

Submission from the Management Committee of Stepping Stones for Life, St Margaret's Uniting Church, Hackett, ACT

to

The Inquiry into Provision of Social Housing in the ACT.

The following submission from the Stepping Stones Management Committee (SSFL) draws on our involvement in the disability sector in Canberra over the past nine years, the experience for over thirty years of individual families associated with our committee and the combined experience of the families being assisted in their pressing issues by Stepping Stones for Life. Stepping Stones is a small organisation that was established by St Margaret's Uniting Church 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. Such situations involve a range of housing solutions as well as longer term care requirements. Our core constituents are families affected by moderate to severe physical and intellectual impairment.

We are mindful of the debate in the community regarding differences in individual needs, the need to foster independence to the greatest extent possible, the reasons for de-institutionalisation and the potential problems with congregate living; but we also see the problems of people with disabilities living in the community without adequate support and friendship, and of aging parents seeing only a glimmer of light at the end of a long tunnel.

While we are far from satisfying the housing needs which we face, St Margaret's and Stepping Stones have been involved in the following housing arrangements for people with disabilities:

- Long term care by parents in their own home with and without outside assistance;
- developing a form of family governance process which is now implemented at a purpose built ACT Government house in Ainslie for three women with disabilities requiring 24 hour care;
- the design, construction and management of a home on church land for five people with special needs but with a greater degree of independence;
- A privately owned home being shared by younger people able to provide some mutual support.

In addition some of our families have individually experienced a range of housing over many years with very mixed satisfaction and in some cases desperation.

We acknowledge that the achievements of Stepping Stones for Life to date have been with the cooperation and support of the ACT Community Services Directorate and with other community organisations such as Uniting Care and Carers ACT, and with a significant financial contribution from the Federal Government stimulus package for capital works.

Through our church community we are also in touch with a number of families who have struggled with obtaining appropriate stable accommodation and treatment for family members with mental illness, where needs are different but no less real.

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.

Our submission addresses a number of the terms of reference of the inquiry, drawing on experience which is detailed in attachments. We acknowledge ACT Housing's response to the audit report and look forward to the proposed changes. We therefore were pleased to hear of the review and to be invited to make a submission. Our comments lead to some specific recommendations for improvement of social housing in the ACT, and we would welcome the opportunity to discuss these observations and recommendations with the Committee in due course.

Some Underlying principles

Before discussing the terms of reference individually it may be useful to set out some principles which we think are relevant to the provision of appropriate social housing for people with disabilities.

(a) Physical

The outstanding characteristic of the disability cohort is the great variety of individual physical conditions, circumstances, personal and family resources and therefore the variety of physical accommodation circumstances which need to be found or created. In designing a policy for physical provision of accommodation it is necessary to recognise that (as enunciated in the SSFL 3 Pillars structure, see attachment (e)) it is possible to envisage specific solutions being created in the public, community and private domains. There is a need to recognise the over-riding importance of individualised solutions while at the same time drawing together types and grades of disabilities to facilitate some generalisation of physical solutions.

The principle governing accommodation policy formulation in this context is, it seems to us, to provide for a wide variety of options which are adaptable and sustainable.

(b) Financial

Again, a major characteristic of the SSFL families is the variability of financial resources (as in the wider community). It is also necessary to recognise that a shift in accommodation arrangements to provide greater independence for vulnerable family members can, and usually does, mean significant change and often reduction in financial means for other purposes in order to direct funds to accommodation needs. This does not mean that social accommodation options have to be at the cheapest part of the market. [Other characteristics of the accommodation may be more significant in some individual cases.]

Again, an appropriate principle seems to be to provide for a variety of options.

(c) Management and Funding

This may well be the most complex area in the provision of social housing for people in the area of disability with whom SSFL is concerned. This means that physical accommodation provision within financial means is not the complete context for a policy setting in the social housing area for those with disability. This is why the SSFL 3 Pillars structure postulates 'Support' as the second pillar beside 'Accommodation'. In our view, no model will work satisfactorily if it is not managed wisely and funded adequately.

The principle underlying this policy area is to ensure availability of necessary support funding to ensure a viable household through not only rental subsidy or other accommodation support but also through disability funding of some kind (ISP/Block Funding etc)

(d) Personal

The third Pillar of the SSFL planning structure is 'Alternative families'. This addresses the need for people to 'have a life'. Provision of accommodation itself is clearly a major element in this but where one lives, who one lives with and major life style issues are also major elements.

One principle underlying this policy area is to provide a variety of options in a variety of places and to set up a mechanism for recognising or creating potential coherent 'households' and providing appropriate funding and support.

Another principle seems to be the acceptance or even encouragement and funding of arrangements such as 'intentional villages or complexes'. These depend significantly on cooperative management and personal life styles.

Maybe a message here is that social housing should, if possible, be tailored to the specific needs of the prospective residents ie it should not just be putting people in somewhere. A tall order!

Discussion of our experience relating to the terms of reference:

1. The findings of the 2011 ACT Ombudsman's Report in relation to the ACT Housing priority housing waiting list, Assessment of an Application for Priority Housing, June 2011;

The issues associated with the families with whom we deal are generally long term and fall into the High Needs or even Priority Housing categories and can stay that way for a very long time before an accident or illness of the primary carer dramatically changes the situation. The immediate need may then more likely be met by respite which is a last resort.

2. The demand for social housing including an examination of the current waiting lists and eligibility criteria for priority and high needs housing;

The demand for social housing for people with disabilities is high, although not well quantified, and masked by parents taking the responsibility for longer than they are reasonably able. The imbalance between supply and demand can be met by either increasing the supply of housing (by building or acquiring by other means) for people who need more care and support than those who are more able, or reducing the demand by providing more support and options in other ways. The proposed introduction of the National Disability Insurance Scheme may give families more opportunities to choose appropriate housing and relieve some pressure on the supply of government housing, but will place greater demands on the present inadequate supply of trained support workers.

For those with disability on the waiting list, the eligibility and criteria for progression needs to take more strongly into account that the transition to a new living situation is more successful when the timing allows the aging parents to be actively involved in the transition. Delaying until a crisis has occurred denies the aging parents the peace of mind of knowing that their family member has a suitable living situation for the future and impacts on the ability of all family members to have the opportunity of a good life.

3. The management of waiting lists, innovative strategies to reduce waiting lists and the development of the Social Housing Register (the new centralised waiting list for social housing in the ACT);

The Social Housing Register was used in the selection of residents for the Ross Walker Lodge, with the very successful cooperation of Housing ACT and Disability ACT in a

selection process jointly with Stepping Stones committee members. We commend this strategy for the appropriate selection of residents for available shared accommodation, where compatibility and the opportunity for the development of friendships and mutual support is most important.

4. The current range, availability and suitability of social housing stock, including new models of social housing (such as the intentional village model designed for people with a disability and sustainable housing models) and any financial implications;

As stated, Stepping Stones has direct experience with two models of social housing stock, and two models in private housing. These are discussed more fully in the Attachments to this submission. We consider that the social housing models discussed at Ainslie and Hackett have been very successful for the residents and appreciated by their families, and form useful models to be replicated and adapted more widely in the ACT either by further building or by acquisition and modification.

5. The management and maintenance of social housing stock including the development of an asset management plan;

The two residences referred to above are new. One was built as part of the ACT's residential housing stock and when constructed the other had a requirement for the provision of an asset management plan to be submitted to Housing ACT. This places an onus on the managing agency to ensure that routine servicing of equipment is carried out to keep the facility in good operating condition.

How this fits into a wider asset management plan for the whole of the social housing stock is not clear, but there would be management advantages in the ACT Government having a clear picture of the extent and condition of its range of stock that is suitable for people with particular needs such as wheel chair accessibility and adaptability for aging in place.

6. The needs of social housing managers and all social housing tenants, including but not limited to:

- o current tenants;
- o prospective tenants including those on waiting lists; and
- o people socially and geographically affected by social housing allocation.

In the two properties referred to the current tenants are well cared for by the respective managers, Hartley Life Care/Canberra Community Housing and UnitingCare. These three agencies exhibit a strong social responsibility and concern for the individuals. In the case of the Ainslie House a model of family governance has been developed with input from the families, the managing agent and Stepping Stones, although we now have no direct involvement. In the case of Ross Walker Lodge a Management Committee exists for the house which has representation from St Margaret's, Uniting Care, the resident's families and the community. Both these models should ensure that the welfare of the residents and the opportunity for them to maintain as much independence as possible for as long as possible, is the primary consideration

Prospective residents and those on the waiting list have not been an issue to date after the initial selection, and both houses are covered by the Social Housing Register. Where direct approaches have been made to us for Ross Walker Lodge they were referred to the Register, where the prospective tenant could nominate their preference at the time.

The location of allocated social housing is important to the residents for the acceptance and friendliness of the community in which it is located and its proximity to facilities such as familiar shops, bus routes and employment opportunities. It is also important to families and friends to assist visiting opportunities in both directions. Selection should be mindful of the need to avoid social and geographic isolation for the residents and families.

7. Any other related matter.

We acknowledge that the enquiry is about the totality of social housing, of which disability housing is not numerically the greatest component. However it is an important component which requires more individual attention to residents and appropriate housing features and fittings which usually go beyond the typical requirements of social housing and requires a range of solutions. We have therefore made some recommendations that apply specifically to housing for people with disabilities.

Recommendations

1. Where the most appropriate accommodation for a person with a disability is in their family home, it is recommended that the ACT Government reduce or defer the need for the provision of social housing by:
 - providing financial assistance with necessary modifications to the house to improve access, hygiene and quality of life;
 - and where appropriate provide alternative entry arrangements to the home for the disabled person and carers to reduce disruption to other members of the family.
2. Where relocation of the family home, or provision by the family of more independent accommodation for the disabled member and carer or support person(s) is more appropriate, it is recommended that the ACT Government reduce or defer the need for the provision of social housing by:
 - assisting with relocation costs for purchase of the more suitable property, including estate agent fees, stamp duty and modification costs.
3. While being mindful of the requirement for individual assessment of the needs of disabled people before allocation of social housing, it is recommended that the ACT Government take immediate steps to increase the stock of social housing suitable for people with disabilities, by:
 - programming and funding a range of housing in a variety of locations for small groups of people, including those with disabilities;
 - assessing and allocating suitable residents during the detailed design process, and incorporating any special needs into the design;
 - thereby meeting the needs of individuals while shortening the delivery time for those in most need on the waiting list;
 - and also considering the successful models at Ainslie and Hackett for the design, development, resident selection and management of such properties either purpose-built or by acquisition and modification.
4. It is further recommended that the ACT Government should consider the availability of land from community and church organisations that are interested in the provision of social housing for people with special needs:

- to enter into partnerships with government meeting the capital cost and the organisations having a continuing role in management and the provision of informal support;
 - thereby reducing the overall cost and improving the prospects for community support.
5. Where a person with a disability is being relocated to more appropriate housing it is recommended that such a decision is taken to encourage community engagement:
 - By considering their access to community facilities;
 - And ensuring where possible that their existing connections with family work and community are not made more difficult through distance and lack of suitable transport.
 6. The Government should take steps to re-examine the separation of serviced for the aged and for those with a disability, allowing greater flexibility to enable accommodation and care arrangements which suit the families concerned:
 - such as in retirement villages where a son or daughter has lived all their life with parents who are now aging;
 - and to avoid forced relocation of the disabled person on the death or incapacity of the parents, where alternative care can be accommodated (as would have been possible in the parents' home).
 7. That accommodation of people with disabilities in intentional villages should be viewed on the merits of the intentional community and the opportunities being provided for residents, and not dismissed as has sometimes been the case in the past in the name of "normalisation" or through a blanket objection to congregate living.

Keith Baker
 Chair
 Stepping Stones For Life Management Committee
 St Margaret's Uniting Church
 November 2011

Attachments:

(a) Experience with living at home with parents.

When SSFL started, all families had their adult children with a disability living at home with them, but this is no longer the case. This has many benefits, if circumstances permit it, but it is rarely sustainable in the long term because parents age and usually die before their children. (This is a recent phenomenon brought about by improvement in medical science and a more inclusive society.)

Advantages are that:

- parental and family support is usually of superior quality to that supplied by others;
- the individual is more comfortable in a known environment;
- Involvement in local community, in which they are known, is easier;
- parents have greater peace of mind concerning safety and security;
- More economical for government; no new buildings and less paid care needed.

Disadvantages are:

- The necessary or desirable support services are not always (rarely!) available;
- The health of the parents can suffer;
- The financial cost to the parents can be high e.g. house modifications needed, opportunity to work may be restricted etc.;
- The design and location of the family home may not be suitable as the individual and the parents age;
- Problems can arise when parents become frail and are in need of help themselves;
- If the individual does not relocate before the parent dies, then he or she has the double trauma of losing a parent and changing their living conditions at the same time.

Inheriting the family home

One SSFL family had long-term plans in place for their daughter to have the use of the family home after they had gone; she would have another lady with a disability, and a carer, living in the house with her. Their wills were arranged so that the estate would not be wound up while ever the daughter had need of the house. Unfortunately the plan was never implemented, due to several reasons, and alternative arrangements were made. This model has clear social and economic benefits and, while not suitable for all families, it does provide another option. See also the second example in Attachment (d) which has similar aspects.

(b) Experience with a purpose built house at Ainslie.

From 2006 Stepping Stones worked with Disability ACT, community agencies and interested focus families to develop a model of Family Governance which was then applied in the development of an ACT Government house for members of some of the families concerned.

This model provides for shared 24 hour live-in care for three friends with moderate to high dependency, with the security, company and activity needed to avoid isolation while maintaining frequent family contact. We consider more facilities of this type would cater for those with high dependency needs and would be valuable additions to the social housing stock in the ACT.

The key aspects are set out below.

Physical: 4 bedrooms (3 residents with disability + 24 hour Carer) one ensuite, one bathroom with island bath and one shower and toilet combined with laundry

2 living areas, dining area, kitchen, wide passageway, double, high carport, landscaped gardens, other details.

Generally high quality dwelling.

Location selected from HousingACT available sites & with their advice, close to shops & public transport

Dwelling constructed by HousingACT.

Planning, development and construction over period September 2006 (first idea formally mooted), occupation June 2010

Financial: public housing with normal public financing regulation

Block support funding for individual carer needs based on normal ISP assessment

Family augmentation as desired

Management: managed by Hartley Life Care and Canberra Community Housing as

HousingACT agencies under a 3 way-MOU with residents' parent/carers Family Governance model.

Characteristics of significance for social housing example:

Public housing with all normal financial regulation

Supported accommodation with normal block-funding from Disability Directorate.

Professional Agencies management

Family Governance Residents Committee

They chose where to live and who to live with

Close to shops and transport

(c) Experience with Ross Walker Lodge

St Margaret's, with government stimulus funding, recently built a home for 5 disabled residents and a live-in resident adviser. Each resident has his or her own bed-sitter with space for bed, table, chairs, with built in storage, kitchenette and desk. This provides personal space, privacy, independence and a home of their own in which to age in place, to a far greater extent than the normal group house. At the same time there is communal space in the form of a kitchen, dining room, living room, laundry and outdoor gardens and barbecue areas for eating and socialising. Each bed sitter has an adaptable en suite and separate entry/exit to the resident's own pergola and garden area.

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 consider more facilities of this type would cater for those who do not have high dependency needs and would be a valuable addition to the social housing stock in the ACT.

The key aspects are set out below.

Physical: Single building in suburban street with appearance of small townhouse development

Six adaptable bed sitters with ensuite, internal and semi private garden access, communications cabling and emergency call buttons

Level entry and wide corridors, and design avoiding institutional feel

Communal entry, kitchen, laundry, dining and lounge, visitors bathroom, outdoor recreation areas and accessible storage room for mobility scooters and bicycles

Carport and secure storage shed, fenced access to street and St Margaret's car park

6 Star energy rated with gas boosted solar hot water, double glazing, solar orientation, underground rainwater storage.

Financial: Constructed on Uniting Church property with \$1.2Million Commonwealth stimulus package money and HousingACT project management support
Internal furnishing and landscape planting donated through St Margaret's and Stepping Stones.

Operationally self funding through residents payment of board and lodging with all meals (generally from disability pensions) and Commonwealth rental assistance

Management: Constructed by partnership between St Margaret's and HousingACT, with formal Operation Deed between Uniting Church Property Trust and Territory
Planned over considerable period by Stepping Stones committee working with project architect before funding secured

Ross Walker Lodge Management Committee chaired by St Margaret's and includes Community Services Directorate, UnitingCare Disability, UnitingCare Aging, community and resident representatives

Day to day operation by UnitingCare Aging under MoU with St Margaret's

Live in Resident Adviser provides support and receives discounted rent

Coordination of support services and promotion of resident independent living through 2 year non-recurrent funding from DisabilityACT to Stepping Stones

Characteristics of significance for social housing example:

Early days, but residents are enjoying the feeling of greater independence, friendship and pleasant surroundings

Management and families are very happy with what has been achieved to date.

(d) Experience with privately owned shared house.

The mother of an adult son with cerebral palsy has bought a town house in Canberra for him to share with two other residents to give him a greater degree of independence. He is studying part time, but has limited oral communication and hand control. In consultation with Disability ACT, Stepping Stones agreed to engage an experienced coordinator to work with the family and assist in the selection of other residents and the process of settling in.

The townhouse has 4 bedrooms and is in a small secure group with friendly neighbours. Renovations have been generally to bring the fittings and finishes up to standard and make the main bathroom more accessible, without the house needing to be wheel chair accessible.

The first “house mate” to be selected has a disability pension and works part time. She had been living independently in single flat in a large ACT Housing complex for some years, and welcomed the opportunity to move to a more pleasant home where she has the main bedroom with its own en-suite. Being of a caring nature she was willing to provide support with some oversight and meal preparation. Her main worries were how she would cope with the new role as it unfolded if demands became greater, and the uncertainty if she relinquished her flat and the new arrangement didn’t work out. With encouragement from her parents she has been in the shared house for five months and the arrangement is working reasonably well.

The young man has found that he needs more personal support than the seven hours personal care he had available from an agency. The support provided has at times been less than satisfactory and this has placed greater demands on his house mate and his mother. With various delays the third resident has not been selected. Once this happens it should make a more even sharing of duties, but will still rely on friendship and good will as well as cooperative support agencies providing trained staff support.

This model has some way to go to demonstrate that it is sustainable, but it has the potential to provide mutual support and satisfaction and a degree of independence for the three residents, and improve their quality of life at minimal cost to the public purse.

Another variant on this model is on the following page.

The key aspects are set out below

Physical: A 4 bedroom established single level townhouse, with renovations and modification to main bathroom to make it more accessible for assisted showering.

Financial: Purchased and modified by the disabled resident’s mother, kitchen and main bathroom renovations were subsidised by Home Care/Disability ACT
Residents pay rent with rental assistance and share food and utilities

Management: Interim coordination provided by Stepping Stones Coordinator in consultation with Disability ACT, to select residents, assist with settling in and development of house rules and identify emerging issues and support needed, coordinate support agencies, assist to establish carer routines
Meetings between families and Coordinator to assess progress and plan actions
Expected to be fairly self managing with residents and families over time

Characteristics of significance for social housing example:

Low cost to government for appropriate residents where family can provide house
Requires sufficient outside care which potentially could be shared

As mentioned above, another variant of the privately owned shared house involves two disabled women in their forties who occupy a four bedroom suburban house which has been provided by the estate of the late parents of one of the residents. It is an unmodified family home on a single level other than having steps front and back.

The “owner” resident who has cerebral palsy occupies the bedroom with ensuite bathroom, while two other bedrooms and a shared bathroom are available for her carer and the second resident. The fourth bedroom is used as an office.

The house is managed by Life Without Barriers, with personal care provided by Koomari.

Both of the residents work three days per week away from the house, but when they are home they have 24 hour care provided with a live-in carer.

The housing works well under the present arrangements, with the aged mother of the second resident able to visit or have her daughter home or on outings or holidays when it suits, and with the security of knowing her daughter’s care is not dependent on her being always available. The expressed down side of the arrangement is the uncertainty of accommodation if her daughter lives longer than the owner resident, as the house would be sold after a stated six month period during which an alternative would need to be found.

It is a higher care situation than the previous example of private ownership, and more resembles the model of Attachment (b) in Ainslie which involves an even higher level of care. The critical factor is not necessarily private or public ownership, but housing and accompanying care that suits the individuals and gives security of tenure for the residents. Parents also deserve the peace of mind of knowing that their son or daughter, for whom they have cared for many years, can have a good life when they are gone.

(e) The Stepping Stones 3 Pillar Structure

Stepping Stones for Life –Family Governance model schematic for a group of households for 1 to 3 persons with disability + live-in carer

Arrangements to be put in place before parents are no longer able to provide care and continue with present accommodation arrangements.

ACCOMMODATION	SUPPORT	ALTERNATIVE FAMILY
3 broad options: Private - the 2008 situation for all nine families Community - professional support agencies Public - through HousingACT	Professional and para-professional paid support Covering daily ‘brought-in’ care, overnight care, emergency care and attendance, supplied through the offices of a service agency Help with employment search Help with contacts with activity and other community groups Management of the affairs of the household via family governance group and group coordinator supported by service agency Assistance with financial planning, legal services (eg for tenancy matters), advocacy and pastoral care via the group coordinator	Creating an “alternative family” before parents can continue. Through Circles of Support (siblings, friends, volunteers) and working with family governance groups and coordinator. Activities and mutual support gatherings
Owners and landlords	DACT, Agencies	Circles of Support
SSFL Coordinator		
Family Governance groups (guardians, siblings, supporters)		