SUBMISSION FOR PRODUCTIVITY COMMISSION'S INQUIRY INTO DISABILITY CARE AND SUPPORT

OBJECTIVES FOR A DISABILITY CARE AND SUPPORT SCHEME

One reason why a new approach to disability care and support should be considered is that all people with disabilities should be on a equal footing. Under the present system, there are instances where people with acquired disabilities are afforded assistance that is not available to people, who have had a disability since birth.

By the same token, people who have acquired disabilities and those that have received compensation payouts should not be totally abandoned by the disability system, because they are considered to be “wealthy”. Having a disability can be costly and sometimes large compensation payouts, do not equate with a person being wealthy or having financial stability for the rest of their life.

ELIGIBILITY CRITERIA

Severe or profound disability should not be the the only criterion when it comes to assessing the support needs of people with disabilities. While it is true that people with severe/profound will always need a high/intense levels of support, there are also some people with disabilities who only require intensive short term support to acquire basic independent living skills to enable them to gain long-term independence. This cohort are typically those with mild disabilities, who do not rely on day to day disability support, but on occasional support.

Sole parent/carer or families who have a family member with severe/profound or moderate disability and who don't have a lot of informal supports around them, should be eligible to receive at least a considerate level of disability support, particularly to prevent a crisis or whilst they are in crisis mode. This is not to say that people with disabilities, whose needs are not at a critical stage should not receive funding, but rather should be considered for a lower level of funding that covers their most essential needs.

Carers' needs must also be taken into account when considering disability support and care, particularly when they are caring for a person 7 days a week, 24 hours a day, particularly if they receive no informal supports. A carer's health and general well-being should come into the equation, when it comes to funding. More liaison between the Commonwealth, State/Territory Governments and Carers' support group/organisations may be necessary to gage the needs of carers in Australia.

It is also helpful for all sectors of government not to assume what carers' need, but to ask what their needs are. Often, Government Departments bestow upon carers, programs and schemes that do not adequately meet their support needs or have so much bureaucracy surrounding them, that they can escalate the problem of carers, instead of relieving them. Instead of telling carers what is best for them, government departments should be listening to carers, who are in the best position for knowing what they need.

In order to make eligibility processes fair, consistent and transparent, there should be a nation-wide criteria for the eligibility for disability care and support. This criteria should be widely publicised and State/Territory Government, along with the Federal Government should develop mechanisms on reporting back to the community on how disability support funding is being use on an annual basis. This reportage should go beyond the Annual Report, and should be published via media outlets and internet.

Another factor associated with eligibility is early intervention. An example of this could be an early intervention program for a child with Autism could mean that while they receive short term intensive disability support, this support may negate the need for the child to access long-term disability support funding in the future.

NEEDS INFLATION COMPREHENSIVE SCHEME

In assessing the needs of people with disabilities, there should be no differentiation between new and existing cases of disability, but rather the degree of a person's disability, the nature of supports to be provided and what needs are being met through informal supports that a person has in their life. It is important for people to be seen as “people” and not “cases”.

If putting short term supports in a person's life is going to prevent them from needing long term supports, these supports should be put into place. People needing short term support should be re-assessed every 3 months, while those need long-term support and whose support needs remain static for long periods of time, should be re-assessed annually.

DECISION-MAKING

Guidelines should be established on how people with disabilities and/or their carers can spend individualised funding, furthermore, people with disabilities and/or their carers should be made aware of these guidelines and should be penalised if they do not adhere to such guidelines.

By the same token, service providers who manage individualised funding should not only report to government departments, but must also provide a monthly report of expenditures to the recipient of the individual funding and/or their family/carer. This mechanism should be made mandatory.

Service recipients should be able to save monies for future purchases of equipment and support, as long as this funding is being use within the guidelines, it should not be time-specific.

People with severe/profound disabilities or moderate disabilities or have health issues related to their disability should have access to individualised funding. Individualised funding should be for people who have significant support needs, whose disability is lifelong, and have carers who are experiencing illness and/or aging.

Individualised Funding should be used for providing services such as respite care, in-home support, accommodation support, community access, accessing educational or vocational programs, therapy programs independent living skills or buying essential equipment related to a person disability. Individuals and services could keep receipts or copies of employee time sheets to prove where monies are being spent. People should treat funding as monies to be spent on the types of support mentioned above and as such should keep this money separate from other income.

If a primary carer is providing care to their family member and receiving a carer's pension, they should not be eligible to be paid out of the person's individualised funding, however, if another family member regularly gives them a break, and does not receive any other type of payment for looking after the person, it is appropriate for them to paid out of individualised funding, although it is preferable that this agreement is made through a service.

The funding body should be responsible for monitoring such funding. Service Providers could also monitor funding and liaise with service recipients, if there are any irregularities on the way funds are being spent.

THE NATURE OF SERVICES

There is a role for both individualised and block funding of services. Block funding could be use by people with disabilities who need short term support and should be used at the discretion of service providers. Block funding can be used in emergency situations or to top funding packages where the people are awaiting for additional supports to be granted through those packages. Block funding should never be a permanent solution for people, but rather provide them with support until a more permanent solution can be sought.

The most important services provided are those services which give people with disabilities and their families or carers, a decent quality of life, these services include respite care, accommodation support, in home support and in some instances community access. The predominant users of these services would be those with severe/profound or moderate disabilities.

All service providers should aim to provide high quality and cost effective services to people with disabilities. Service Quality could be monitored through annual questionnaires to service recipients and annual reviews, as well as service audits. State/Territory Governments should also ensure that service providers are adhering to relevant guidelines, procedures and legislative Acts, relating to the provision of services for people with disabilities. It should also be mandatory that services require some form of input by service recipients and/or their families, when it comes to planning services.

Services could be structured in a way that encourage people to work or participate in volunteer roles in their community. A portion of a person's funding could be use for community linking and in some instances this support could decrease over time. Also people with disabilities should not automatically be deem ineligible for support, just because they have gain employment and seemed to have "integrated" into the community.

These people should be eligible for services provided by the Home and Community Care Scheme or block funding by service providers. In some instances, they may be eligible for small funding packages and could make small contributions to maintain the services they receive.

There should be scope for small co-payments for the services people receive. However, these co-payments should be kept small, as to not become financially burdensome for individuals/ families who are unable to pay huge sums of money for services.

Specialist disability service providers should provide only services that are unattainable through mainstream services, for example, if someone is unable to use therapy services through any of the mainstream Allied Health services, they should be able to receive these service through disability specialist agencies. Disability specialist service should also be a source of information on disability, especially when they specialise in a particular disability eg: the Autism Association should have information on Autism.

When trying to purchase a premium service eg: an advanced wheelchair, people should be subsidied to the tune of what it would of cost them to purchase a basic wheelchair. For example an advanced wheelchair costs $750, but a basic wheelchair cost $350, the person should receive funding up to $350 for the advanced wheelchair.

ASSESSING NEEDS

The present system requires people with disabilities, their families/carers to repeatedly tell their story for each service provider with whom they receive a service. It would be helpful to develop a system where people only have to have one needs assessment and this assessment could be distributed to multiple service providers of their choosing and with their consent. This would stop people from having to tell their story repeatedly.

SERVICE CO-ORDINATION AND LINKAGES WITH MAINSTREAM SERVICES

The biggest problem with service co-ordination and linkages with mainstream services is that sometimes people with disabilities and their families/carers may be dealing with multiple services, therefore multiple co-coordinators/managers. Even within a single service, a person might have to deal with multiple contact persons, for example, someone may receive both In-Home Respite and Centre-Based Respite, these two services could have two different points of contact. It would be advantageous if a “case manager” system was to be devised, where a person would only have one point of contact and that person would co-ordinate all of their support needs across all of the person's nominated service providers.

UNMET DEMAND

Unmet demand should be measured monitoring the applications for individual funding submitted in each State/Territory, as well as data being collected by a variety of services, including Government agencies, Non-government Organisations, Carers Support Groups/Organisations, Advocacy Organisations, Disability Sector Bodies and the Australian Bureau of Statistics.

If the Unmet demand in the disability sector is not addressed soon, this crisis will spiral out of control, with the very real possibility that some people with disability be either rendered homeless or imprisoned. Some families are at breaking point- where the only real option is to abandon their child upon the footsteps of parliamentary houses or have a nervous breakdown.

WORKFORCE ISSUES

Sometimes, disability support work is not seen as a “real job” by the general community. Quite often, disability support workers have stated that their relatives/friends have asked them “When are you going to get a “real job”, instead of “playing around” with people with disabilities?” Other members of the community have stated that disability support workers must be “saints” to work with “those people”.

The government could avert these attitudes by promoting people with disabilities and the role of disability support workers in a more positive light. Strategies could include addition advertising during Disability Awareness Week, including community in training and information sessions, marketing to raise the profile of people with disabilities and working within the disability sector and offering traineeships.

Some advertisements and job descriptions could also be rewritten to make jobs more attractive and there could be more use of local disability networks. The disability sector could also enhance links with Universities as a recruitment strategy. Sector-wide recruitment strategies that are clear cut should also be introduced nationally.

There are various skills and workers required by the disability industry. The most important skills needed by those working in the disability industry is an ability to focus on a person as a person and not just focusing on their disability, as well as the ability to play a variety of roles including facilitator, advocate, role model, friend, Community Worker, carer and confidante. Disability Support Workers can also play a role in providing positive opportunities for people to grow and develop and challenging societal assumptions about people with disabilities.

Government can play a role in upgrading the skills and training opportunities available to workers by offering traineeships, developing schemes to assist with the training and development of staff, measuring turnover (finding out why workers are leaving the disability sector), reward and recognition incentive programs, and providing subsidies for employee counseling .

A scheme could be implemented where the administration could be more streamlined and where multi-levels of administration and management could be eliminated. The fringe benefits that senior management of some disability organisations could also be examined-is it necessary for everyone to have big offices and flash cars.

Costs can be saved by a case manager doing a single needs assessment on a person with disabilities, instead of the person being assessed repeatedly by each individual organisation that provides them with support. The introduction of case managers could also make services more streamlined, which would mean the restructure of some disability services, it could also mean that instead of paying for unnecessary administration/management positions, more funding could go towards direct service provision.

The introduction of a case management system would also mean that a person with a disability and/or their family/carers who have to presently deal with a number of different people and services for their support needs, would only have to deal with one person, their case manager. Case managers would have to come from an independent body and be prepared to advocate on behalf of people with disabilities and/their families. While this concept would mean the forming of a new agency, it would also mean downsizing most existing agencies and would be to the betterment of the people being served.

Transition arrangements could people currently working in a case management-type position in small or even larger organisations could be recruited for the newly formed agency, the criteria for the provision of services could change and services would have more time to spend on service quality issues and the recruitment, training and development of staff.

The time to build up a workforce for a case management based system may vary, depending on time it takes to structure and implement such a system. This system could be divided into two main streamlines, those who want to purchase service through compensation payouts or those with individual funding, and those who apply for services that are block-funded.

Under this system, services would be provided with a certain number of block funded hours from State/Territory Governments, the HACC programs and the National Respite Carers' Program. Case Managers can assess people with disabilities as requiring a certain number of hours, they could then liaise with service providers regarding how many hours the person could be granted and how the service could be delivered. The case manager could protect the interests of the service recipient, while the service provider protect the interests of their employee.

While disability support workers may be required to complete some form of disability or community studies before obtaining employment within the disability sector, this does not guarantee that they have the right values set for the job. Some people may be over qualified for the job of disability support worker and yet may seriously disrespect and devalue the lives of people with disabilities. It also needs to be spelt out to those who work within the disability industry that they are there to assist people with disabilities, not to control their lives.

There are instances where disability support workers/allied health workers are being sent to people's homes and they do not know how to use or handle certain equipment required to do the job, eg: hoists, wheelchairs, etc. It must be made mandatory that all disability and allied health workers know how to use all equipment relating to job, before they are given shifts/jobs requiring them to use such equipment. It is also important to clearly spell out all the Workplace Health and Safety requirements of the job, before anyone commences work within the sector.

When the needs of a person with a disability can be met by volunteers or mainstream services, they should do so. Examples of volunteers and mainstream services playing a role in the lives of people with disabilities could include: a volunteer helping a person with disability to do some gardening, artwork, reading or writing. A mainstream service could provide maintenance or domestic services to someone that lives in their own home, or a person with disabilities may want to use recreational/ leisure activities, that are not disability specific.

All workers within the disability sector should have training on areas associated with Workplace Health and Safety, how to treat people with disabilities-including Social Role Valorisation and values based training, including how to communicate with people with disabilities, treating people as individuals, making choices and decision-making.

It is imperative when recruiting people to work within the disability sector to not only check their certification requirements, but also life experience. The fear is that some people who would make great support workers are not even considered for the job, because they don't have the appropriate qualifications.

National accreditation can play a vital role in the disability sector, as it puts all States/Territories on the same page and aligns them with the federal Government. It also assist those workers within the disability who like to travel around in gaining employment in any State/Territory in Australia.

Opportunities for advancement of disability support workers within the sector may improve productivity and efficiency. If a disability support worker has no chance of advancement within the field, they may be of the opinion that they are working hard and long hours, sometimes in a very stressful job for nothing. They may leave the job, due to the fact they there is no career advancement and there are much better paid jobs elsewhere.

GOVERNANCE AND INFRASTRUCTURE

An Independent Statutory Body should be appointed to administer the scheme to avoid conflicts of interests, especially when a number of government departments are working together and have a variety of interests in a particular project, avenues of accountability should be made clear in tis instance.

A new management structure should replace the existing system, as it is quite clear that the existing system is not working and actually contributes to some people being plunged into crisis mode. Two advantages of a case management are: 1) the system focuses on individuals, rather than groups; and

2) if implemented properly, there can be better use of resources.

There needs to be better communication and reporting mechanisms between governments, relevant departments and service providers. This may mean a boost of reporting requirements to government, and/or more liaison between government departments and the staff at ground level. The new scheme could interact and communicate with existing scheme by networking, involving face to face meetings, forums, electronic message boards and forming committees.

A database in each state/territory as well as federally, should be developed to gather information on outcomes, costs and individual records, should be developed. This system could be kept in the Divisions responsible for the provision of disability services in each state/territory and all disability service users could be identified by a code or password, in an effort to maintain confidentiality. This system would take 2-3 years to complete.

For the new scheme to be accountable and transparent, there would have to be a provision made for some kind of annual report. The scheme could also keep the public informed through a website, message-boards and newspapers. In an effort to be more accountable to people granted individual funding, service providers could provide monthly account statements, advising service recipients of how their individual funding is being used.

The need for form-filling and unnecessary re-assessments would be eradicated, if the case management system were to be adopted. The role of a Case Manager could be to assess a person, find information about appropriate disability service providers that could provide services to the person and help the person to apply for services from these service providers. The Case Manager could also help the person to apply for any funding in which they are eligible, including disability funding from Commonwealth and State/Territory funding bodies, Medical Aids Schemes, Incontinence Aids Schemes, etc .

Costs and service quality standards can overcome red tape by having a "one-stop shop" for people with disabilities, their families and/or carers. Instead of people with disabilities, their families and/or carers, having to collect information from ten different Government Departments or service providers, an agency could be established where people could get information on both Commonwealth and State/Territory disability service providers and funding sources. This agency could be a national agency and could have outlets dispersed throughout Australia, with a toll free number for people living in rural/remote areas.

The guidelines for personalised funding accounts should be made clear and there should be penalties for those who misuse the system. Government monies that are granted individually to people with disabilities should be set aside to purchase individualised support, whether it be personal care, in-home support, education/employment, community access, recreational/leisure, advocacy services, providing a subsidy for pharmaceutical/medical services that are related to the person's disability, or disability-related equipment such as wheelchairs, walkers, etc.

While initial consultations/forums should be held on the new national disability insurance scheme, once the new scheme has been established for a period of 12 months, stakeholders should be given a say through representation on the advisory board. People with disabilities, as well as families/carers should always have representation on any advisory board that is established, as it is their lives who are more affected by the decisions being made at this level.

People with disabilities and their families and/or carers should always try to resolved their complaints at service level, before taking further action. If they are dissatisfied at the service's response, they should be able to take their complaint to a disability ombudsman. The main

difficulty with centralised complaint arrangement processes is that sometimes it is a "Caesar judging Ceasar" atmosphere and people are complaining to the same department, which are the subject of the complaint.

Independent boards should be established to handle complaints of a non-criminal nature, if they were unable to be resolved at a service level . Of course, all complaints of a criminal nature should be dealt with by the courts.

An appropriate dispute resolution process should include the complainant trying to resolve the dispute with the other party directly involved, if this is not appropriate or the matter is not resolved, the complainant should go to the person's direct superior- if this is not successful, the complainant should approach senior management and if this fails, they should be able to approach an independent board.

People should be able to find out what they are entitled to by a range of sources, including online, an one-stop shop and service providers.

The new national disability scheme should be continuously evaluated in its' infancy to ironed out any "kinks in the system". The continuous evaluation phase should remain for up to the first 2 years of the scheme's life. After this phrase, evaluations of the scheme should be carried out every 2 years.

Research and innovation could play a very big role in a national disability scheme. There is the possibility that the national disability scheme could be improved by doing research on Overseas funding and service provision models, as these models might be more cost effective and more “user friendly” than what is currently offered in Australia. The same sentiment goes for innovation, innovative ideas could be more cost effective and could lead to better quality service provision.

Research and innovation could be promoted through the availability of a series of “one-off” funding grants and through government departments responsible for the provision of disability funding and services in each State/Territory, as well as those responsible for disability services and funding on a federal level. The research component could be done by a mixture of Universities, independent researchers-including people with disabilities, the Disability Studies and Research Institute or disability advocacy groups.

Effective governance means listening to the people who will be most affected by the decisions being made-that means listening to people with disabilities, their family and/or carers, friends, advocates, disability support workers and service providers. Traditionally government departments have not done this well and have made presumptions about what people with disability need, without and substantiating evidence.

IMPLEMENTATION ISSUES

To avoid substantial risks to people with disabilities, carers, governments and service providers, the the national disability scheme should be slowly phrased in across a five year period, with the first 2 years devoted to setting up the workforce and administrative components of the system as well as beginning to design assessment tools, leaving another three years to devote to promoting the system and implementation of the new assessment tools.

The infrastructure of the system should be implemented as soon as possible to allow time for setbacks. People with disabilities and their families and/or carers who are currently living in crisis mode, due to the fact that they are living with very little or no support, should be the first people who benefit from the new national disability scheme. This cohort includes sole parents looking after a child/children with very severe disabilities, primary carers of people with severe disabilities who need 24 hour care, and aging carers looking after their adult child/children at home.

The major priority for immediate development is to get some kind of support or financial assistance to those who are struggling or are in crisis mode, due to their disability or the disability of a loved one to prevent them from reaching a breaking point and taking drastic action, such as abandoning a loved one at the steps of parliament house.

Consultations and forums could be held to engage stakeholders during implementation stage and to get their input into the system. Discussion papers could also be published to inform stakeholders on how the new system operates, as well as other promotional material.

State/Territory and Commonwealth governments could work together by the Disability Ministers of each State /Territory and the Commonwealth Disability Minister coming together at least once a year to plan and strategised the implementation of the new national disability scheme, as well as providing the opportunity to evaluate the scheme on an annual basis. All government factions could also keep in contact and discuss things via electronic noticeboards and e-mails.

The Commonwealth Government could also regularly call upon State/Territory Disability Ministers to make submissions on a variety of issues that affect people with disabilities, their families and/or carers in their State/ Territory. These submissions, as well as research could provide the basis for decision-making in how the national disability scheme is implemented, measuring its' success and how improvements to the process could be made.

Representatives from each jurisdiction should be elected to ensure that State/Territory governments are cooperating on key issues associated with disability. Representatives should include people with disabilities, their families and/or carers, independent advocates/allies, disability advocacy organisations or disability industry organisations e.g: ACROD, Queensland Disability Sector Training Fund.

BENEFITS

The benefits of a new disability care and support scheme could include people with disabilities, their families, carers and friends having more confidence in the fact that their needs might be met in a more appropriate manner and the fact that huge amounts of funding are not being poured into disability programs that just don't work. If the scheme is structured correctly, the funding will get to where it is most needed-the people who are struggling to survive and are living from crisis to crisis.

Additional resources are best spent on early intervention programs, rehabilitation programs for people with Aquired brain injuries or spinal injuries, people with profound/severe disabilities and people with disabilities, who have ageing carers.

The criteria used to assess the merits of different models of disability care and support should include:

- capacity building strategies to assist communities to include people with disabilities.
- Capacity building of people with disability, their families and/or carers to envision what is possible, to plan for the future and to build a good life for themselves.
- A disability service system that is responsive to need.
- Capacity building of research and development to identified the way forward as society changes.
- Transparency accountability measures for both service and users.
- Empowerment of people with disability to direct their own lives.
- Social inclusion and participation of people with disability as with any other citizen of Australia; and
- are people getting the the right amount of assistance at the right time, by the right people?

There is the possibility that there could be existing studies undertaken overseas that could provide valuable lessons in the rigorous assessment of options in this area.

One possible unintended consequence from the introduction of a disability care and support scheme, could be that it could build a divide between those who receive individual funding and those who do not. To prevent this from happening, the eligibility criteria for the scheme will have to be clear and transparency to both people with disabilities, their families and friends and those responsible for making the decisions.