Cara's response to the Productivity Commission Draft Report Disability Care and Support April 2011

Cara is the second largest non-Government provider of accommodation and respite services for individuals with a disability in South Australia and has a 60 year history having developed from the Spastic Centres of South Australia (SCOSA). Cara is committed to supporting people with disabilities and their families to live full and rewarding lives. We support over 400 children and adults, operating across 43 metropolitan and regional sites in South Australia. Cara's client group focuses on individuals with severe and multiple disabilities however like many agencies due to a demand on services Cara's client group is diversifying. Nevertheless there remains a focus on those with complex needs who are among the most disadvantaged in the community. Approximately 90% of Cara's clients have an intellectual or cognitive disability.

Services include supported accommodation in community houses, children and adult respite houses, Youth Getaways, Camps for Kids, in-home attendant care support services, Families for Families (host family). Vacation respite for teens and independent living skills training.

Approximately 58% of Cara's clients are under 18 years of age and 42% are 18 years or over. 73% of clients receive respite support and remain living with their families and 27% receive accommodation support.

Cara welcomes the Commissions draft report on Disability Care and Support and in particular the recommendation for the introduction of a National Disability Insurance Scheme (NDIS). As many of the clients supported by Cara remain living with their families it will be a great relief for families that there is an entitlement to support provided in a timely manner.

Many Cara families hold grave fears for their family member with a disability as currently the only way to receive accommodation support is to abandon the family member, usually at a respite service. One then has little if any control or say in the long term accommodation support option the family member ends up receiving. A NDIS will also allow for a gradual move to out of home support rather than the current all or nothing approach which prevails in South Australia.

An NDIS will also allow Cara greater flexibility to meet client need by being able to shift funding to areas of demand rather than the rigid program funding that currently exists.

As an organisation with shared services and supports such as in group homes Cara is aware that moving to an individually funded model will present challenges. However an NDIS places the power and control where it should be - and that is with people with a disability and their families. This view is fully supported by the Cara Board of Directors.

Please find outlined below feedback on a number of areas of the report for your consideration.

1 Training

Cara is concerned about the lack of training benchmarks. The scheme will bring about a significant increase in individual support resulting in unsupervised workers. The potential for increased vulnerability of those with a severe and multiple disabilities is considerable.

Cara developed from the Spastic Centres of South Australia (SCOSA) and part of SCOSA's services was a nursing home staffed by nurses and operating on a medical model. There were many that believed that those with severe and multiple disabilities could not live without the support of a medical model and needed to be in a nursing home. The nursing home closed twenty years ago and part of the move was ensuring that a skilled and supported workforce continued to be available including the skills and support to meet client's health support needs. Nowadays experienced Registered Nurses assess client health support needs, develops a comprehensive health support plan that can be easily followed by non-nursing staff, train staff to follow the plan and provide ongoing support to the staff. Such a system is critical for many Cara clients to live safely and successfully in the community. The concept is that your health support needs should not dominate your life and dictate where you live and how you receive support.

As the majority of Cara clients have a cognitive disability in addition to a severe physical disability - a lack of training benchmarks will leave clients very vulnerable and place them at risk of death. Another possible outcome could be a return to medical models as it could be perceived due to lack of training and support that community living does not work despite twenty years of success.

Cara currently requires staff to have a minimum of Certificate III (Disability). In addition there are regular updates and training in a number of areas including:

- First Aid
- Medication administration and general health training such as epilepsy and standard precautions
- Specific client health related training by a Registered Nurse with the client with a disability. For example training staff to administer nutrition via a gastrostomy for a particular client following the client's health support plan. This is resource intensive but ensures client safety.
- Manual Handling Cara clients have complex manual handling needs
- OHS&W
- Mealtime Management- completed by a Speech Pathologist to ensure staff feed someone appropriately who is at risk of choking such as someone with cerebral palsy.
- Nutrition and healthy eating
- Positive Behaviour Support
- Food handling
- Specific disability type training e.g cerebral palsy

Due to recruitment issues Cara will meet the costs of a staff member completing a Certificate III (Disability).

2 Protection of those who are very vulnerable

Those with severe and multiple disabilities are very vulnerable, particularly those individuals who have no-one independent of the service system to assist and support them. It will be imperative that sector wide independent safeguards are in place such as the Community Visitors Scheme operating in Victoria. For those who cannot represent themselves such safeguards are critical particularly during the transition process as we must not allow those who are most at risk to be victims of experimentation in the new way of operating. We must protect people as the changes are occurring and re-evaluate the safeguards once a new way of operating is well established and the risks clearly identified.

Cara is aware that some groups will argue that such safeguards are not required and for many people with a disability such safeguards will not be necessary with such individuals wishing to get on with their lives without bureaucracy and interference. Those that do not require the safeguards must not preclude this very vulnerable group from receiving them.

3 Benchmark pricing

As outlined above many clients supported by Cara are extremely vulnerable and require skilled staff who are well supported. A well trained support worker supporting someone with very complex needs will need a solid infrastructure of support behind them in order to be successful. They need ongoing training, drop in support and emergency backup. Pricing frameworks will need to take account of such costs.

Due to the physical support needs of many Cara clients they require expensive equipment in order to live in the community successfully. Examples include; electric beds, special bath, wheelchair, overhead lifters and specialised transport. Cara trusts that such equipment will be available in a timely manner and funding will be available for such equipment.

4 Commission's recognition of the issue/complexity of individuals with an Intellectual Disability

The Commission is to be commended for including coverage for those with an intellectual disability who are not easily covered by the definitions, i.e. *Intellectual disability not already included (50 000)*.

Although Cara only supports a very small number of individuals who would come under this category such individuals are very vulnerable and their inclusion is recognition that they have particular needs that left unmet will result in such individuals being homeless and open to abuse and neglect.