Personal Response to Disability Care and Support Inquiry

From The Lower Clarence Carer Support Group

Suggestions for improvements

Creation of a National Disability Register/ Database.

- Individuals are registered at birth or on diagnosis of disability

- Individuals can have their diagnosis formally registered on the database along with the medical documents for confirmation and service providers can use the Database to check client details so that individuals are not constantly required to provide paperwork proof of having a disability to different service providers or other organisations that require this proof.

- Contact information such as the acknowledged carer, parent, guardian or spokesperson for the person with the disability can also be stored to avoid any misrepresentation of the person with the disability.

- This Database will have the ability to cross state boundaries to assist people with smoother transitions when moving from one area to another or one state to another.

- Centrelink Customer Reference Numbers can be used to identify individuals on this register or the Register has its own Client Number.

- All persons with a disability should be on this register and be able to access the NDIS as even people with mild disability can have changes throughout life that may have significant impact on them and they may need support or services.

Improving the Provision of Services to People with Disability

- Fund the individual with the disability instead of organisations.

- Give the person with disability an account that is held in trust by the National Disability Insurance Scheme or a national organisation designed to manage funds. The individual is then allocated funds into their account for provision of services based on an assessment of the individuals needs. The account balance must be available to the person with disability via web access or other means so that they can ensure that they are managing their funding adequately.

- Assessments must be made by a qualified panel of professionals that has been authorised by the National Disability Insurance Scheme. They can work from current organisational locations in cities, regions, towns and outreach when necessary. The assessments once made can be validated for 12 months to 5 years depending on age, change of circumstances over time, current need or in response to crisis. Individuals can bring medical or professional recommendations along to the assessment process to support their need for service and how much may be needed. For eg: a specialist may recommend intensive speech therapy for six months or that the person may need an accommodation placement permanently.

- The assessment panel recommends funding to be allocated for the needs of the person such as personal care, mobility or transport allowances, therapy (physio, OT or speech), respite, behaviour management, counselling or psychological support, additional educational needs, day programs, employment support, community programs etc. Each person must have an allocation made available for support coordination or case management which can be accessed when needed. The NDIS then will send out a letter with a list of approved services or supports that the person can access. Should a change of circumstances or a crisis situation occur an application can be made with supporting evidence to have the extra services funded.

- The educational needs of people with disabilities need to taken into account, if all people have equal access to good education with support levels as required they may be better able to participate in the workforce.

- The person with the disability or their guardian then should have the choice of who provides the services to them. They can discuss their needs with the service provider and then choose if they think that service provider will meet their needs. The person may also choose to change service providers if they feel they have not had their needs met adequately or they can request that the Ombudsman can audit the service to establish the quality or professionalism of the service being provided. Services that are “disability” specific or mainstream services can be used in this model. This will improve understanding of people with disability within the wider community as more people will see people with disabilities going to the same places as them and using the same services increasing opportunities to make connections and reduce barriers.

- The NDIS will provide the client with an ID code to be used when dealing with services. This ID code will enable the service provider to access information about the client from the NDIS to verify that they have approved funding for the service requested. After services have been provided the client/ person with the disability must receive an account detailing the services provided and the cost, the person/ client or carer/guardian then signs the account to acknowledge that the services have been provided at that cost. The service provider can then send the account to the NDIS to receive payment for their services.

- Our suggestion of this service model is based on the premise that if the services have to earn clients by providing a quality service then the standards of staffing may improve as a result. Too often we are trapped into using services that are restrictive and who employ staff who are not trained to understand the needs of people with disability. This lack of understanding creates much distress and frustration for the person with the disability and their family, carers or guardian. Too often people are employed in the disability support sector because they want to help someone more disadvantaged than them. The staff have little or no formal training and are often shocked at the range of circumstances that they work in and the behaviour of some people with disability. They often have little understanding of duty of care and use inappropriate language and behavioural management techniques that create negative outcomes rather than positive ones.

- This model will also support accountability for funds at all levels. When an organisation receives funds to provide services there is no accountability at the client level that the service has been provided. Funds can be misappropriated without the client’s knowledge and paperwork can be done to make it seem as though the client has received more than is provided.
  From the client side, this model will prevent misuse of funds and also prevent clients from falsifying their own records for financial gain. Also this takes into

account that many people have not acquired the skills or the confidence to manage their own funding allocations.

- Accommodation options can be increased with this model as the person with disability will have the ability to choose the appropriate supports to enable them to live more fulfilling lives. Some individuals who currently live in supported group accommodation may be able to live independently with the opportunity to access transitional support and then reach a level of agreed support that meets their needs.

- Employment support can be increased with this model as when the individual receives the funding for this service they can access any employment support organisation for service instead of hoping that they can qualify to access “specialised” disability employment services which can be discriminated against by prospective employers because of the disability label. This would be another barrier that can be lessened over time by allowing people with disability to access the same services as the rest of the community.

- Case Management is also an important part of this model, every person with disability must have a case manager. The individual can choose to have the case manager playing an active or passive role depending on their needs. When life changes as it always does the change in circumstances for an independent person may create the need for a case manager to step in to support the person through a crisis or transitional period of change after which they may once again successfully manage on their own again.

Feedback on what works

- There are some current pilot programs operating that are allowing some families to receive and manage funding for respite services in a flexible manner. We have been the recipient for one of these funding allocations and our options in respect for respite services have increased markedly. Our children with disability have been able to access community activities that were previously out of reach for them, they have been able to access Centre Based Respite also and we have been able to get more flexible respite in home so that we can attend workshops and even have overnight stays. All of these options have previously been unavailable due to funding constraints and organisational structures. Some of the foreseeable issues with this type of pilot is that some families may not have the skills to organise the funds appropriately or to source other options. This is where a case manager can be of assistance.

- Centre based Early Intervention therapy appointments. We used to have these appointments and we travelled once a week/fortnight/month to the service provider or a location nearby and the child had access to Physio, Speech and Occupational therapists in the one appointment, the therapists worked with the child and modelled to the parent or caregiver the appropriate therapy for the child, the carer/parent had the opportunity to give feedback from previous appointments or to communicate changes in the child. This was a very successful and fluid way to receive services which I think would have worked until teen years or adulthood. There was also a playgroup available for under 5's on the same day that was run by a behaviourist and parents had opportunity to connect with each other and have a safe play environment for their child that would not have otherwise been available.

Funding Sources for NDIS

- The Medicare Levy can have a percentage added on to it to partially fund the Scheme

- Families or individuals can be offered the opportunity to create a trust account of their own to be used for accommodation or services for the person with the disability. A set amount can be volunteered to be put into the account through regular payments or to be taken out of income received, these funds should be tax deductable.

- Monies from Income Taxes can be used also.

- With current model of funding there is money wasted in layers of bureaucracy, potential is there to stop this waste and the existing budget will fund more people.

Comments

With 1 in 5 people having a disability of some sort it is time that this issue was addressed properly. The majority of people with disability have the ability to be productive members of the community and enjoy leading fulfilling lives. Imagine if the unemployment rate included people with disabilities currently on pensions that are able to work but don't because they can't get support to enter the workforce. It's long overdue that 20% of the population had the opportunity to live up to their potential and they and their families can step out of a disadvantaged lifestyle due to lack of support and service.

Our Demographic

This group has parents and carers of people with disability from the ages of 2 to 45. Some of the disabilities represented in our group are Williams Syndrome, Down Syndrome, Cerebral Palsy, Autism Spectrum Disorder, Intellectual Disability, Foetal Alcohol Disorder, Paraplegia, Vision Impairment , Dysphasia and Erbs Palsy.

Carers are aged from their teens to their seventies.