorder. Some of the other temporary disabilities also require more rigorous review more frequently.
- If we accept the premise that **the level of care and support required by the disabled person and their carers determines** the level of funding for Individual Support packages, then over a period of time those with temporary disabilities should expect to have packages reduced as level of support and care decreases. In the case of many behavioral disorders a combination of medication and behavioral therapy significantly reduces the need for high levels of support. As there is no regular rigorous review of the level of care and support required by the disabled person, they continue to use the services long after the need has passed.

Response to the following Key Questions

At present there is too much administration to deliver too few services with too little money in a fair and equitable way.

How to finance a new scheme so that there is enough money to deliver the services
I believe there is a need for a universal scheme similar to Medicare levy.

Kinds of services that need to be increased or created

- Recognize the importance of caring for the carer. Respite services should be fair and equitable. At present it occurs on an ad hoc basis with some getting a lot and many getting little. At present I get 4 hours respite per month. I effectively lose an hour of the respite taking my son to and from the venue .That’s not much respite support for looking after a severely disabled son on a fulltime basis.
- Quality respite is necessary to maintain the long term viability of disability care by the family unit. It is medically recognized that ongoing fatigue, stress and anxiety takes its toll over time. Taking a break is the best way to manage that situation – In order to plan for a break you have to know when the respite will be available. An allocated respite break should be available to the fulltime carers of disabled children. I suggest one respite week per year or two respite weekends per year would be a step in the right direction. This could be built in to the funding structure for the Individual Funding packages that I discuss later.
- There needs to be more social activities for adult disabled. There are many activity services for the disabled who are school aged. There are very few available for the over 30 year olds.
- There needs to be a transitional pathway for disability housing. Research shows that those who access community housing in their 40s-50s do not adjust well. Due to the severe disability housing shortage that is precisely when many access disability housing.
- There needs to be a much more lateral approach to housing options which give the disabled a wider choice. Community Residential housing units in the suburban houses do not always provide the best options for the disabled. There is a wide variation in the standards from unit to unit. There are many options that have been in use overseas that could be explored- pod houses with a centre community, houses attached to university housing projects, housing cooperatives, purpose built accommodation similar to old age hostels.

How to give people with disabilities or their cares more power to make their own decisions

How to improve service delivery

Getting rid of wasteful paper burden and overlapping assessments

Present situation

I believe my son's disability supports a whole administration industry. There are a lot of people filling in forms, with little or no service delivery.

Case in point: I had a wedding and I needed someone to look after my son so I could attend. I firstly rang Manningham Council. They came out to the house, complete with council car and interviewed me for two hours. Result was that yes I was eligible but they could only offer 2.5 hours. They advised me to ring Villa Maria or Yooralla. Both agencies requested an interview in the home. Two workers from each agency came to the house with car and interviewed me for two hours plus. After six hours of interviewing, I was placed on several waiting lists but got no respite time. For the cost of that process I could have hired someone myself to look after my son for at least a week. Two years later I am still on waiting lists for two of the aforementioned agencies.

Suggestions moving forward:

- There should be a simplified way of establishing eligibility for care and support services that is valid for all agencies. A system similar to getting a Passport where you have checks and counter checks by producing several documents to meet criteria for varying levels of support and care.
- There needs to be only an initial recognition of the diagnosis of the disability. The disabilities that are forever i.e. Prader-Willi will only require one diagnosis. Other disabilities may change over time so ongoing reviews will be required...
- Since most diagnoses are initially made by a medical practitioner this should fulfill one criterion. Centrelink already requires detailed information for establishing eligibility for Career's Allowance and Disability Pension so this could fulfill another criteria.
- I suggest that the system needs to have a mechanism that builds in continuity and recognition of the important transition periods in the life of a disabled person. Each transition period has its own special set of needs and these must be recognized in the service delivery provided for the care and support of the disabled.

This continuity would eliminate the need to establish eligibility for care and support for the disabled as you move from stage to stage. At present when you move from the RCH to adult medical care you have to start from scratch to find doctors that service adults, when you move from high school to TAFE you have to set up new support mechanisms, respite services cut out at 18 years and you have to find new services and so it goes on. At present this doesn't happen automatically and you have to tell the same story to each new provider who places you on a new set of waiting lists. More administration and more costs and fewer services.

This mechanism would work best if parents /carers are recognized as equal partners in the planning for the following transition periods and the needs of the family unit were considered during the transition periods.

1. birth – pre kinder – early intervention program planning –family support

2. Kindergarten to Grade 6- education needs planning –family support

3. Year 7- End of Schooling - education needs planning –family support

4. Post schooling – work/Day Placement – employment skills training-travel training –personal/social skills –family support

5. Post- sibling household –middle-age- employment skills training-travel training –personal/social needs –-options for transition housing ,family support

6. 40 years -Old age –housing planning, employment skills training-travel training –personal/social skills.

- I would envisage that this mechanism would involve the following features

1. Funding to be attached to the disabled person rather than an agency .Funding to be based on levels of need for each disability. The disabled person/care would nominate an agency to help formulate plan for each transition period to establish priority needs of support and care based on level of funding. This could be reviewed if needs change.
2. The plan to be submitted to Centrelink/Medicare /Discare or what ever body will be set up to monitor the care and support program. If there is a gap between needs and funding in specified instances this could be appealed.
3. This data would also allow the government to better predict future needs.
4. Parent/Career/disabled person together with management agency requests services to suit needs according to allocated funds.
5. There is an ongoing research program as to the best practice care and support for the disabled and their families. Housing options for the disabled researched using best practices used overseas.
6. Education program /information sessions to support and inform choices made by the families/cares/disabled persons for their care & support plans.
7. Ongoing education about rights of disabled and the responsibilities of carers
8. Appeal mechanisms simplified.
9. Regular accreditation and accountability of the support agencies similar to that for nursing homes.
10. Review of the funding levels to keep pace with award rates for service providers, transport costs and other service costs increases.

- Service delivery is crumbling under the sheer weight of numbers requesting services and the inability to increase services due to the cost of wages and travel. Regional areas receive even fewer services and the ability to staff programs and fund travel costs is even more problematic.

  In order to make the distribution of finite services more fair and equitable I suggest the following:

  1. Allocation of Individual Support packages based on an agreed amount which is determined by the level of support required for the disabled person. This should reduce the over servicing of some at the expense of others, with equal needs. At present, some parents "work" the system and neglect to tell assessors of the many other services they are accessing.
  2. Individual Support packages would allow the disabled to access the programs that interest them, not what they are told should interest them. The forces of demand would soon weed out programs that were not delivering quality services in a cost effective way.
  3. Individual Support packages will only work when the agencies work together to deliver a variety of services that caters for the wide range of needs and abilities of the disabled in our community. Innovation and lateral thinking should be encouraged. Programs that develop on going interaction and skill development should be encouraged.
  4. Parents /Carers must be readily able to access information about these programs from a central data base that is easy to access and regularly updated. The total cost of the program must be included so the parents /carer in collaboration with their agency facilitator, can effectively devise a care and support program
  5. The introduction of a regional service delivery model whereby the programs for activities based respite move from regional area to regional area (a bit like the visiting arts programs that tours the states.) for set periods each year. This would augment existing programs.
  6. Tendering process must be reviewed. It is way too costly and ties up valuable and experienced personnel for weeks. The purpose of the agencies is to deliver support and care to the disabled. Administration should not use up the bulk of their resources

How we care for our disabled is truly the barometer of the health of our community. The system needs a real overhaul with an innovative but sustainable approach that will deliver the care and services needed to allow the disabled members of our community a happy and purposeful life.

If any clarification of any point is required please feel free to contact me

I wish you well in your pursuit.

Regards

Kate de Josselin
Vic