Submission from the Aged and Disability Services Committee of St Margaret's Uniting Church, Sponsor of Stepping Stones for Life

to

The Inquiry into Respite Care Services in the ACT.

The following submission from St Margaret's Aged and Disability Committee (ADC) draws on our involvement in the disability sector in Canberra over the past eight years, the experience of individual families associated with our committee for over thirty five years, and the combined experience of the focus families being assisted in their pressing issues by Stepping Stones for Life. Stepping Stones was established by the ADC in 2002 to assist people who are ageing, people with disabilities and especially families in which ageing parents are caring for an adult family member with a disability, to assist them to plan and arrange long term care when they are no longer able to provide it directly. While such long term situations involve significant needs for respite care as well as longer term solutions, St Margaret's Ageing and Disability committee and Stepping Stones has been successful to date in working through a number of relevant issues. These include:

- building trust and a sense of hope replacing despair for the future, among 9 focus families;
- developing individual family plans for the focus families concerned;
- developing a family governance process which is now being implemented at a purpose built house in Ainslie for three women with disabilities;
- the design and impending construction , through the government stimulus package, of a 6 bedroom home for people with special needs, particularly people who are at risk of homelessness and social isolation, people with limited mobility, people with disabilities and older people;
- expanding our care network to include social, recreational and capacity building activities for people with disabilities outside the primary focus group; and
- recognising that there are families in our immediate community where younger parents with profoundly disabled children are struggling to survive with the limited support available.

We acknowledge that the achievements of Stepping Stones for Life to date have been with the cooperation and support of the Department of Disability Housing and Community Services and with other community organisations such as Uniting Care and Carers ACT.

We are making this submission because we consider there is a breadth and depth of experience within our network membership which should be of value, and we believe that people with disabilities have a right to equal opportunities and dignity within the community. Equally their carers have a right to a fulfilling existence which can be shared with other family members; a right which can be very much enhanced by appropriate respite care arrangements.

Our submission addresses a number of the terms of reference of the inquiry, drawing on experience which is detailed in attachments. We understand a number of our network members will also be making individual submissions. We acknowledge the Department's response to the audit report and look forward to the proposed changes, but consider that some recommendations and responses don't go far enough. Our comments lead to some specific recommendations for improvement of respite care services in the ACT, and we would welcome the opportunity to discuss these observations and recommendations with the Committee in due course.

Discussion of our experience relating to the terms of reference:

Auditor General's report

While the report highlights some shortcomings in respite care in the ACT, it suggests that Key Performance Indicators (KPIs) are being met, and that ACT is performing as well as Australia as a whole. However KPIs and averages don't recognise range of disabilities and differing needs. We disagree that access to respite services was provided to people with the greatest need, and as indicated below, we consider that some of the greatest needs are not being met.

We agree with the key finding concerning the inadequacy of present funding; a demand of $11.1m compared to the supply of $2.8m in the ACT is an alarming statistic. This means only 25% of the needs are being met. We refer the enquiry to the Commonwealth Government's Senate Community Affairs Committee's report of 2007 chaired by the ACT's Senator Humphries. He described the disability sector as being, in many ways, fragmented and dysfunctional. The case for the input of an additional $11 billion (billion, not million) per year into the sector as a whole was well made. A seachange is needed in the thinking of the wider community, and through that, government, into the funding needs of people with disabilities. The sums involved are huge, but so is the need.

Carers, mostly parents, and frequently elderly parents, have been providing care for 30, 40, in some cases 50 years thus saving governments (society) millions of dollars for each person cared for. This needs to be recognised and acknowledged in a practical way. Substantial additional funding for the disability sector as a whole is urgent, and a significant part of that should be for respite services.

The needs of care recipients

The Audit Report does not go far enough in distinguishing between various degrees of disability. A 'one size fits all' approach cannot work for the family of a severely disabled young adult who needs help with every action.

- What is appropriate for individuals is a person centred approach catering for individual needs. Every person is unique; every person with a disability is unique, unique in terms of type and extent of disability and unique in terms of care needed. Respite services should cater for individual differences;
- Since respite in groups is often seen to be necessary, the management of aggression and other risks inherent to groups could be improved if quiet clients are placed together and aggressive clients are treated separately. As indicated in Attachment (b), inadequate supervision of aggressive care recipients can lead to serious physical harm;
- separation between the sexes may be necessary at times, and particular care is needed to avoid abuse from inappropriately selected or inadequately trained carers.

The needs of staff who provide respite care

We agree with the audit report that many staff members provide wonderful care. However it is clear from a large staff turnover that:

- More adequate training needs to be provided for skill and knowledge development e.g. it is not appropriate to have carers who have not been taught how to lift, or don't have

the required hoists etc. Attachment (b) cites respite carers who refuse to lift a teenager on OH& S grounds, while expecting the parents to do so;

- There is insufficient pay based on qualifications to retain staff. Social Role Valorisation (SRV) is all about giving people a valued role in society. Usually this is applied to the person with a disability. It should also apply to the staff who provide care. They provide a very valuable role and this should be recognised by way of training, remuneration, status, expectations placed upon them to be trustworthy, responsible and professional. A huge investment needs to be made in staff. Attachment (a) indicates some of the difficulties with high turnover of inexperienced lowly paid staff.

The range, availability and suitability of respite care services

A common point made is 'the worse you are the less care you get' There seems to be a need for:

- Longer respite duration;
- More respite care in the home e.g. for bathing and personal care needs;
- Special respite care during holidays e.g. two consecutive weeks respite once annually for a family holiday;
- More respite accommodation. The worst cases don't seem to have a home to put them into. We recognise two types; In Home and Out of Home. Most commonly known is Out of Home, accommodated respite, normally for 1 week in a special group house. Most people attend for 1 week in 7 or 8;
- We see a need also for semi permanent accommodation, say for 5 days a week, every week, with the family member returning home for weekends; and
- We see a need for extra day respite i.e. a carer taking the client for number of hours during the day and returning them home at night. This might be to transport the person to and from work, or some other activity. Parents can often cope better at night than during the day.

Unmet need

There are a range of needs that are not being met, sometimes because those in need are not aware of what is available, but more often because the needs that they attempt to express fall on deaf ears.

Advocacy

- We recognise that carers are not necessarily the best advocates for their loved one with a disability. They are often out of their minds with stress, worry and grief yet they must find out for themselves what help they are entitled to. We strongly believe that the appointment of a liaison /advocate, who could act for each family according to their needs, would be most beneficial.

Longer term care

- Longer term care is needed as a form of respite in cases of profound disability, and for aging carers.

Communication

- for family carers to empower them by fully knowing and understanding their entitlements, and to enable them to act with the appropriate providers. They cannot do

this if they don't know what they are entitled to, or who the providers are e.g. government providers, sponsors? Charities? Private providers?
- With staff, especially regarding staff changes and keeping care recipients and families informed;
- Between State and Federal providers, and communication of who is responsible for what so that client families may avoid the current confusion.

Interaction between government and non-government providers of respite care

We believe strongly in co-operation between government and non-government bodies, particularly in regard to social services, including respite care.

- Part of the success which Stepping Stones For Life has enjoyed is due to very good and continued co-operation between government (Disability ACT) and non-government (St Margaret's)
  - government gets more value for its money;
  - clients get more personal help;
  - staff work under more flexible rules; can therefore be more innovative.
- Relating to the issues of advocacy and communication mentioned above, families need to have a knowledge of the type of respite that is available to them. For example: What type of respite is available through agencies, i.e. in-home; flexible respite services, centre based etc.

Other related matters

It is difficult for a principal carer to find suitable employment, even part time, during the years when the disabled child attends school.

- When it is school holidays the principal carer has to be at home each full day. This generally means having less chance of getting suitable employment or having to relinquish a position;.
- Children with disabilities are more likely to be unwell more often and the nature of this often cannot be communicated. There is often a need for home care when the child is sick, or a frequent call to collect the child from school. A very understanding employer is a requisite;
- School holiday programs are not available or very few in number for severely disabled children;
- It is desirable that respite be available to enable continuity of work during school holidays.
- Availability of suitable after-school or respite care would also assist;
- As a result, families with severely disabled children are at great economic disadvantage.

Recommendations

1. Funding. Higher pay and status recognition is required to retain good staff.
2. Advocacy. An official client advocate be appointed to act for families to government and providers
3. Training and systems. Standardised training be implemented BEFORE staff are appointed with proper recognition in salary and status
4. Greater range of options and physical facilities
5. Greater length of continuous respite to allow families to function

Attachments:

(a) Experience of Stepping Stones for Life Focus Families with respite care.

(b) Experience of a young family with a profoundly disabled teenage daughter.

(c) Appropriate models of housing for respite (and long term) accommodation.

Attachment (a)

Experience of Stepping Stones for Life Focus Families with Respite Care

Stepping Stones for Life, with funding provided by Disability ACT, works with a number of families in which ageing parents are caring for an adult family member with disabilities. Stepping Stones staff assist the families by helping them explore options, plan and implement solutions to their long term accommodation needs. We call these our 'Focus Families' to differentiate them from a number of other people and families who are involved in our other activities. There are currently nine focus families.

The majority of the Stepping Stones focus families use respite on a regular basis through Disability ACT Respite Houses. The respite that is offered is generally one weeks respite every 6-8 weeks. This ongoing respite is much appreciated by all the families as it allows them to have a regular break from their caring role.

Comments from Focus Families

Out-of-home respite in a group house for one week every 7 or 8 is very welcome. 'Eleuora', in Charnwood, the house most of our people go to, is reasonably well maintained. Rooms are plain and furniture simple. But they are kept clean.

- . Quality of staff has varied over the years.
- Older, experienced staff members are very caring.
- Casual staff, are often poorly trained and inexperienced.
- Better training (and pay) is needed.
- But experience and attitude are important - and should be rewarded.
- At least one experienced staff member should be on duty all the time.
- . There is little stimulation for residents by way of activities.
- Staff is busy accommodating, feeding and transporting residents to and from work, with little time for other activities.
- Free time seems to be spent in front of TV.
- Picnics, nature walks etc better option than dinner at the local club.

In-home respite is valued but seems much harder to get.

- More emphasis should be given to this.
- Less expensive for the government. (not 24 hour care)
- Carers (parents) can cope better with occasional breaks.
- Allows for innovation. Could be infinitely flexible

Some of the families on occasions have also needed to access the respite service at very short notice generally because of a medical emergency and the Respite staff have always been excellent in managing to cater for the individual needs.

For some families getting their sons or daughters ready for stay at respite care can be more of a chore than a break. For example organising medication; communication of their family members needs; and reorganisation of transport for scheduled activities for the week can be a difficult task to manage.

Attachment (b)

Experience of a young family with a profoundly disabled teenage daughter

One family with which St Margarets has contact has different circumstances to our Stepping Stones Focus Families, and has different needs which we consider require particular consideration. They are a younger family, with parents in their forties, and a family of four ranging from 19 years to a baby. Their second child, now 17 years old, is a severely intellectually disabled daughter who needs 24 hour care. She needs to be fed, bathed, dressed, and needs someone to change her pad as she is incontinent. She is also non verbal.

Her grandparents live in an adjacent suburb, and although they are willing to assist with care, they are not physically able to manage their granddaughter because of her size, weight and difficulty in walking or helping herself.

The disabled teenager attends a special school, and the parents avail themselves of the limited respite care that is available, both in home and out of home.

While she is generally placid, her inability communicate sometimes may annoy others in school or respite care, and she has been subject to severe physical bullying when the carers have not been sufficiently attentive. The parents consider that respite houses need to place people with similar needs and personalities together to avoid having aggression and serious injuries that may occur.

They also report that lack of systematic arrangements or staff training can often mean that possessions, including shoes and clothes, which go to respite care are not returned.

Respite in the home is also of the utmost importance to assist with bathing and other personal care needs of a disabled teenager. While the parents are very thankful for in home assistance, they have at times experienced unhelpful and inadequately trained staff who have refused, for example, to help lift the disabled daughter into the bath, while expecting the parents to do so. Yet the parents have been unable to obtain assistance with obtaining any mechanical lifting aids.

The parents do their best to have a normal family life and provide outings and holidays for their children. They consider regular weekend respite to be very important so families can function normally and do things with their non disabled children. They note that siblings of disabled people suffer terribly due to the lack of normal family outings.

This particularly applies to annual holidays for which they need at least 2 weeks of consecutive respite annually so that the family can enjoy a normal holiday. This is generally not available, and even a nominal week is in fact only a few days.

Attachment (c)

Discussion of appropriate models of housing for respite and longer term accommodation

There is an anomaly in government respite housing;

- DACT favours independent living over communal living;
- yet respite houses operate as group houses;
- but we understand the practical (financial) reasons for this.

.We believe a variety of accommodation models should be available for respite;

- independent living options;
- group houses, as at present;
- a limited number of bed-sitters under the one roof, as discussed below.

St Margaret's, with government stimulus funding, is currently building a home for 5 or 6 residents. Each resident will have his or her own bed-sitter with space for bed, table, chairs, en suite etc. This will provide personal space, privacy, independence, a home of their own, to a far greater extent than the normal group house, such as Eleoura. At the same time there will be communal space in the form of a kitchen, dining room, living room (both indoor and out.) for eating and socialising. We see this model as providing for as much independence as the resident wishes but the security and company needed to avoid isolation and loneliness which often comes with independent living. We think a facility of this type would cater for those who do not have high dependency needs and would be a valuable addition to respite services in the ACT.