The Committee Office
ACT Legislative Assembly

Dear Committee Members

Attention: Grace Concannon

I wish this letter to be regarded as a submission to the ACT Government's Inquiry into the Provision of Respite Services in the ACT.

1. I am the mother of Kylie, aged 30, who has Down syndrome. Until May 2009, we resided in the ACT. Kylie was born in Melbourne, and the family moved to the ACT when Kylie was 20 months old.
2. It is my strongly held view that all services for people with disability in the ACT are – and have always been – significantly underfunded. Respite care is but one example of support for families with a child with a disability that is seriously impacting on the welfare and wellbeing of people with disabilities and their families. The lack of any foreseeable change to the existing level of support for my daughter and myself was one of the significant reasons for our move to Sydney.
3. Kylie's use of Disability ACT respite services ceased some years ago prior to the Fisher house being closed. Increasingly she was returning home unhappy – sitting around all the time, too many takeaway meals, too little meaningful interaction. When Carers ACT opened Fraser Guest House for respite accommodation, Kylie accessed that facility on several occasions per year until our move to Sydney, and always had a really positive experience. Fraser Guest House is our one great loss in our move to Sydney. The staff were great, the facility is lovely, and genuine interest was shown in each individual.
4. In Sydney, Carers NSW quickly responded with support (via Anglicare) for myself, and particularly for Kylie (4 hours per fortnight to do travel training, Sydney awareness, etc). When I needed to have knee replacement surgery before Christmas an organization called FRANS (Family Resource and Network Support Inc.) immediately responded to my approach for support for Kylie. With no funding in sight, Kylie was organised to stay at their respite house at Croydon from Friday afternoon till Monday morning; she had a carer take her to and fro the FRANS office at Croydon where she worked as an office volunteer from 9am to 3pm Monday to Friday, and on week nights the carer slept over at our home with Kylie. This lasted for two full weeks. As everyone knows who accesses respite for their children with disability, not having to worry about anything to do with their 'child', especially whilst one is hospitalised, is unbelievable. FRANS provided that care so I was able to concentrate on my recovery and wellbeing.
5. In the event, due to delays in the transfer of Kylie's ACT ISP funding to NSW under the National Portability Agreement, FRANS is taking steps to recover the costs of the care then provided.
6. From June 2009, House with No Steps in Sydney has been able to provide Kylie with 4½ hours per fortnight to enable Kylie to learn to get about Sydney and to have some social outings.

7. The NSW Department of Ageing, Disability and Home Care (DADHC) took some time to interview Kylie and I, and then to appoint a case worker. Just before Christmas we met with the case worker who assessed Kylie's needs. In February we were contacted by a new case worker, and put in touch with a respite house at Ryde. Kylie has visited the house for a meal, and will shortly stay overnight there prior to being given the opportunity to access respite there for up to about 10 nights a quarter, depending on our needs at the time. This level of support is based on a detailed interview process which results in the collation of points representing the level of need Kylie and I have for respite.
8. Kylie and I have contacted and visited other respite facilities in nearby suburbs. Whilst they would be available for Kylie to use, in some cases the clientele were much older and less interesting from Kylie's perspective. We have also visited a Catholic Care respite house which we found to be suitable. We have not registered with that house or service but we know it is there as a backup should we need it. These facilities have a daily fee, unlike the DADHC house at Ryde.
9. The FRANS respite service is available to Kylie on a brokered basis – ie. using funding Kylie attracts through other funded services – but, on the basis of Kylie's volunteer work whilst I was in hospital, FRANS offered Kylie employment for 15 hours per week, Monday to Wednesday 9.30am to 3.30pm. Kylie commenced on 22 February this year, and has also signed up for a traineeship to undertake, at FRANS, a Certificate III in Business.
10. I knew that it would take some time for services to fall into place in Sydney, and it has. It is too soon to say that the respite support we can access in Sydney is sufficient, appropriate or well-run, but to both Kylie and I at the moment it appears to be at least satisfactory.

Recommendations:

1. It is obvious that in a city such as Sydney with a larger population there must be a greater choice of service available. It is my view that the limited Disability ACT respite facilities in Canberra are insufficient to meet the needs of all people and/or families desperate to have regular and appropriate access to respite. Therefore it is imperative that a greater choice of respite facility be made available on the basis of the needs of those requiring the respite.
2. I have not had the time or the ability to inquire into career and pay structures for staff in NSW respite facilities, but I am strongly of the view that Disability ACT's under-resourcing has not enabled it to entrench satisfying career structures for its respite staff, let alone a commensurate and rewarding pay structure that recognises people for the jobs they perform. I do acknowledge, though, that over some years before we left the ACT significant effort went into attracting and retaining not just suitable but committed staff.
3. I notice from the ACT Auditor-General's Office *Performance Audit Report (Management of Respite Care Services)* that record keeping, performance audits and reporting procedures are commented upon. I suggest that any shortcomings in these areas would directly be linked to the under-resourcing of all aspects of disability funding in the ACT. It is

imperative that respite care be funded to the level of need already identified – and preferably as anticipated in the next decade – by the ACT Government.

I look forward to the Committee's report.

Yours sincerely

Evelyn Scott OAM