

My submission is based on personal experience from having a family member with severe intellectual disabilities.

1. Recommendations for change

The key recommendations that I would recommend to the review to consider are outlined below.

1.1 Coordination of services - Social worker/case manager

Although there is reasonably effective coordination of services for disabled people that are school aged (up to 18 years), this is not the case for adults with severe intellectual disabilities in NSW.

Carers suffer from problems such as lack of access to different service providers and spend much of their time coordinating with all the different health and specialist service providers that are necessary for their child.

A Government-funded case worker for each adult with severe disabilities would be an important improvement and may also allow lower cost of services for disabled adults as the case workers may be able to negotiate better rates with the service providers.

The case workers could be familiar with a range of different specialists and service providers and discuss particular needs with the disabled adult or their family. These services could include physiotherapy, occupational therapy, speech pathology, doctors specialised in disability health and could even extend to other services such as music and art therapy.

Further, the case manager could provide the disabled person and their family with information about the costs of replacing important equipment such as wheelchairs, an understanding of the level of subsidy that would be received from the Government, and information about when it might be reasonable to request repair or replacement of these items.

At the moment it is a time-consuming process to research and find these various services and there are problems with a lack of knowledge of reasonable costs for each of these services and the level of service that should be expected from each provider. Being able to rely on a case worker for this help would be extremely helpful and would also provide a sense of support to carers who are trying their best to provide the best opportunities for their child.

For those disabled people living in supported accommodation, the case manager could be helpful in resolving issues between the disabled person/family and the operator of the supported accommodation. Currently, if there is disagreement on a matter, there is often no recourse to mediation to work out a fair outcome.

The final reason why this would be an important initiative to introduce is because without very motivated parents, many of these important services may never be accessed by severely disabled adults. An active case manager would be of enormous benefit for these people.

1.2 Subsidising or providing specialised services

Once a person reaches adult age in NSW, many services such as physiotherapy must be paid for out of the pocket of the adult or their family. Home visits for physiotherapy can cost \$150 per hour and although there is limited funding through Medicare for the first 5 visits, the remaining costs need to be paid by the disabled person and their family.

Specially trained physiotherapists that are familiar with disabled care needs could be employed by the State or federal Government on a much wider scale so that access to this important specialised service could be possible for more of the disabled population.

1.3 Increasing opportunities for Group Home care

For many disabled adults, access to Group Home care will only become available due to the death or ill-health of their parents. The incredible care provided by family members for the disabled should be supported by the opportunity for their child to enter a Group Home with similar aged people as the ability of their parents to care for them decreases with age. This will ensure that parents are not constantly stricken with the fear of what might happen to their child if something were to suddenly happen to them. The relationship between the family and the disabled adult can also markedly improve because their time spent together is quality time.

Of course this will place added pressures on State or federal budgets, but there would also be added benefits from allowing carers the opportunity to re-enter the work force. There are also likely to be significant health benefits for each of the family members because of the reduced amount of stress that can occur from the high demand nature of caring for a disabled adult - especially those without any independent mobility.

It is not a simple task to suddenly develop a new workforce to staff the additional group homes, but there could be Government incentives to encourage disability care training (for example, five years continued employment in the field after receiving accreditation could be rewarded with a refund of study fees incurred to that date).

1.4 Post School Options

Although I have been encouraged by new initiatives for disabled people to access self-selected programs and activities for their day time activities (in NSW, this is called My Life, My Choice, My Future), there are still a number of hurdles that mean the take up and success of these programs is limited.

This has raised the important point that although great initiatives with good intentions are announced in jurisdictions across Australia, because the implementation is not as carefully considered, the initiatives never deliver the expected benefits from the reform.

For example, many disabled adults cannot stay out for the whole day because of special medication processes or because of continence issues. For many disabled

adults living in supported accommodation, the option to have an individual carer through the self-selected programs is limited because they cannot access entry to their Group Home during the day with their individual carer to attend to these needs. Similarly, those who are living at home will need their parent to stay at home during the day in case they need to return to attend to these needs which means that the freedom for the parent is curtailed if they would like their child to have an independent self-selected activities option.

Even if a parent is interested in taking up these options, it is difficult to access information about the different workers that could provide this individual program care for their child. Further, parents are concerned about the risks of taking their child out of a day-program centre because that place in the centre may be hard to re-access if the individual program does not work out for some reason.

1.5 Reducing red tape for the disabled and medical practitioners

In many instances, parents are required to seek medical confirmation from doctors and specialists in order to act on behalf of their child. This can include for arranging parking permits, setting up and withdrawing money from a bank accounts, for dealing with Centrelink and other reasons.

For those severely disabled adults in Australia that do not have any prospect for a change in their condition, it would be reasonable for the State or federal Government to establish a card that could recognise the condition of the disabled adult and specify the identify of the person authorised to act on that person's behalf.

This would not only save time for the families of disabled adults, but also free up the time of the medical professionals that are often required to fill in detailed forms to confirm the disability of the person. Similar initiatives for the Victorian taxi scheme (see Multi Purpose Taxi Program) were recently introduced but I believe that there is considerable scope to expand this to a federal program in the future.

2. Positive Aspects of Disabled Care

Having made these recommendations, I would also like to take the time to comment on the positive aspects of disability care and support in Australia, and particularly in NSW.

2.1 Group Homes

Although the access to Group Homes is still far too limited in Australia, the idea of providing for disabled adults to live in a home environment with carers and other disabled adults that they are familiar with and can trust is an important improvement.

The ability for a disabled person to live in a home and not an institution makes the transition from the family home to NGO or Government provided care far easier for the disabled adult and also for the family. It also allows for far greater interaction in the community, better personal care, and allows disabled adults to feel a sense of independence.

2.2 Equal Opportunity Initiatives - Companion Cards

The recent introduction of the companion card in NSW and Victoria is a positive step for disabled adults that are seeking to interact more in the community. The costs of attending shows and different attractions can become prohibitively high when the disabled adult has to pay for both themselves and their carer to attend an event.

The companion card is also a great initiative to highlight the importance of equal opportunity and I have noticed that Group Home staff are far more interested in offering to take disabled adults in the home to events such as a music show because their costs of entry are no longer an issue.

2.3 Care for disabled children

I would also suggest that the level of care for disabled children is also a more positive aspect of disability support and care in Australia. At this age, disabled children often have access to stimulating programs at school, access to case managers that assist with arranging important support for families such as physiotherapy, occupational therapy and other needs.

There is also a good amount of interaction for disabled children with other members of the community. Often, there may be partner arrangements between a disabled school and other local schools to provide an excellent opportunity for interaction between the students. These initiatives should be encouraged to continue into the future.