26 March 2010

The Chair
Standing Committee on Health, Community and Social Services
Legislative Assembly for the Australian Capital Territory
London Circuit
Canberra ACT 2600

Dear Committee Chair

Inquiry into Respite Services in the ACT – Submission from Parents

By way of introduction, we are the parents of a profoundly intellectually and physically disabled teenager. We would like to share our family's experiences of respite care in the Australian Capital Territory.

Background

Our child has occasional seizures, and requires significant personal care such as with meals and toileting. There is also significant lifting involved in [redacted] personal care, and [redacted] frequently wakes during the night. Therefore we are unable to employ a 'babysitter' such as we otherwise would have (a teenager across the road, for example). On the other hand, respite care workers are first-aid trained, focused (usually!) and able to manage our child.

We have limited assistance from family and friends. One set of our parents live in a rural area interstate (but still are able to assist on the rare occasion, with planning) and the other set of parents, also interstate, have different priorities and obligations. Friends who may have been able to assist also have their own commitments, including work and children. In addition, it is a significant humility to ask for assistance from friends; however we have been grateful for their support in emergencies.

Up until our child was three and half years old, we had only two respite care sessions, due to a lack of services and resources. Fortunately since late 2001 (or early 2002) we have benefited from more frequent respite care.

Respite care services – our experience

Luckily, we heard about Family Based Respite Care (FaBRiC) and were eligible for respite care through that agency. We were eligible for more hours than we preferred to use, with us normally using less than ten hours per month. This worked well for some time, as we had largely consistent carers, with whom we built positive relationships. (Of course, there were occasional unavailabilities, cancellations and lapses, and there were some temporary carers that were clearly unsuited to the task at hand).

Since FaBRiC was merged with another respite care organisation to become Tandem, we have not been quite so fortunate. We are not sure whether this is a result of lack of resources, or whether it is simply coincidence that the respite care service has diminished.

On at least two occasions we have been significantly financially (and socially) disadvantaged because of a failure of a carer to show up when appointed (such as when we have purchased theatre tickets which we were then unable to use). Despite such gross failures, these carers have been kept as casual employees, presumably because of the

dearth of carers available. At other times we have had to rely on the goodwill of friends to help us when we have been let down by paid respite care workers. Consequently, we feel that we cannot truly depend upon the respite care services for which we are eligible.

In addition, Tandem has placed restrictions on weekend care, due to cost factors. We understand why this is done. However, often weekdays are not practical times for family members or primary carers to receive respite as they may have work or family commitments. We know for ourselves that respite care provided during the week would be more of an impracticality, disturbance or difficulty than on weekends. As a result, we have opted to have fewer hours, on occasional weekends.

Following Tandem's restructure of respite care to favour care during the week, we have heard that a significant portion of care workers opted not to continue working, because pay rates during the week are considerably lower than pay on weekends (particularly Sundays). This disturbs us on three fronts. Firstly, this points to a devaluation of the care worker's employment and by implication, the client (the person with the disability); and secondly, that the care workers employed by casual respite care agencies are primarily motivated by money. Thirdly, we are very concerned about inadequate funding.

How and why we use respite care – and associated issues

Our preference is to use respite care on an ad hoc, in-home basis, because we do not wish to exclude our child with a disability from our family life.

Respite care for us is primarily to enjoy social occasions as a couple without children, because as mentioned, we cannot use the usual kind of babysitters. We believe that time spent together as a couple benefits the well-being of our family and the relationships we have with our regular children as well as our disabled child. (Many marriages and families dissolve due to the strain of caring for a child with a disability).

We also use respite care for occasional family outings where it is not appropriate to bring our disabled child (for example, a film which [redacted] would not enjoy, and at which [redacted] may be noisy). This means that we frequently have a month or two pass before using respite care for four or five hours on a Friday or Saturday evening. Yet at times, we feel pressured to have a more formalised, regular respite care arrangement. It appears to us that this is the preference of respite care services, even though it is not our own preference. (We suppose this is because it provides more regular hours for care workers).

Very infrequently, we have used respite care to facilitate our work commitments. Our working lives and caring commitments have meant that one of us works part-time or not at all while the other works full-time. We have tried using out-of-school hours care, but found that the inclusion support worker was often commandeered for other duties and did not support inclusion for our child in the way (presumably) the program was designed. We acknowledge that respite care has a role in providing such 'stop gaps' for some families and primary carers. However, we think some of the ongoing problems with the use of respite care to facilitate working arrangements should be addressed within three broader strategies for disability services. Firstly, to ensure that inclusion programs in out of school hours care programs are actually fulfilling the role of inclusion; secondly, to ensure that there is adequate out of school hours care programs for high school aged students with a disability; and thirdly, to support carers in the workforce more broadly. There are both psychological

and financial benefits for carers working; in addition, governments benefit through less 'drain on the public purse', and increased tax revenues.

Overnight care – not an option

We have described how we have used respite care services. Now let us describe one way in which we have not used respite care services, and the reasons why.

We would love to be able to have a night away. As it stands we don't see an option for this to be achieved. A Tandem worker could potentially do this, but we would be using (and paying for) considerable hours when our child and the worker would be sleeping. Although we recognise that we only pay a percentage of the actual cost, we still consider that this would not be good value for money for our respite care dollar.

We understand from contact with our child's school and social workers that we would be likely to be eligible to access centre-based respite at Kesse House overnight. However, we are very uncomfortable with this arrangement. Because our child is unable to talk, we cannot be sure of [redacted] happiness and safety, particularly in an unfamiliar environment and with unknown carers. We have also heard from other parents that staff turnover means that familiarity, which enables safe and secure relationships to develop, is usually unable to be built over time (as it would if there was more staff stability). Another concern relates to some quite disturbing scenarios we have heard about from other parents, which we are not willing to risk for our own child.

A way forward

We believe respite care should be for the convenience of the person with the disability and their family or primary carers, and not for the convenience of the respite care agency or at the whim of government funding.

Although we are commencing to build a circle of support, we do not like to impose on our friends' and family's lives or ask for assistance. We would not like them to feel taken for granted or obligated.

We would like to see parents and permanent carers of people with a disability allocated their own set of hours or funding for respite care, which they can manage as they see fit. For example, going forward, we see our son (currently ten years of age) being able to assist with the care of his older sibling. We would rather see him paid to care for our child than a stranger, who does not know [redacted] or [redacted] history, or who understands what [redacted] is trying to communicate. This could be paid work for him rather than adding to demands of our family by us driving him to work at a shop in the Mall, for example. (Of course, relationships with carers and between a carer and our child with a disability can progress over time, but this does depend on a level of commitment from the care worker, and not a rapid turnover of care workers, or mismanagement by respite care agencies assigning a different carer on each occasion).

As it stands, it is unlikely that someone such as our son, or a family friend, is able to be remunerated for providing respite care to our child, even though this would be a rational solution. In addition, we feel that providing some payment would take some of the pressure off asking family or friends, and our family or friends potentially feeling obligated.

Consultation

Thank you for this opportunity to outline some of our experiences with respite care services in the ACT.

One final issue we wish to raise relates to the invitation to a forum next Wednesday (7th April 2010) which we are unfortunately unable to attend, as we have prior commitments and will be interstate visiting family before a wedding.

We understand that the forum is open to families and primary carers, as well as respite care service providers. We are a little concerned that such an open forum, which seeks the views of all stakeholders at the same time, will have the effect of preventing families and primary carers from speaking freely about any issues they may have with their respite service. We know some other parents who are anxious that if they express their views candidly in front of their respite service provider, they may risk having their service cut or suspended. We believe that in order for it to be an effective consultation process, it would be appropriate to hold separate forums, and/or assure anonymity for written contributions.

For this reason, we would also request that this submission remain confidential, or at least have any identifying details removed prior to inclusion on a website or in a report. Thanks in anticipation of your understanding and cooperation.

We trust this information will be useful to your inquiry.

Yours sincerely