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Discrimination
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Disability Care and Support
Productivity Commission
GPO Box 1428
Canberra City ACT 2601

By email: disability-support@pc.gov.au

Dear Sir/Madam

Submission on Disability Care and Support

The Disability Discrimination Legal Service Incorporated ("DDLS") is an independent, community organisation that specialises in disability discrimination matters. It is a not for profit incorporated association that provides free legal service to people with disabilities. It also provides community legal education and undertakes law and policy reform projects in the areas of disability and discrimination.

A committee of volunteers manages the service. The DDLS Management Committee includes people with disabilities. Many people with disabilities, volunteers and students contribute their efforts to the work of the DDLS.

Through its work, the DDLS has been involved in matters which necessarily involve the experiences of people with disabilities and their receipt of services through the State (Victoria) and the Commonwealth. As a result, we make the following observations and recommendations to some of the key questions posed by the Productivity Commission.

Communication Rights Australia (“Communication Rights”) is a human rights community based not-for –profit organisation driving fundamental social and cultural change within the general community to eliminate the disabling barriers that impact on people accessing their rights. To achieve this objective Communication Rights provides advocacy for people with little or no speech, information and community education to all key players within the system.

Communication Rights is funded through the Department of Human Services Victoria and managed by a dedicated Board who consist of people who are committed to the mission and goals of the agency. Their role is to provide guidance and direction to the agency by providing a sound foundation from which to negotiate the vision, mission and strategic planning of the agency.

Over the last 12 months the issues of Disability Care and Support has involved 60% of our advocacy cases. Some of the problems raised with us were:

- Standard of Care;
- Level of Support;
- Quality of Planners and the planning process;
- Quality and training of staff and nature of service.

Based on data collected over the last five years we submit our response to the Productivity Commission. It is accepted that our comments are also made with the understanding that when clients come to us they have tried to alter the system themselves but with no success and feel they have not been listened to.

Communication Rights Australia supports the government policy being to ‘to enhance the quality of life and increase the economic and social participation of people with disabilities and their families’ but have difficulty with how the government has implemented some programs and the level of financial resources allocated to achieve policy.

The DDLS and Communication Rights have the following comments to make to the Productivity Commission in relation to the new disability care and support scheme.

1. Who should be eligible?

a. Who should be in the new scheme and how could they be practically and reliably identified?

It is our position that any person with a disability should be eligible for the new scheme. If a person has a disability related support need then they should be provided with support. For individuals to exercise their human rights under the Convention of Rights of Person with Disabilities (CRPD) they must be afforded these supports. Exactly how the scheme would support them would be determined in other ways. There are a number of existing documents that should be used to define “disability”. We endorse the following documents, which could be used conjointly:

Disability Discrimination Act (Cwlth) 1992
International Classification of Diseases (“ICD 10”)

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

The question above is difficult to answer, bearing in mind that “groups” of people with disabilities contain individuals whose needs can be quite different. Recent reports on the experience of people with disabilities reflect that there is no one group that is having its needs catered for adequately.

With the above in mind however, we believe that people with mental illness, Autism Spectrum Disorder (“ASD”), Deaf people with disabilities and people with complex communication needs (people with little or no speech) have and do suffer considerably due not only to a lack of services, but a lack of appropriate services.

Consideration should be given to the need for a Flexible Funding Approach which will allow for people to access services when they are most in need, but during times when their need may not be as complex, to draw back from services. Most people do not want services in their lives if they can do without them, but they do need to know if there is a need that the service is available.

The approach of identifying who is in most need is counterproductive, as once a person is deemed to be eligible for the scheme then they should receive support in order that the policy goals can be met. There should be no means testing but a basic coverage to all.

b. What could be done about reducing unfairness, so that people with similar levels of need get similar levels of support?

The DDLS believes that the *International Classification of Functioning, Disability and Health ("ICF")* can be used to achieve this goal. There is no point in inventing criteria and classifications of functioning when these tools already exist. It is important that government agencies providing assistance do not create a system of their own. It is fraught with risk for government departments that have an interest in meeting budget to develop systems which are fair and equitable for people with disabilities.

A good example of this is the Victorian Department of Education and Early Childhood Development's "Program for Students with Disabilities". This program has re-created definitions of disability which completely exclude students outside the seven "approved" disabilities. The outcome is a completely inequitable system where schools try and balance the needs of all children with disabilities by taking funds and resources from those who have met the criteria, to give to those who did not.

There is a conflict of interest between those whose interests are administrative, and those who are interested in achieving outcomes for people with disabilities. The ICD-10 and ICF are endorsed by the World Health Organisation and there is no reason why they should not be used in Australia.

What is required is a commitment by government for lifetime care and support to those in need. Waiting lists are completely inappropriate, and should not be part of the scheme. Choices between individuals or groups as to who is the most deserving should be abolished with the new scheme. Sufficient funding is required in order that all those in need receive it. Those needs must be attended to immediately to avoid mental and physical deterioration in people with disabilities, their carers, and relinquishment. The scheme must be sensitive to changes in people's health, well-being, family and living circumstances.

A lifetime care support approach will provide the community with a greater sense of unity that dividing people into age or disability groups can avoid. Further the issue of unfairness of services to people with similar needs will be addressed through this approach.

2. Who gets the power?

How should the amount of financial support and service entitlements of people be decided (and by whom)?

People with disabilities should be able to make decisions on service entitlements. Naturally there needs to be a framework for those entitlements.

Historically, government appointed “specialists” have been renowned for their perceived lack of understanding and compassion in dealing with those who are disadvantaged. Examples of gross dissatisfaction with such appointees are evident when dealing with WorkCover medical practitioners, Commonwealth Medical Officers, Departments of Education, Mental Health Review Tribunals and so on.

In relation to decisions regarding which services should be provided, the DDLS and Communication Rights Australia believe that such a framework should be a rights-based framework. In our view, the most appropriate framework should be that contained in the UN Convention on the Rights of Persons with Disabilities (“CRPD”). Australia has ratified the CRPD, and its Optional Protocol. By doing this, Australia has endorsed the human rights contained therein, and has, by virtue of ratifying the Optional Protocol, invited scrutiny of its treatment of people with disabilities pursuant to the CRPD. Bearing this in mind, there should be no objection to the Commonwealth using these rights as a framework for its services. It is bound to comply in any event, and formalising such rights in the general provision of services to people with disabilities would be a natural progression in our view.

As stated earlier in the document all people should be provided with a basic level of coverage based on the assessed needs to meet the policy goals of the program.

The Canadian Approach has had an Entitlement program for over 40 years and people have been able to access supports as needs develop. There is no waiting list. There is training attached to the Entitlement which covers such topics as monitoring, accountability and openness to change. People have received their allocation very successfully with few problems and little wastage or rorting.

3. What services are needed and how should they be delivered?

a. What kinds of services particularly need to be increased or created?

i. Best practice accommodation services for people with ASD

Such specialist services exist internationally. We refer you to the Jay Nolan Community Services www.jaynolan.org.

ii. Positive Behaviour Support Teams.

It is clear that disability support staff remain undertrained, and often unable to treat clients with difficult behaviours in anything other than a punitive fashion. In fact it would be the view of many working in the sector that undertrained staff are responsible for many of the behavioural problems experienced by people with disabilities.

iii. Speech Pathologists expert in AAC.

Such professionals are required to train staff who are working with people with complex communication needs in the particular communication mode that person requires. Such training needs to be ongoing until such time that the staff in question can fluently communicate with those they work with.

iv. Applied Behavioural Analysis Programs/Trainers

Staff working with people with ASD should receive specific training in working with this group, realising that their needs are unique and different to those with other disabilities.

v. Auslan training

Partnerships with educational institutions to train staff in Auslan need to be fostered in order that services with signing Deaf clients receive those services through people that they can communicate with.

vi. Aids and Equipment

A national approach to the provision of aids and equipment is required which includes access to communication devices. Further as the community is moving to mostly on-line services access to telecommunication equipment should be co-ordinated but not necessarily funded through a national program.

Overall there needs to be a cultural change as well as services change from government to ensure that we move away from a welfare mentality into a rights framework.

b. How could the ways in which services are delivered — including their coordination, costs, timeliness and innovation — be improved?

Services should not be developed in a market framework but instead be able to be adapted to individual needs. This may not 'fit' with an economic rationalist approach but it complies with the CRPD.

Planning is an important element for government to manage demand, however what has been reported is that the thousands of plans developed on behalf of people over the last few years has had little impact on their inclusion into the community. Our experience is that Planners do not really get to know either the person nor their preferences. Plans cannot buy friends or community belonging.

People will need to do be creative and innovative in their approach as result of having to support people with disabilities. Individuals ask for less money if they do not have to go to program controllers with cap in hand. Leadership and role models should be resourced. Training, education and mentors should be an important component of services. Information that is realistic should be available. Goals should not be driven by politicians or rhetoric but real life.

Not everything needs to be paid for under the program, but rather consideration should be given to what do we need to support the inclusion of people with disabilities in the community.

i. Language Access.

Currently, there are very few services that provide access for Deaf people using Auslan, and people with Complex Communication Needs ("CCN") who rely on Augmentative and Alternative Communication ("AAC").

Such refusal is often financially based, or simply reflects a lack of respect for the person with a disability-in other words there is a view that it is not important for the providers of disability services to communicate with their clients.

There are a number of examples within service delivery where people with disabilities who require Auslan or AAC are not receiving access. One important example indicative of the problem is the formal language policy of Victoria's Department of Human Services ("DHS").

“Minimum critical points for Department of Human Service programs and funded agencies

The Department of Human Services has identified the following minimum critical points at which people with little or no spoken English should have access to information in their preferred language:

- ☐ *Life-threatening situations.*

- ☐ *Obtaining information from the client (and carer where appropriate); undertaking assessments and care planning, including conducting tests; and forming diagnoses to inform treatment and service provision decision-making.*

- ☐ *Communicating to and receiving important information from clients to enable them to make informed decisions about services, options, and the implications of these options, such as:*
  - *information about entitlements, fees, rights and responsibilities, for example, privacy and confidentiality;*
  - *assessment outcomes, test results, or diagnosis;*
  - *treatment options;*
  - *referral options; and,*
  - *information about procedures, treatments, prescribed medications and medication regimes and other interventions.*

- ☐ *Direct service delivery that is based on conversation or other form of verbal/signing communication, eg counselling, speech therapy.”*

There is no right for people using Auslan or AAC to receive every day services through their language. The point at which this has the greatest impact, is when people with disabilities are spending significant portions of their time in language deprived environments, such as Community Residential Units or Day Placements. There is no requirement by DHS for it, or its subcontractors to commit to having staff who can communicate with these clients. The result of this is that the clients described above can spend most of their lives without being able to properly communicate with those around them. The ability to communicate is a basic right and affects choice, decision-making, occupational health and safety, and duty of care amongst other things.

The refusal to provide language access to deaf people and people who have complex communication needs is a breach of the Convention on the Rights of Persons with Disabilities, State and

Federal discrimination law and a number of other international conventions.

Case 1. Kindilan Society, trading as Focus, sub contract to the Department of Human Services and provide accommodation to people with disabilities. From approximately 2003 to March 2009, two deaf residents resided in one of their Community Residential Units. Staff working with the deaf residents were not required to have fluency in Auslan. Therefore, for approximately 6 years, apart from contact with one signing deaf part-time staff member, the residents had extremely limited ability to communicate their wishes, had limited social interactions with those they lived with, and were unable to convey anything but the most basic communication with those who they were dependent upon for meeting all their needs. Their father advocated numerous times on their behalf to both Focus and the Department of Human Services. At no time was there any acknowledgement or agreement that the deaf residents should have access to services that were culturally and linguistically appropriate. The father of the deaf residents committed suicide

c. Are there ways of intervening early to get improved outcomes over people's lifetimes? How would this be done?

Communication Rights and DDLS strongly support early intervention. Families need support as early as possible to ensure that as a unit it survives, so that it can in turn support the child with the disability. Huge pressures exist on families during these early years as they adapt to having a child with a disability. Once the family starts to move into Early Childhood services they can be faced with a culture that does not support inclusion. This brings untold pressures upon them which if not supported can cause family breakdown.

From observation, much of the service provision required by people with disabilities is caused due to those persons' significantly substandard educational experience. In Victoria, the Department of Education and Early Childhood Development ("DEECD") is frequently sued by parents of children with disabilities in relation to their refusal to meet individual needs.

An example of this is services available for children with ASD. FAHCSIA has recently begun providing funding for early intervention for children with ASD. When that funding runs out while children are in early primary school, the DEECD provides insufficient assistance for children to continue in any meaningful way, the therapy that they began and require. Recently, children with Asperger's Syndrome were a target of further cuts, and money for social skills programs, speech therapy, ABA Programs, and so on is not available for children with ASD unless they sue the Victorian government. Therefore, at the other end of their education, young people with disabilities can often leave the school system with significantly less skills and abilities than their potential allows them. Research has proven that children have the greatest learning capacity when they are younger. Unfortunately, often by the time children with disabilities leave school they have been "disabled" by the education system, requiring more government assistance than would normally be necessary.

The Commonwealth needs to adopt a more directive approach with state departments of education, and ensure that by the time children with disabilities leave school they have been equipped as much as possible with an education, social skills and are free of psychological illnesses actually caused by their schooling experience.

Those individuals will then need less support through the Commonwealth and have greater capacity for successful inclusion into our communities.

The key to improved outcomes for people is to ensure there exists flexible and responsive services. Increased techno-bureaucratic managed intrusion into people's lives need is to lessen. The key is to provide a system that meets the basic needs of people without adopting a welfare approach.

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

We refer to the comments above in relation to the state Departments of Education. If the Commonwealth's aim is, as it should be, for people with disabilities to have meaningful lives and involvement in their community, it is important that they be equipped with the skills to undertake further learning and employment. With the current paucity of appropriate educational approaches taken towards children with disabilities, the goal of employment is often abandoned. This is an extremely undesirable outcome and inappropriate for a number of reasons, including economic reasons.

Currently, attendant care services to people with disabilities are not sufficiently robust to provide dependable, regular services. Bearing in mind some people with disabilities rely on attendant carers to actually enable them to get out of bed, get dressed and leave the house in the morning, if these services cannot be relied upon, the goal of employment is not going to be achievable.

For some reason, it seems that poor performance and low wages are acceptable in the field of disability care, despite the dire consequences of incompetent assistance.

Case 2. A man with severe cerebral palsy who relies on attendant carers to enter his home and get him up every morning, was left without assistance until 7 PM that evening. It was only due to a housemate arriving home, that the client was not left without food or the ability to go to the toilet, for almost 24 hours. When a carer finally came, they did not have sufficient training to assist the client

Attendant care agencies need to be held to the highest standards, and employ trained, competent staff. Their administrative systems need to be exemplary, due to the seriousness of them not fulfilling their functions properly. In Victoria, there are extremely low expectations of attendant care agencies, due to their history of incompetence, lack of training, refusal to spend money on training additional to that which is most basic. People with disabilities will not be able to enter the workforce if they cannot even plan on eating and getting dressed every morning.

Carers will be more able to find employment if they have respite, and their children are receiving competent services whereby they do not need to be contacted every day for assistance from the service provider, thereby preventing them from getting a job. The mental health problems suffered by carers are impediments to gaining employment - such mental health problems are often to do with lack of appropriate service provision to the child. When some of the other issues regarding service provision are addressed, it would be hoped that the rate of mental health problems in carers will decrease and employment will become more of an option.

Resources should be made available for role models, leadership development, training and education, and mentors for families and individuals with disabilities. Advocates who can navigate and negotiate the system to help people in times of crisis should be easily available. Any planning should be realistic and truthful in its approach. Raising expectations unrealistically, can be damaging to families and individuals, but future services should not be limiting of a person's development.

4. Organising and implementing a new disability policy

Some of the issues, in brief, that are relevant to implementing a new disability policy and therefore service are the following:

a. Increased payment and training of disability support staff. There are too many reports of abuse occurring against people with disabilities in care. This is likely to be a result of low pay and general lack of expectations of disability support staff.

   Working with people with disabilities, particularly those who have multiple and complex disabilities, is an area that requires expertise. Instead, to date, we have given these jobs to people with minimum training and qualifications. This must stop.

   Higher rates of pay need to be allocated to these workers in order to attract competent staff.

b. Money needs to be set aside for training and interpreters.

c. Placing a positive duty on all government funded service providers to comply with domestic and international human rights laws and conventions. Current data required by government focusing on outputs rather than outcomes encourages substandard service.

Overall Communication Rights and DDLS believe the new disability policy should not be market driven but rather needs an “entitlement” approach. A good model is the Scandinavian long-term care system approach funded through a Disability Level similar to that of Medicare. This provides individuals with the confidence of a level of support necessary to live independently within the community. Extra financial resources will be required for training, education and so on of both the recipients of entitlements as well as their staff.

The DDLS and Communication Rights believe the worth of people with disabilities is not currently reflected by the Australian and State governments and this review provides a long-awaited opportunity to address long articulated difficulties with the service system.

Yours sincerely

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