COUNTRY WOMEN'S ASSOCIATION OF NEW SOUTH WALES

SUBMISSION:
NEW INQUIRY – Disability Care and Support

To: The Productivity Commission
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From: Social Issues Committee
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Disability Care and Support

We thank the Australian Government Productivity Commission for the opportunity to express our views and recommendations on the Inquiry into Disability Care and Support.

Australia’s disability support system, while consuming billions of dollars of taxpayers’ money, is fractured, inequitable, under-resourced and slowly collapsing under the weight of its own inadequacies.

Our main concern is that there should be a big picture attitude taken for any long-term disability care and support schemes. As with so many government funded and run schemes, there seems to be a great waste of resources, duplication of administration and, in some cases, simply a lack of understanding of the schemes that are being controlled. One is tempted to say “scrap the lot and start again”, but so many more cases of need would fall through the very wide cracks in the time it would take the Government to train and co-ordinate new services.

One hopes that with new funding arrangements (and therefore new management announced by the Federal Government) of health schemes in general some of the waste and duplication (and most importantly buck passing) will be eliminated.

Children/young adults with severe/profound disabilities such as spina bifida, muscular dystrophy, congenital limb deformities etc., chromosome disorders, intellectual impairment, multiple sclerosis, infantile arthritis etc. are well looked after by their informal carers (usually family including parents/ grandparents/siblings) at great emotional, physical and financial cost. They have regular visits from therapists and welfare workers to check on the home, care, orthotics, respite, schooling, apparatus including hoists, walkers, wheelchairs and transfer (if possible) to sheltered work, just for a few hours a day to get them out of the home and to social outings. These disabilities will last their life-time, there is no betterment.

However, once they are adults and receive a disability pension they seem to fall through the cracks. In this day and age a lot of detail is known about individuals and we fail to see why paperwork on every client who will always need help, care, new appliances etc. cannot be centrally registered. This information would be accessible to every worker in disability so information can be obtained immediately on when a client last visited, respite and doctors’ reports. Is the client in need of additional appliances? Is informal or formal care adequate?

The carer should be given the name and contact number of the person in charge of the case; if that changes the carer should be notified of the

replacement's details. The carer should not have to wade through menu-pressing systems to make contact.
A member of this committee drew to our attention a case in South Australia where a mother is caring for her 55 year old daughter who has had major and profound disabilities since she had an accident at 2 years of age. She cannot speak, walk, feed or toilet herself, is prone to epileptic fits when stressed and has major brain damage. Sadly, nothing has changed in 53 years of her life. However, every 12 months the mother receives a phone call with the demand that she put her daughter on the phone so the departmental officer can establish that the daughter is still in need of disability support. Despite the mother explaining that this cannot be done, she has been told on more than one occasion that, if she does not co-operate, she will lose all benefits. (It is a shocking indictment on that department that the only reason the mother received the annual phone call was not to see how the two were managing and did they need any help? But to check whether the disability allowance was to continue.) The daughter enters respite care every quarter to give the mother a break from her demanding role and that information should be on her file. However apparently, these two departments do not communicate. Information on clients with a disability should not be compartmentalised.

The one thing consistent with those phone calls was the total lack of compassion and understanding of the caller. A different caller each time. This committee queries the ability and training of those working in the government departments handling disability care. We firmly believe that every person in those departments should be required to undertake a minimum of one week's professional development training with a family or person with a disability every year, to enable them to see the stress and anxiety that informal carers endure. Departmental heads and supervisors should perhaps have more training in the field to ensure they do not sit in ivory towers making casual, upsetting phone calls, and churning out edicts that are distressing to those members of society who need all the assistance and understanding they can get.

Other types of disability are caused by intellectual impairment caused by illness, drugs, traumas etc., and post accident amputations/injuries through accidents and illness, cancer, diabetes etc. With some accidents insurance eventually pays for treatment, but it is a great drain on the disability fund, providing carers, equipment, counsellors, and steering them back into the work-force.

This year has seen a startling increase in the amount of people on disability payments with two reasons given. First, formal carers are losing nearly $200 a week when their client/charge dies, forcing them on to lower unemployment benefits, while seeking new positions (this applies to nearly 5% of the carers – about 6,300 on an annual basis). Secondly (and this does not involve children with a disability) parenting partners and singles who, in the past received the parenting allowance until the youngest child was 16, now have to enter into an Employment Pathway to look for work (dole) when the youngest child turns 6 or 8 for a single parent. Both groups **somehow** end up on disability payment.

Not enough recognition is given to the informal (family) and formal carers. Without them, the whole disability system would collapse. Families keep their disabled children/ young adults/ seniors at home with them as long as they can. But then, where are the appropriate facilities available to take on permanent care of these disabled family members? There are not enough respite centres for any or all of these age groups to give carers a much needed break, and this committee has heard of instances when carers (parents) exhausted physically, emotionally and financially when allotted a respite break for their charge do not return to take him back home. They can't take any more.

Some members of this committee know of many cases where carers/parents become so tired, confused, frustrated with the endless forms to be completed and trying to find the services they need, that they just give up. This should not happen. The carers should be visited regularly and given all details of approaches to obtain better service for their families.

Over two decades ago, the Richmond Report closed large institutions in which people with disabilities had been looked after, but the governments failed to replace them with a modern support system that was comprehensive and forward thinking. There are many homes/hostels for the low care maintenance disabled, but very few for the high-care, severely handicapped as they are too costly to run.

The present system does not always give carers and other family members enough support for when the disabled person becomes older and their needs change. For many disabled people the normal ageing process begins much earlier so, sadly, with very, very few disability specific hostels/nursing homes available, they have to go into aged care services. This is so inappropriate.

It is thought that Local Government could do more to help the disabled. Streets, roads, rail, gutters, pavements should be made more wheelchair/walker/scooter accessible. Also, family homes now being built should be planned to cater for possible future ownership by the disabled or elderly with for example:

- doors/exits inside and out to be widened to allow for wheel-chairs
- ramps to accompany steps
- indoor stairs to be able to be fitted with chair lifts.

Age appropriate respite/nursing homes must be built not just for physically disabled from birth or post accident but also for cases like arthritis (juvenile) and Multiple Sclerosis sufferers. We constantly hear of 30 to 40 years old people with disabilities being housed in aged retirement centers, and we have seen in the media cases of a husband, who can no longer look after his young wife with MS at home, and unable to bear the thought of her in an old people's home, having to fund raise to build a nursing home for the young. This should not have to happen. Just as communities should not have to fund raise for wheel chairs for the disadvantaged in their community.

The situation regarding availability of sheltered accommodation for the disabled is bad enough in the city and regional areas but, in the rural/remote areas it is appalling. Also, the disabled in these areas who do not have informal or formal carers have to rely on district nurses for their care and, sadly, it is a case of the client having to fit in with the busy nursing staff's schedules, and not the caring being centered on the disabled person. This committee knows of several such cases like the disabled woman in her fifties who lives alone, has had both feet have been amputated because of pressure sores and needs assistance to get out of bed, bathe, get dressed for the day and then get dressed for bed at night. Depending on the nurse's availability her get up times vary from 7.30am to 10.30am and the evening shift varies from 5.30pm to 10.30pm. This is appalling; the woman needs sheltered accommodation where there is a 24x7 carer on site, and where she can enjoy social interaction. On the Central Coast and large city areas this type of accommodation is being developed but, no doubt, the bush (as usual) will have to wait or go without such services.

Finally, it must be acknowledged that those with a disability, their family and carers are the most vulnerable in to-day's society. They must be looked after properly, contacted on a regular basis (not by phone) but personally by fully trained professionals and their condition/needs reported to a central listing system.

These professional workers must have had training, not just "theory", but "on the ground training e.g. living 24x7 in a home with a disabled person. There should be more hands-on workers out in the field, and less "workers" sitting in ivory towers overworking the phones.

We acknowledge that care for the disabled is costly, and will become even more so with the natural increase in costs for care, formal and informal, therapists, welfare workers etc., apparatus, respite, schooling, progress to sheltered work, age appropriate hostels and nursing homes and affordable housing. But, it must be spent.

A member of this committee, a mother of a disabled person states:-

"Parents/family members/carers are told we can stand up and fight for our rights and for those of the person for whom we care. If we had not done this for the last 50 years, the system wouldn't have progressed this far. When does the fight stop and the system start to work?"

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