CASA

(Committed About Securing Accommodation for people with Disabilities)

CASA is a parent group that has over two hundred members. We came together over the lack of funding for desperately needed services. Accommodation is the core main concern of our families.

We were formed in 1999. We are a united and committed body of parents, with a vision of securing permanent supported accommodation for people with disabilities, and supporting their rights to plan to live independently in the community, when the time is right for them and not reliant on a family crisis. Our goal is to make the governments aware of the critical unmet need in accommodation, respite and therapy services for people with disabilities.

Preamble

Our families welcome the Productivity Commission's Inquiry into the Disability Care and Support, as they feel that they fall through the cracks, they live with the uncertain future of "what will happen to their son or daughter when they die?"In a prosperous country like ours how can the governments allow seventy, eighty or ninety year old still care for sons or daughters, while their own health is failing.

Families are let down as neither of the tiers of government have taken the leadership role into addressing the critical shortage of disability services to allow our children to become valued members of their community. We read regualry statements like the one below.

"People with disabilities and their families are valued and are equal participants in all aspects of life."

For our families to achieve this we need appropriate services and supports. Are we equal when we are required to continue caring when our children should be living an independent life and families can enjoy their twilight years knowing that their child is in a safe secure environment.

Federal Government Productivity Commission
Inquiry into Disability Care and Support

A response from members of the

Submitted: 30 June 2010

1. How should a scheme be designed and funded in the long term to meet the long term needs of people with disabilities, their families and carers:

- Those with disabilities and their families need flexibility and some control over their lives, and a Medicare levy style system, which could be administered by individuals or their families, would be most appropriate. The funding through the system could be used to buy in appropriate services as needed.

Example: a young male adult, who lives at home and whose parents receive adequate levels of Intensive Family Support and Post School Options funding, must have their funds managed through an agency. The parents are almost always unable to get support workers on weekends, despite having sufficient funding as the agency that runs their funding finds it difficult to get support workers to work on the weekends, does not like to pay penalty rates, and does not like to “deplete” their stock of workers for the week. They also appear to need considerable time to organise staff, meaning the parents are unable to ever take advantage of spontaneous invitations. If the funding was self managed, families could recruit their own carers, and arrange care at times most suited to them.

- There needs to be recognition for various life stages, when different levels of funding and support might be required. These include key stages such as early intervention, school, transition from school to employment or Post School Options, and independent or supported accommodation. Most especially, accommodation needs should be planned for and well thought through and available when required, and not become a crisis issue as is almost always the case in the current situation. Included in this funding should be consideration and support of changing equipment needs which will allow the person with a disability to be independent as long as possible, or for their family carers to continue to provide support as long as they are able to, and wish to, without suffering the often extreme financial disadvantage currently experienced. For example, an adapted vehicle could make a significant difference to many people with disabilities and their families, but this should not become a financial burden.

Example: A young man is left at the emergency department of a hospital because his single mother can no longer cope with his tantrums. No suitable accommodation can be found so the man, who is now extremely distressed, is sedated and kept under ‘guard’ in hospital for nearly two weeks before an emergency respite bed can be found. He is moved three times before finally moving into his ‘permanent’ group home placement. The mother, racked by guilt and unofficially advised by Disability Services workers to not become involved, has a complete nervous breakdown as she suffers guilt and anxiety for abandoning her much-loved but challenging son.

- If adequate support is provided, parents who are also carers can continue in the workforce, contributing to the broader society, paying taxes, maintaining self esteem and most especially, having the same choices other parents may have in regard to continued employment. There is clearly a significant financial disadvantage experienced by families with disabled members, as in almost every case, at least one parent gives up work in order to be the primary carer. This is also obviously an especially serious issue when the person with a disability is cared for by a sole parent. Many couples, where one partner has stayed home when the children are young, return to the workforce as the children grow, and most especially enjoy the opportunity to boost their super funds, travel and plan for their retirement with the extra income. For parents of children with disabilities, this is never an option, and the financial burden increases, and the financial disadvantage continues.

Example: the parents of a young man, who have both managed to work throughout his school years because of shift work and weekend work, and who both enjoy the mental stimulation of interesting careers, as well as the financial independence security paid employment provides, can no longer manage to keep it up once their son finishes school and the hours of support decrease, and the established routine collapses. One parent stops working to become a primary carer, causing social and financial issues to arise.

2. How to determine the people in most need of support, the services that should become available to them, and the service delivery arrangements the costs, benefits, feasibility, and funding options of the alternative schemes.

- All people with disabilities should be treated equally, and support should be available when it is needed, no matter what the age of the person with a disability and no matter what the age or circumstances of the family/carers. The system has been crisis driven for far too long, and parent carers often have to be seriously ill or incapacitated by age before securing care and support for their adult children. People who have disabilities have often had no choice either, and have had to live at home whether they wished to or not. Physical and intellectual disabilities are often treated in similar ways, and each individual needs their particular requirements assessed and opportunities provided that will most easily allow that individual the best quality of life, opportunities and ability to participate in society. The parents of a disabled person should also be able to plan for their child's future, and not go to their graves not knowing what care will be provided for their child. The current system of having to highlight your child's worst features, listing the critical incidents and issues, and revealing personal details of your own and your families dysfunction in order to secure funding is unnecessary, demeaning and humiliating, and many parents just cannot do it as they feel it betrays the very person most dependent on them.

- People born with disabilities have different needs at different life stages. As with any family there are also periods of crisis and difficulty, be they emotional, financial, illness or environmental. If additional supports were available when parents identified a need it may prevent family breakdowns, keep the person with a disability at home longer and ensure the carers are able to continue to cope. As identified earlier, many carers would prefer to work, but are left with no option but to stay home and care, leading to social isolation, low self esteem, and usually, financial disadvantage.

- In respect to identifying need, most people with disabilities are assessed by numerous agencies and experts ranging from therapists to medicos. While accepting the extensive screening is necessary, at least once, sure when a child is identified as profoundly disabled and gone through the system, it is obvious that their skills are not going to miraculously improve or change, and the substantial files with records of their (dis)abilities should be sufficient for assessment purposes.

- In terms of delivering and managing the funds, most parents would like to be able to self manage and would be able to do this with the support and assistance of their LAC.

3. How the scheme will interact with the health, aged care, informal care, income support, and injury insurance schemes; its impact on the workforce; how any scheme should be introduced and governed, and what protections and safeguards could be part of the scheme:

- Early interventions should be provided as soon as possible after diagnosis or acquired brain injury, in order to secure the best outcomes, and should be continued as long as intervention is deemed helpful, not cut off at a certain age, no matter what the person's ability or progress. For example, the school leaver age is nonsensical for people with intellectual disabilities, as they continue to learn slowly, and often, at the time they are required to leave, are just starting to mature and pick up on language and other skills. As there is no where else for them to go, and work is not usually an option, remaining in a school or learning environment is sensible, would provide structure and purpose, and allow the person to continue to develop life skills. To cease therapy at a particular age, with no regard for the individuals' circumstances, is also nonsensical and continued therapy could often lead to maintaining mobility, for example, thus keeping the person with a disability out of hospital or a more intensive care facility. The scheme should be a lifelong process, covering all stages, and negating the need to change over to aged care at 65.

- Assessment agencies need to coordinate their activities so that once a person with a disability – either lifelong or acquired – is diagnosed and assessed, the same file and information is used by all agencies, negating the needs for repeated interviews, procedures and upsetting examinations.

- Services and funding should be consistent across the nation. If a family wishes to move interstate that their funds should be portable, so the support is continued and the family can stay intact.

- Carers supports should be enhanced in a meaningful way. Well intentioned morning teas do not make any difference to the quality of a carers life – funding, recognition and adequate financial support will.

Australia is a wealthy country and our families only want services and support to allow their child to have a live where they can participate in their community as valued members. Families want to see A National Disability Scheme that provides care and support for our children that have been neglected for many years, and to give parents peace of mind.

Disability can affect any one whether it is through the birth of a child, or acquire a disability through an accident or as we age, so our community expects:

That people who require assistance get the help they need.

No one would say that children born with a disability should not get the therapy they need!

No one would say that families with very large caring responsibilities should not get the breaks they need to keep going!

No one would say that families should be left to collapse under intolerable difficulties without help!

No one would say that parents caring for children with disabilities should have to forgo the opportunity to earn a living, to save for their old age, to plan their retirement!

No one would say that people with disabilities should not receive the support they need in order to contribute to the work force.

No one would say that people with disabilities should not receive the support they need in order to leave the family home and live independent adult lives when the time is right for them.

Regards

Carol Franklin
Co Founder of CASA