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Committee Secretary
Senate Community Affairs References Committee
PO Box 6100
Parliament House
Canberra ACT 2600

Re: Submission to Senate Enquiry into Planning Options and Services for People Ageing with a Disability

Dear Sir/Madam,

Thank you for the opportunity to make comments in relation to Planning Options and Services for People Ageing with a Disability.

Background to CLP

The Community Living Project (CLP) was incorporated in 1985 through the leadership shown by a small group of families in the southern region of Adelaide who gathered under the banner of Parents of Disabled (South). These families started CLP because they didn't want their adult sons and daughters to spend their lives locked away in an institution. They dreamt of being able to feel secure in old age, knowing that in addition to having a secure place to live, their sons and daughters had the vital and caring day-to-day support that each family knew would probably always be needed to enable them to live safely as members of their local community.

CLP now supports people who have an intellectual and/or other disability to live in a home of their choosing in southern Adelaide. Some of these people share their homes with others (eg partner, friend, boarder), while a number of people choose to live alone. 10-15 other people receive help while still living at home with their ageing families – although many do so only because the CLP doesn't have the funding resources to provide the day-to-day support they would need to realistically make a choice to move out. In each of these situations the CLP provides the individualised, daily support each person needs to make his or her house a home, while also helping them to build relationships in, and contribute to, their local community.

Along with direct support services provided to people with disabilities, CLP has invested in family members in assisting them to have control over their services. Innovative and highly successful services models have been offered by CLP, which are family directed and managed. CLP's philosophy and approach places the person with disability, together with their family and support network, clearly at the centre of all planning and decision making processes and works with each individual person and their family to provide support that reflects their individual needs, aspirations and dreams for the future.

We work in a model of partnership where each person and their family and are encouraged and indeed expected to take active control over the decisions that affect their future.

Our first goal is to develop a relationship with the person and the family that engenders trust and facilitates our capacity to work in ethical partnering arrangements with individuals to understand what makes a good life from their perspective, their goals and dreams, and their plans (and fears) for the future. Some of the questions CLP supports people to think through include:

- What the person does during a typical day or week
- Where the person lives or where they spend their time
- With whom the person lives or spends their time
- What types of support are most relevant and appropriate
- Who provides informal and paid support.

From a shared vision of the future, we support people to identify longer term goals and strategies that focus on the person's wellbeing, relationships and community connections.

CLP's Values

CLP believes a "home" is much more than simply the bricks and mortar that make a house. When we talk of "home" we are thinking of the unique environment which most people typically seek to create; a place that provides a sense of security, pride, privacy, retreat and sanctuary, and an accepted place in the community. For a person with a disability who remains living with their family for many years, CLP's role is to provide the support they need in a manner that deeply respects the family home and yet which also enables them to make contributions within the home as well as build an identity and life outside of this context.

In terms of "relationships," CLP believes that people who have a disability will often need assistance with the complexities of developing and nurturing a relationship, just as other people in the community might need assistance to respect and value the contributions made by a person who has a disability. For many people who have a disability, freely-given relationships will often have been largely restricted to members of their family or to others who have a disability. Many attempts at friendships may have failed for various reasons and in turn might result in a reluctance to try again. With this in mind, CLP has in recent years developed a "Circles" initiative which grew from the recognition that many people who have disabilities may have no-one to "look out" for them as they age, after their parents have died or after a long period of institutionalisation. It began with funding in partnership with the Macquarie Bank Foundation and Julia Farr MS McLeod Benevolent Trust and more recently has been fortunate in obtaining funding from Disability SA.

The Circles Initiative intentionally invites people to come together and support a person who has a disability for the purposes of protecting their interests into the future, not with the expectation that this group might necessarily have responsibility for "caring for" the person, but with the expectation that if asked and/or if required, people would be pleased to make time to join with others from their circle to "look out" for that person.

'Strong social networks can support longevity as well as having a direct positive effect on physical and emotional health' ALSA (2006).

What CLP has learned

CLP has a strong reputation for providing highly personalised support and has repeatedly demonstrated over 25 years that with thoughtful, well-constructed support, it is possible to enable any person, no matter what their level of disability, to live fulfilling, contributing and meaningful lives in a home of their own as participating members of our local communities.

Over this time, many CLP-supported families have quietly and independently committed their energy and resources to crafting 'ordinary' lives for their sons or daughters in the family home or in a home of their own choosing. CLP first met their sons and daughters when they were in their twenties and older, and now they are 45 – 75+ years old. Some disabilities experienced by these people have become more complex or more intense. Hours of support provided for individuals have mostly remained static over the years of their support, while allowances for inflation have lagged behind real costs and the administrative demands on small non-profit organisations have spiralled.

Parallel with people's increasing needs, are the increasing needs of many of the parents who are now in the 60 – 100 year age group who have added tensions around managing their own health, or that of their partner, while still providing part or full time care for their son or daughter. Many families are reaching fracturing point.

Parents are expressing fear for their childrens' uncertain future and their inability to foresee or plan their childrens' future support needs. Some parents' biggest fear is that the universal answer of group homes is the *only* option that will be on offer, where suddenly their son or daughter will no longer have a "home", they will have "accommodation".

Parents ask us "how might it feel if a family crisis results in their son or daughter:

- being moved to a place *not* of their own choosing, away from their local neighbourhood where they know many people, and in return are well known by them?
- being made to share with three or more complete strangers who may not necessarily welcome an "added extra"?
- being stripped of familiar possessions and treasures?
- may now have to get up at a specific time, eat at set times, go out only if everyone is well enough to do so, or stay indoors if the weather is too cold/wet/hot?
- being dependent on adequate staffing levels to support them to do those things that they love?"

'Participants across the board placed high value on community based supports in helping them to remain living in their home and participate in a fulfilling, socially connected life...Participants expressed a clear preference to remain in their own home for as long as possible.' Ellison et al.

CLP strongly believes that:

Low and declining levels of parental wellbeing will contribute to the reduced capacity of parents to care for their son or daughter and lead to increased demand pressures on formal disability services, which are already demonstrably unable to meet current needs.

'Carers, usually parents, are vital to the wellbeing of people with disabilities. These parents make a substantial contribution to the social and economic wellbeing of the community, providing around 70 per cent of care to people with disabilities. The imputed value of this unpaid workforce in 2005-06 is estimated to be \$41.4 billion nationally – for an estimated 1,039,000 carers. This compares with the estimated \$28.9 billion of total government expenditure on welfare services in 2005-06.' (AIHW, 2007:310).

Collaborative family planning is needed now for the near future – older families urgently want to plan for the future needs of their sons and daughters. Their ideas of how best to do so are practical, cost-effective and most importantly allow their son/daughter to remain in their own home - maintaining all that is secure and familiar. This is a fundamental need desired by every one of us and is what the average person takes for granted and does not even need to consider. Many of these families have saved Government literally hundreds of thousands of dollars over the lifetime of their son or daughter, because of their support, love and teaching of pro-active and developmental social and daily living skills. These families' ingenuity and determination have given their sons and daughters an “ordinary” life, not a “special” life. These families are now looking for a practical future plan that meets the vision of the individual person and their broader family.

Now is the optimum time to put good plans in place – while everyone is well enough to collaborate. It is less expensive and far more humane, in the long term, to fund some increased ongoing support hours now in order to set up a great and successful outcome, rather than sort out the costs around supporting a person with disability at more intensive levels should their parents experience long term health problems (illness, hospitalisation, convalescence) which would prevent them from maintaining their current familiar routines.

Additionally, it can be strongly argued that supporting families to plan now for a known and secure future will have an immensely positive effect on carers' current well-being and capacity to continue managing for the longer term.

The solutions are likely to be multifaceted and require a degree of coordination, but such considerations should not preclude the initial discussions to gather information and ideas about what solutions might be reached.

Some illustrative examples

Sarah lives independently as possible in her own home - a HousingSA unit. Sarah is an outgoing woman who enjoys physical activity, music and the theatre. Sarah has an intellectual disability, and some repetitive behaviours which relate to anxiety. Sarah has been successfully supported to live in her own home for many years due to three key factors:

- Sarah lives in her own home from Monday – Friday. Paid support is provided for only 10 hours per week.
- Sarah goes to work at a sheltered workshop on weekdays.
- Sarah stays at her parents' home from Friday evening until Sunday evening every weekend.

This is a great model for many families looking for ‘another way’ - one that is not a shared or community house where individual needs are often compromised by other people's greater needs, or timetable routines, or low staff levels, or roster issues. These are some of the everyday impediments and frustrations around the failure to realise a lifestyle tailored to each individual's preferences.

Now Sarah's parents are over 80 years old, and are very worried about their ability to maintain the current levels of assistance that they lovingly give to their daughter. They are often distressed about their inability to plan for Sarah to remain in her own home.

However this is an achievable goal, practical and cost-effective, through an ongoing investment of extra hours of support (perhaps 10 hours) across Friday to Sunday – the weekend period that Sarah currently spends at her parents' home.

Sarah does not want to live in a group or community home. In her own home, Sarah has her own routines and manages well. She decides what is best for her, what she wants to do (there are no compromises when the well-being of other people takes priority, as occurs in community group homes). Sarah would remain in control of her life, make the greatest use of her capacities and talents, and look forward to a positive future.

Anne and her mother Margaret

Anne lives with her mother Margaret in a charming home that is beautifully decorated and maintained by Margaret. Anne has great comprehension and adequate communication, and she is physically able, though she needs assistance with daily living skills. She has significant disabilities including intellectual disability and Tourette's syndrome.

Margaret is facing an increasingly precarious situation through Anne's increasing demands and Margaret's own increasing personal health needs. It is Margaret's absolute vision and determination that Anne remain in her family home in the future. It is also her greatest fear that currently there is no clear plan for this future, or steps to make this plan a reality.

Margaret has actively applied for and gained support and respite services from several agencies so that she and Anne can both enjoy time together at home, and have time apart - Anne's intense and energetic character requires significant attention to her needs when she is at home. Until recently Anne worked at day employment from Wednesday to Friday. Unfortunately for all, Anne has been asked to take time off – potentially permanently – because her Tourette's tics have manifested into a major form, and she spends much of her time constantly "sitting/falling down" (mostly in a controlled way). Anne's neurologist has been unable to influence Anne's compulsive actions.

Needless to say, this compulsive repetitive action is distressing for both Anne and Margaret, however Margaret is determined that it is in Anne's best interest and maintenance of optimum well-being that Anne remain at home.

So the model for Anne's long term future - without Margaret, and with 24 hour support in her own home - might include a combination of the following, managed by an accommodation support service in conjunction with other interested parties:

- Anne remaining in the family home - Margaret has provided for Anne in her will.
- Anne sharing her home with a tenant – the rental income supplementing funding for support.
- Anne sharing her home on a basis of 'reduced or free rent' in return for some support responsibilities, eg commitments to remain at home with Anne overnight.
- Regular daytime activities - Anne working, volunteering or attending to hobbies/interests.
- Combinations of paid support.

CLP has some past experience of successfully providing and managing such a scenario.

Margaret is now 70 years old. She would welcome discussions that could enable her to plan for maintenance of Anne's present and future 'accommodation' needs, and which revolve around Anne being supported to remain in her home. When asking Anne about the possibility of moving out of the family home, she will clearly state that she does not want to do that. She also says that she does not want Margaret to move out.

Margaret hopes that this is an 'achievable goal'. Margaret wants to stay in control of a positive future vision of her daughter's life, even when she is not here to be part of it.

Michael, son of Jan and Terry

Recurring and serious health issues intensify the current worries of Jan and Terry about their son Michael. The family situation is a clear example of many older parents whose worries concerning the lack of certainty around securing sufficient support to allow their son or daughter to remain in their current home are intensified as they attend to their own major health issues.

Michael has an intellectual disability and some obsessive/compulsive traits and is often quite anxious, but he also has great comprehension and adequate communication. He is physically able, though he needs assistance with some daily living skills. Michael is a restless person who has much energy. His greatest pleasure is listening to his extensive music collection and he is an excellent dancer.

Currently Michael's funded support - in his HousingSA home - covers mornings, evenings and overnight (passive) across his working week from Sunday evening to Friday morning. Each Friday afternoon Michael goes to stay with his parents for the weekend until Sunday evening because there is not enough funding to support Michael across this period.

Michael has an energetic and fast-paced attitude to life, and he rarely relaxes. While Jan and Terry welcome their son each Friday afternoon, they see that he is bored and restless when indoors for long periods. Jan and Terry see that this is unfair to Michael, so they devise outings that Michael will enjoy, and they all go out together. While this arrangement sounds charming, in actual fact Jan (in her 70s) and Terry (over 80) are both very unwell and tired. It is also unfair to Jan and Terry as they know that they cannot relax on weekends, and they often decline social invitations that Michael might not enjoy.

Jan has survived cancer on 3 occasions, and Terry has diabetes and advanced osteoporosis with chronic spinal pain. Additionally, their daughter and a grandchild also have serious health problems, and this family need and rely on Jan and Terry to support and assist them as much as possible.

In particular Jan is extremely worried that should her health deteriorate suddenly, and should she be admitted to hospital, Terry is not well enough to support Michael in their home alone on weekends. Jan's question is "What will happen to Michael then?"

Some years ago Michael went to live with his sister. This was planned in response to Jan and Terry needing some respite around caring for Michael. Michael's sister managed this arrangement for a considerable time but Jan realized that Michael's sister was "worn out" by the intensity of the arrangement and also managing a full time job. Michael returned to his parents' home until HousingSA was prevailed upon to allot Michael his current home.

Michael is very happy while at his home, and is increasingly pleased to be at home rather than staying with his parents every weekend. Jan and Terry's ideal plan for Michael's future is that he should be supported to remain in his HousingSA home and maintain all that is secure and familiar to him. Jan and Terry are highly aware of the costs of funded support however, and they know at present that it is far from certain that Michael could be funded well enough for the necessary support to remain safely in his home.

The model for Michael's long term support, in the absence of Jan and Terry's support, and with almost 24 hour support in his own home, might include a combination of the following, managed by an accommodation support service in conjunction with other interested parties:

- Michael remaining in his current HousingSA home. He is an excellent tenant.
- Michael sharing his home with another tenant - with approval from HousingSA.

- Michael sharing his home on a basis of 'reduced rent' in return for some support responsibilities, eg commitments to remain at home with him overnight.
- Michael being at home alone for short periods (maybe for an hour after work each day).
- Regular daytime activities – Michael working, volunteering or attending to hobbies/interests.
- Combinations of paid support.

Michael does not want to live in a group or community home, and his parents have no wish for that to be his future. In his own home Michael has his own routines and manages well.

In summary, CLP strongly recommends that the Senate Enquiry recommend future options that enable people ageing with a disability to remain in control of their lives and as fully participating members of their family, neighbourhoods and community. The insight, wisdom and vision of the older carers of these people should be capitalised on in terms of developing joint plans with them for sustainable, effective and affordable community based support – before these families reach a crisis situation.

Yours sincerely,

Prue Gorman
Executive Officer

References

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