# Submission to Productivity Commission

# Inquiry into Disability Care and Support

### Disability Professionals Australasia – South Australian Chapter (DPA-SA)

## About DPA-SA:

Disability Professionals Australasia (DPA) came into being in response to a need for professional recognition and encouragement of people who work in a variety of capacities in disability and related human service areas. A centralised Australian based structure has been developed to accommodate the needs of workers in not-for-profit organisations across all Australian states and territories and to allow our New Zealand colleagues to also participate. Each geographical area has developed, or is in the process of developing, a 'Chapter' to represent their interests on the National body.

Each region in Australia and New Zealand has different histories in terms of professional groups representing people working in disability. In South Australia, the Developmental Educators Association (DEA) was formed in the early 1990s to represent the interests of graduates of university based disability courses. Over time, this group became the DisAbility and Rehabilitation Professionals Association (dArpa) in order to capture a wider field of representation from professionals working in the disability sector.

However, a large number of people working in the disability sector, both in paid and voluntary positions, did not see the relevance of this association. A decision was made to change from dArpa and to become part of the National DPA group that encouraged membership and representation of ALL workers in the disability sector, irrespective of qualifications. At the AGM in November 2009, DPA-SA came into being.

## Rationale of this Submission:

For many years, workers in the disability sector in South Australia have been aware that the current provision of services to people with disabilities in this state has been largely dysfunctional and crisis driven.

In its last 'Report on Government Services 2010', the Productivity Commission reported South Australia as having the lowest expenditure per user of services in Australia. Recently released figures from the December 2009 SA Government 'Disability Services Unmet Needs List' show that, in the previous year, there was an increase of 26.3% in the number of people with disabilities placed on the Category 1 Crisis List. And this Category is defined as those people whose needs are 'critical' and who present a 'high risk of harm to self or others'.

Unfortunately, it is often the workers providing direct 'hands-on' support who are most aware of the issues and problems being faced daily by people with disabilities and their families. It is also those workers who are the people who have to deal with these issues directly.

This Submission follows 'The key questions' outlined in the Productivity Commission paper. It focuses on some of the major issues of concern to workers in the disability sector. It in no way claims to be an exhaustive outline of the issues but the authors believe that this Submission represents the views of the majority of direct disability workers.

DPA-SA feels strongly that the views and opinions of the workers in the disability sector are of great significance to this Inquiry.

## Eligibility:

It is clear that the number of people with disabilities is increasing. Most people, including people with disabilities, are living longer and acquiring more disabilities as they grow older. There is evidence that disabilities at birth and acquired through life are also increasing. It is now even possible to pick up resistant bacteria and viruses causing life-long disabilities from a period of hospitalisation for a simple medical condition.

It is also clear that the number of people available to provide necessary services and support for people with disabilities is decreasing with the aging of the Australian population. For the past 30 years, across all jurisdictions and in all areas of disability, there has been a crisis in the recruitment and retention of disability workers.

This shortage of staff has led to major issues which must be addressed by any proposed scheme:

- families who suspect that their child may have a disability are often unable to access any professional assessment and may need to wait, sometimes for years, before any support can be provided. This lack of early intervention usually delays the treatment or support of these infants and children with disabilities and often allows those disabilities to become more severe over time. This delay also often increases the costs of necessary treatments and supports when they are finally provided.

  **Any proposed scheme must provide early assessment, and early interventions if appropriate, for ALL children with suspected disabilities. This is of critical importance in minimising both the individual's level of disability and the on-going costs of support.**

- mental illness can be a major disabling condition for many people. Governments often seem to reduce costs by simply moving people between health and disability services. The person then 'falls through the cracks' and receives little or no real support for their problems.

  **Any proposed scheme must provide adequate services to people disabled by major mental health issues.**

- the range and complexity of disabilities is immense. Each person's disabilities are completely unique to that person and often their individual needs may differ depending on their particular situation. Those disabilities may be present at birth or may develop at any stage of life due to accident or illness. It would be grossly unfair and inequitable to even try to distinguish between differing types and levels of disability and the services that should be provided to each group.

  **Any proposed scheme must provide equal no-fault services to ALL people with disabilities of any kind (including mental illnesses) at any stage of their life and for any necessary duration. These services should be available to ALL people up to the age of 65 years when they can currently move into other health and pension support services.**

## Power and control of the scheme:

- A major criticism, by workers in the disability sector, is that too often key decisions about the on-going treatment and support for people with disabilities are made by managers and bureaucrats who have little or no real practical experience in or understanding of disability support practices. These decisions are usually made on financial and funding grounds without any consultation or discussion with workers or family members who may know the person's particular needs intimately.

**Any proposed scheme must encourage the involvement of families and direct support workers in the decision making process.**

- The SA Government began a trial of a 'self managed funding scheme' in 2009. It had some difficulty in recruiting 50 families into that trial because many families simply do not want to take on the responsibility of controlling all the funding provided. Many families and workers are also concerned that, given the history of government funding schemes over past years, such a scheme may provide a real threat to currently available services as government and agencies withdraw those services and replace them with a user pays system.

  **Any proposed scheme must provide greater choice and options for people with disabilities and their families**

- many people with disabilities have great difficulty in communicating clearly with others. This can present major problems for people with disabilities when seeking adequate and appropriate medical help or treatment. Very few community GPs and medical specialists have the time to spend with these people and often it requires family members or disability workers to advocate and force the resolution of medical issues for these people. If not supported in this way, many people with disabilities receive very poor treatments including chemical restraints and over-prescription of drugs. Even though in many cases there may be Medicare funds and programs available for on-going treatment or monitoring options, these are often not accessed.

  **Any proposed scheme must provide sufficient rewards to encourage specialist workers, especially GPs, medical specialists and other Health Care professionals, to provide adequate services to people with disabilities.**

- Although 'person centred planning' is currently championed by governments and service providers, in reality, people with disabilities are still often forced to choose between unsuitable 'programs' and options. It is always cheaper to fund one program rather than tailor services for 20 individuals.

  **Any proposed scheme must be truly person-centred and provide greater encouragement for agencies to develop and provide a wider range of services to meet the individual needs of people with disabilities**

- Within the disability system, there is a constant reporting of failures to meet critical unmet needs. Indeed, because of the lack of adequate respite services in SA, we have the case of a mother who allegedly killed her son awaiting trial on a murder charge. There are no structures currently available where people with disabilities, their families or the workers who provide support can lodge complaints or appeal unfair decisions.

  People with disabilities are clearly discriminated against in the area of abuse. Although National Disability Standards raise this issue, there are no statutory methods of reporting and dealing with incidents of abuse. Recently elected Member of the Legislative Council, the Hon. Kelly Vincent, introduced a Bill into the SA Parliament in late July to establish a legal obligation for workers and volunteers in the disability sector to report incidences of abuse or concern and to be protected for doing so. We have had mandatory reporting of abuse laws for children and elderly people in care for many years. It is necessary to extend this to cover an even more vulnerable group in our society.

  **Any proposed scheme must provide a simple, direct and easily accessible system of appeal and complaint for people with disabilities, their families and their support workers.**

## A National Disability Insurance Scheme (NDIS):

While almost any changes to current funding and provision of services would be welcomed, **DPA-SA believes that a no fault National Disability Insurance Scheme, based on the Medicare model, will provide the most efficient and effective change in the provision of services to people with disabilities.**

The system should allow people with disabilities and/or their families to simply access an appropriate service with the cost of that service, at an agreed level, to be paid by the government. An NDIS would allow:

- all areas of disability support needs to be addressed
- a wider choice and range of options in all areas of the disability sector
- one single system of accessing and paying for services across Australia
- easier and faster attention to disability issues
- the early intervention and provision of services to minimise on-going costs
- competition between disability service providers
- the development of innovative and effective services rather than the current duplication and wastage in the services available
- specialisation in particular areas or services by professional disability workers
- better coordination with and links to health, education and other areas of necessary services within the community.

Medicare provides all Australians with a simple system of accessing and receiving appropriate medical treatment whenever and wherever it is needed. Our education system ensures that all Australian children are able to access and receive a basic education.

Both of these systems also allow for a wide range of choices by those using the services. We can attend a doctor or medical practitioner of our choice. If we hold particular views, we can seek alternative treatments. If we hold particular philosophical positions, we can refuse certain treatments or start our own school with a group of like-minded people.

People with disabilities, their families and those of us who work with them deserve no less.

## Funding:

Disabilities can and do occur across all sectors of the community. Any of us can have a child born with a disability, either inherited or caused by an accident of pregnancy or birth. A large number of us may develop disabilities during our lives from accidents, from progressive or degenerative medical conditions and even from common diseases we may suffer. And as we age, we are all likely to develop a range of conditions which are disabling and may require the provision of support.

It is estimated that more than 20% of people in Australia either have a disability themselves or know or are involved with a person with a disability. This is a far higher level of involvement than for people suffering from road or work accidents. As a society, we generally accept that we should pay compulsory Third Party Insurance as part of our motor registration and WorkCover levies as part of our employment costs.

So, because disability can affect all of us at any time, it is fair and equitable if all of us contribute to the costs. A Levy where a small percentage of all incomes are collected by government is one of the simplest ways of achieving this. If the cost demands on the NDIS increase for any reason, the levy can be varied to meet those needs.

The majority of direct costs for individual disability services could be met by a Levy based funding system. However, there is a range of important issues which must still be addressed. The costs of providing these necessary improvements in disability services may still demand direct funding from general government revenues. These issues include:

- **Staff recruitment and retention**, especially for direct support workers providing 'hands-on' support services, must improve. This will require an increase in funding to allow improvements in pay and working conditions in this critical area of disability support.

- **Dual disability**, usually defined as a person having an intellectual disability and also developing mental health problems (eg people with Down's Syndrome developing early onset Alzheimers), is now well recognised and presents a significant support issue.

  Disability SA employs only one Psychiatrist for half a day per week and only one qualified Mental Health Nurse.

  There is a clear need to employ more specialist staff to address this and other similar issues.

- **Support during hospitalisation** for many people with disabilities is necessary when they move from a familiar home environment into a hospital ward. Hospitalisation is becoming more accepted as an area creating major stresses and daily management issues and requiring new support practices for people with disabilities.

  Often physical and/or chemical restraints are used unnecessarily to control a non-existent behaviour because hospital staff have little experience or patience with people with disabilities. False assumptions about the value of that person's life may also be made with the question 'Do you want us to resuscitate this person?' frequently asked of family or support workers.

  These stresses may need to be controlled by having a disability support worker present but this creates new cost dilemmas. Some hospitals will now pay the time costs of a special support worker if they request them to be present.

  Additional funding will be necessary to adequately deal with this problem which will continue to increase as our community and its people with disabilities age.

- **Lack of training** is a major concern at all levels.
  - Training of direct disability support staff has long been considered unsatisfactory. Direct support workers often receive no formal training or orientation before beginning work with a person with a disability. This presents real frustration and stresses for both the worker and the person they are supporting.
  - Training for Certificate III and IV disability qualifications has often been heavily criticised by workers at all levels across the disability sector. We have recently seen clear evidence of Registered Training Organisations providing totally inadequate training to foreign students seeking qualifications for Australian residency. A practical class of over 50 cooking students being provided with only two fry pans is a

joke. Simply changing the heading on notes from ‘Aged Care’ to ‘Disability’ is little better.

  A national review of accreditation and standards of disability training is necessary.

  - In Nursing courses at University of SA and Flinders University, there are no lectures or specific training on disability issues. Nursing at Adelaide University does provide a small number of lectures in a disability topic in 2nd year.
  - People with disabilities themselves often request or need special training to achieve their goals. This can be a major issue for a person preparing to enter the workforce. However, there are few opportunities for people with disabilities to access such training.

Increased funding to improve training across all sectors of disability services will be a necessary and on-going government commitment.

**Organising an NDIS:**

DPA-SA accepts that these changes to the way disability services across Australia are provided will be difficult and will take time to implement fully.

However, we believe it is essential that changes to the current failing state service systems begin as a matter of urgency.

- The Federal government already has responsibility for funding employment and advocacy services across Australia. The National Disability Agreement currently negotiated with State governments provides most of the huge funding requirements of other areas such as accommodation services.

  The Federal government should, and could, immediately tighten the requirements and accountability for funding by State governments in their implementation of disability services.

  Given the years of reluctance to provide adequate services and the constant underfunding by State governments of all political persuasions, disability may well be an area that State governments are willing to pass to Federal control.

- An NDIS system would need to be administered by one central authority to prevent the current duplication and wastage of funds and resources.

  This authority would need to establish a series of criteria for eligibility, parameters and methods of accessing services, payment processes and the roles of various agencies and workers in delivery of those services.

  Hopefully, these decisions would include the involvement and discussions with workers at all levels of the disability sector.

- As stated previously, the disability sector is extremely complex. DPA-SA would hope that the NDIS authority and the services it provides remain flexible and easily open to change and amendment as the issues facing people with disability are recognised and accepted.

Brian Matthews
Chair, DPA-SA

Sue Paech
Committee Member, DPA-SA

Peter Cookson
Committee Member, DPA-SA