

SUBMISSION

TO THE

LEGISLATIVE ASSEMBLY FOR THE AUSTRALIAN CAPITAL TERRITORY

STANDING COMMITTEE ON HEALTH, COMMUNITY AND SOCIAL SERVICES

INQUIRY INTO RESPITE CARE SERVICES IN THE ACT

26 MARCH 2010

Thank you for the opportunity to make a submission on the *Inquiry into Respite Care Services in the ACT*. In our submission, we wish to address three of the published terms of reference, as follows.

To inquire into and report on government and non-government respite care services in the ACT, with particular reference to the:

- *needs of care recipients (including children, teenagers and adults with a disability, elderly people, people with mental health issues and people from culturally and linguistically diverse backgrounds) and their carers*
- *range, availability and suitability of respite care services, including any unmet need*
- *experience of service users who utilise government and non-government providers of respite care*

We have three sons and have lived in the Australian Capital Territory since Australia Day 2002. Our three sons, aged twenty-five years, twenty-three years and eighteen years, all have Down syndrome and live in the family home with us.

Prior to moving to the ACT, we participated in the family-based respite care programme called Interchange Illawarra, based in the Illawarra region of New South Wales. We were involved in Interchange for eight years, during which time we were privileged to have a family living in the same suburb that cared for our four children in our home. During this time, we were involved in an organisation called Worldwide Marriage Encounter, which required us to be away from a Friday afternoon to a Sunday evening several times each year. Additionally, we attended many different types of meetings and events on a monthly basis, which were associated with our work with the Church. This lovely family was always willing to provide care for our children at these times. The great benefit for our children was the familiar surrounds of their own home plus the consistency of carers every time.

Our participation in Interchange Illawarra included our being carers for other children. During the eight years of our involvement, we cared for four different children, sometimes on separate weekends and sometimes two or three together on the same weekend. While we never understood the financial side of the organisation, we always received the respite that we needed.

When we arrived in the ACT, we sought out respite care so that we might continue our involvement in Worldwide Marriage Encounter. We were referred to FaBRiC, the family-based respite care organisation.

We discovered that the service offered by FaBRiC was very different from Interchange and that there was a maximum number of hours we could access, which precluded us from being away from a Friday afternoon to a Sunday evening. As a result, we had to resign from our involvement in Worldwide Marriage Encounter. We were, however, able to access limited hours of in-home respite care from FaBRiC.

The situation improved after some time when we were able to bank our monthly allocation of hours, which enabled us to join two Councils advising the Australian Catholic Bishops Conference on pastoral issues at a national level. Although the total amount of respite in a year was much less than what we had previously had access to with Interchange, the arrangement was sufficient for us at that time.

In more recent years, especially following the change in name and structure from FaBRiC to Tandem, cost-cutting measures have further reduced our ability to access respite care hours. In 2009, Tandem decided to reduce the weekend respite care to a maximum of four hours, with no overnight care and we were accused by the staff of misusing the service and in effect overusing hours. It would appear now that Tandem only wishes to provide respite care where clients are taught life skills on a semi-regular basis. Respite to allow parents to attend to voluntary work or simply to have a break from the family are apparently no longer a service Tandem offers.

Our three sons are brothers and have, over the past sixteen years, grown up with and experienced respite care in the family home. Our eldest son has also been diagnosed with a mental illness. Consistency and regularity are extremely important to him. The consistency of care offered by Interchange assisted him very much in his formative years. However, he has struggled over the past eight years with the inconsistency of the care offered by FaBRiC and Tandem. Until very recently, support over a two-day period would consist of two or three workers on shifts.

Our three boys have specific needs, which would be best met by the provision of a consistent or familial respite care service; workers with whom they could become friends. We, as parents, also have specific needs in our involvement with our Church and in particular the need to spend four weekends a year away from home attending conferences.

More recently, Disability ACT has been proactive in trying to offer services to our family, as a whole, instead of as three individuals, which has been our experience since arriving in the ACT. We are very appreciative of the work of Disability ACT, but we are yet to achieve any sustainability in the provision of respite care services that meet our family's needs as a whole. We are trialling the Disability ACT respite care centres, but have and continue to experience some difficulties. In particular, our second son is very reticent about staying away from home. We are sympathetic with him because he grew up with home-based respite care, which is very different from attending a respite centre.

We find it hard to understand the financial justification of eliminating the provision of in-home respite care for three brothers, where the only cost to the government is the labour cost, in preference of a respite centre, where all costs are born by the government. We do understand that current funding allocations cannot simply be changed to suit one family, but we would like to think that more could be done by the government and its community partners in meeting the needs of our three sons.

We hope that our submission will assist the Inquiry and look forward to some positive outcomes for families wishing to access respite care in the ACT.

We would be happy to meet the Standing Committee to discuss and answer any questions about our submission. Thank you again for this opportunity.