

Legislative Council

Wednesday, 12 November 2008, Page 669

DISABILITY SERVICES

The Hon. A. BRESSINGTON (22:18): I rise to wholeheartedly support the Hon. Stephen Wade's motion highlighting the government's failure to improve disability services arising from the reorganisation of disability services. I also commend the honourable member for his incredibly well-researched and insightful speech, which highlighted the many failings of our disability services system.

My consultations with people in the disability sector showed that there are five major areas of pressing need for service: supported accommodation, flexible respite options, early intervention programs to minimise the impact of regressive or degenerative disabilities, transport, and post-school options. The Hon. Stephen Wade spoke of Mr Edward Carson's case and the gross ineffectiveness of Disability SA's restructuring, and I am appalled that the boasted restructuring came at a time when the community was screaming out for meaningful services through individualised funding and support services that offered family choices.

I have met with several families in desperate need of accommodation and in-home support services, yet none of those services have been forthcoming. Even securing a Housing Trust transfer into more sustainable premises capable of accommodating wheelchairs, special beds and other equipment is impossible for these struggling families. Far too many families have to find the resources themselves to be able to afford supplies of nappies, syringes, swabs, bandages and other basic health care needs, much less medication, and they struggle to do so. Invariably these families are already on a very low income.

Not unlike the story of Mr Carson occupying a hospital bed at \$1,350 a day, similar stories can be heard in other cases where people are placed in mental health lock-up wards after the pressures of homelessness have adversely impacted on their already fragile mental health—at considerably greater expense to the taxpayer than the cost of providing for a house transfer or other alternative solution. Indeed, that is supported by the comments made by Lynn Arnold from Anglicare mentioned in the Hon. Stephen Wade's speech. We have yet to truly measure the real cost of failing to provide appropriate supported accommodation against the cost to taxpayers of housing people in gaols, mental institutions, hospitals and foster care.

I am alarmed by what appears to be an obsession of this government that all access to knowledge and information is vested entirely in the bureaucrats. No longer can a carer with a disabled child speak to another mother who is a volunteer to get independent and helpful advice on where to go for a wheelchair, an extra carton of nappies, one-off transport to a day activity, one week a month respite or an extra two hours in-home support without the entire department of Disability SA being alerted to the fact that such a request may be on the way, and it seems to be pre-empting a situation whereby all avenues for lodging an application will be closed off and their prospects of success greatly limited on some obscure grounds.

Most families do not even know what criteria they must meet even to compete for the meagre goods and services in a fair and equitable manner. How does one get the last respite placement when they might meet the same criteria as 20 others in the same situation? Does it go down to the squeaky wheel syndrome: the person who makes the most noise wins? Or does it go to the family with the most senior advocate within the department, who happens to be the neighbour of a ministerial adviser? Without clear, concise and transparent criteria for

deciding these things, it is easy to see how so many families get very little or nothing whilst a few fortunate families can get by.

The honourable member spoke at length about the top heavy nature of the department's bureaucracy. An additional example of the top heavy nature of disability funding is also demonstrated by the fact that one family, which is now finally receiving a much needed boost in the hours of in-home care, had to wait many weeks before they were able to use the allocated hours because no carers were available.

My office has been advised that far too often, when the preferred carer is not available due to illness or absence, the family is forced to fill in the void any way they can as no replacement has been approved by the department. The difficulty arises because the family is forced to employ a carer via an agency, which charges \$37 an hour as its day rate and \$45 an hour for weekend nights, whilst the carer actually receives a day rate of \$15 an hour. The family is told that the agency has a high staff turnover rate and not enough people on the books willing to do the work.

More than 50 per cent of the funding is sucked up by the middle man. That said, the family is not able to find preferred carers of their choice willing to work for the lesser rate. However, Disability SA will not permit them to bypass the carer agency and employ directly a person of their choice. Individual funding could be a reality today, even partial funding, by nothing more than a phone call and directive to that effect if only there was that will. The potential cost savings would be obvious and immediate. If this bureaucracy has been so successfully restructured for the benefit of people with disabilities, why is it that individual funding and support cannot be obtained simply with the stroke of a pen to enable such a system to operate in cases that demand it?

The Hon. Stephen Wade also highlighted the serious loss of corporate knowledge, history, experience and the degeneration of its values base. Whereas once upon a time the notion of dignity and care and informed consent may have been guided by the principles of access and equity, today we do not even know how to define whether the state owes a duty of care to people with disabilities and what this means in practical terms. It is also true that disability services are losing sensitivity to the special needs of some groups and the uniqueness of their circumstances.

Whilst there is merit in saying that the needs of a family coping with autism should be no more or less important than a family dealing with Down syndrome or an acquired brain injury, it is not the same to provide comparable respite to a young family with one child as compared to ageing carers with their own unique health concerns. The fear of losing precious services is certainly very real amongst families caring for a person with a disability. Not surprisingly, many people feel beholden to a department that exploits the generosity, love and goodwill of families, pushing them to breaking point.

I have made the point many times in this place that we need to have an expectation of striving for best practice, to have the training, case management, policies and procedures in place to solve many issues and, in fact, give the government a better bang for its buck. I share the Hon. Stephen Wade's concern at the top-heavy bureaucracy that exists in Disability SA. I am advised by people in the sector that one professional bureaucrat position could provide monthly weekend respite services for up to 16 families and so much more; instead, we have people employed to tell families that they cannot qualify for the goods and services they so desperately need.

It is interesting to note that, while services are being cut back or delayed, families must still shell out money to make up the difference that would make their lives easier. Just one

such example was the introduction of the 'What I would like you to know about me' website. Despite a \$30,000 grant from the government, the cost of maintaining the website is costing families \$25 to access it—a site designed to ensure that they did not have to retell their story dozens of times to different bureaucrats, professionals and other carers.

In August 2007, thousands of South Australians living with a disability and their families were made worse off than they had been in the two years prior when cuts of \$750,000 to non-government organisations providing vital advocacy and support services were increased even further. In the 2005 budget, the government allocated a mere \$9 million towards disabilities despite some \$25 million to \$35 million being needed at the time. Even the Treasurer himself admitted on ABC Radio on 27 May 2005 that the small increase was not enough and more needs to be done.

I also make the point that societies are judged on how they deal with and manage their most vulnerable and, between disabilities and child protection, this state has a long way to go before we come anywhere near to par. Only three years earlier the government portrayed itself as a champion and underdog of those struggling to cope with a disability, and yet in no time at all the clawback of those promised funds had begun which many had hoped would have gradually increased over the ensuing two years and even led to individualised funding and support services. But those hopes have been dashed, despite the government's restructuring at a time when 10,000 new public service positions were being created.

Still those struggling to cope with a disability were to be told that they must get on with their lives and accept that they would continue to receive absolutely nothing. The budget statement of 2007-08 refers to this in far more glowing terms as a budget saving initiative. I believe the best way to reduce demand is by ensuring that people do not get to the services in the first instance, then you can justify further cuts to services because the need apparently no longer exists if people are not using the services (and I say that sarcastically).

Sadly, this so-called saving initiative will cost the disability sector very heavily so as to affect directly the Down Syndrome Society, the Arthritis Society, the Muscular Dystrophy Association, the Brain Injury Network, the Disability Information Resource Centre, Family Advocacy, Anglican Community Care, the Physical and Neurological Council of South Australia, Deaf SA and the Paraplegic and Quadriplegic Association.

It is my firm belief that specialist and non-government organisations outside of the public sector need to receive adequate funding lest we dissolve into a huge central bureaucracy at great expense to this state, as we are doing so rapidly. The valuable contribution of non-government and charitable groups supporting people with disabilities and their families must not be lost due to neglect of the disability sector. It is vital that South Australian families who are caring for a loved one with a disability have suitable places to go for support, and through its neglect of the sector this government has placed them at risk.

Just a few weeks ago, my office had cause to make inquiries with Disability SA about the process for obtaining an assessment for an acquired brain injury, only to find that getting a straight answer on a simple matter of assessment procedures and options for diagnosis was not going to be that simple at all.

My staff member was bounced between, and questioned by, several Disability SA staff as to her reasons for wanting the information, before being advised that she could not seek to have access to a partial low-level assessment for acquired brain injury through Disability SA on behalf of a constituent, but that the person would have to accept a comprehensive assessment, or none at all, if was to be coordinated through Disability SA. Another service

provider informed us that there was anything up to a two-year wait for a less intrusive assessment process.

Staff of Disability SA vet and veto information that can or cannot be obtained, so there is no independence and even less choice. Only a few years ago, you could still get information about community support services because they actually existed; however, many of these no longer exist, where once upon a time they would have been accessible through various shopfronts, community houses, councils and other networks.

The information and other services provided by the Disability Information Resource Centre were always independent and openly accessible and provided the most appropriate and effective one-stop shop. Now you must go through bureaucrats who act as gatekeepers in deciding whether and what information the public needs.

Many people with disabilities find it difficult to get personal carers of their choice and at times when they may be most needed to help manage personal care and grooming needs, for example. We have heard of stories of people who have been left lying in appalling conditions for hours on end until a carer arrives to help them with toileting and of people having to wait for three days to be showered and changed.

Carers, particularly the elderly and those with other children, are concerned that they are given precious little time to do their shopping and bill paying. Time to recuperate from the physical demands of caring for a person with a disability is difficult to get, much less quality time to spend with other children in the family for recreational and other activities.

Families are reporting that even if they can secure meaningful day activities for their son or daughter, such as employment, education or training, getting them to those places is an altogether different obstacle. We hear that some individuals get access to transport, while others in identical situations simply do not. Often no logical explanation exists to account for the different outcomes.

Access to services needs to be flexible and based on the assessed needs of the individual. There is no point in giving transport access for a person to get to their job at 11am when they are required to start at 8.30am, or to give respite access to a family for five hours a week in one block if they need to run five one-hour errands at different times of the week. It is of little value to offer a person in a wheelchair one hour a day for personal support, if it takes them two hours simply to get out of bed and be ready for the day.

This is a big spending, big taxing government, but what I am hearing and seeing is that key areas are still grossly underfunded, and there is no proper needs assessment in place. A long-term commitment to the disability sector is urgently required. For example, on 21 December 2004, the government announced a one-off payment of \$5.9 million to clear equipment waiting lists for the disabled. Then on 9 June 2007, it again announced a \$5.7 million one-off payment to clear equipment waiting lists.

It is sad that that funding did not get to most of the people who needed to upgrade equipment or to buy new equipment. Clearly, in order to service the hundreds of South Australians with the equipment they need, a greater level of funding needs to be made available. Existing services are struggling to operate at the current rate and it is likely that demand will increase in the foreseeable future from new clients.

Assessments to determine equipment needs and appropriate funding are far better than one-offs, as they provide a level of security for families to know that, if an upgrade is needed, it is actually possible. With this in mind, it is extremely disappointing that spending on non-

government disability advocacy groups was slashed by over 50 per cent in the earlier 2007-08 budget.

In earlier meetings with people with disabilities and their carers, it was highlighted for me that other countries are doing much better in meeting the needs of people with disabilities. I know that ageing carers need the peace of mind to know that, when they pass on, their son or daughter will be cared for, not exploited, neglected and abused. I wholeheartedly support this motion and I congratulate the Hon. Stephen Wade for moving it.

Debate adjourned on motion of Hon. I. Hunter.