

Submission to the Senate Affairs References Committee- Inquiry into Planning Options and Service for People Ageing with a Disability

Perth Home Care Services and Regional Home Care Services (the PHCS arm supporting people in rural areas of Western Australia) appreciate the opportunity to make a submission regarding Planning Options and Services for People Ageing with a Disability.

Perth Home Care Services (PHCS) is a not-for-profit organisation established in 1967. Our vision is “People Living at Home With Dignity”. Services we provide include assessment, case management, crisis care, domestic assistance, nursing consultancy, respite, social support and personal care. We provide support in the homes of people with disability, who are frail aged or who have mental health issues across the Perth metropolitan area, as well as the Midwest and Wheatbelt regions of WA. We assist people in the community of WA to be in control of their lives, connected with family and community, regardless of circumstances, by recognising each persons’ uniqueness and working with them to develop the supports they need. Our work is underpinned by the person centred approach. This means that we support people to:

- Make choices and decisions for themselves
- Grow and develop in their relationships
- Be present and participate in the community
- Have valued roles and contribute
- Develop their talents, interests and abilities

In this submission, we’ve outlined some of the issues and opportunities requiring consideration as support is planned into the future for people with disability who are ageing, and their families. This outline centres around four issues: Access to planning options, Services for people with a disability to ensure their quality of life as they and their carers age, Identification of inadequacies in the choice and funding of planning options currently available and People ageing with a disability and their carers. Although we have discussed these issues separately for the purposes of this submission, it is important to note that all of these topics are interrelated and opportunities for advances in choice of services for example are dependent upon other topics such as access.

People ageing with a disability and their carers

People who are ageing with a disability and their carers are forever intertwined. Sometimes this is cultural and the expectation of the caring role is that people will provide care to their son or daughter with a disability ‘life long’. The separation that occurs usually with adulthood (e.g. moving out of the family home) may not occur. Planning for the future is a daunting task. Sharing the challenges of supporting a son or daughter with a disability with others may not be something that had ever been considered. When planning does occur, it is often with the assumption that other family members will take on the caring role and decision making into the future. Whilst sisters/brothers may have good intentions, things often fall over after the parent’s death. The voice of the person with a disability is not considered and decisions are taken which may ultimately not be what the person with a

disability would want for their own lives, for example selling the family home where they have always lived. Our experience has been that planning for the future and engaging a person's network of family, friends and other contacts is important for both the peace of mind of the carer and to ensure that the voice and wishes of the person with disability are heard and understood. Initiatives to that end used by PHCS include a program called "The Big Plan" which is a series of planning sessions for people with disability and their networks which helps people think and talk about what they want for their lives now and into the future. The Big Plan is conducted with several families together so sharing of experiences can happen and support for each other can be developed. Another initiative is "Time off and Planning" (TOP) is a program which uses flexible respite options for older carers and younger carers of people with disability to give them time off from their caring role. A component of this respite is the relationship built with the Service Development Officer who can begin to have the discussion about what type of support plans have been made for the future and what it might take for those plans to come about. A very specific person centred plan may be developed with people with disability and their networks (families, friends etc.). This planning is done with a facilitator, the person with disability and their network. The person with disability describes their best life-their goals, hopes, dreams and nightmares. Each person in the network has a part in helping the person with disability live their life as they would envision.

Access to Planning Options

Whilst these are excellent initiatives, barriers for accessing this planning do exist both for the carer and the person being cared for. Information regarding planning options may not be readily available, or may be limited for other reasons such as isolation by choice, default or necessity. The most significant barrier to planning options may be within people themselves, even given the opportunity. Traditional service provision has not allowed for people to express what they want; it's more a matter of what program a person fits into. In order to break down barriers in access to planning options, people need to be encouraged to think differently- consider/imagine what the future might look like, plan for more than just 'now', hear the voice and choice of the person with the disability, start a plan of support with the person in the centre of the support instead of merely observing.

In discussing planning options with people who have a disability, sometimes it is the older adult carer who has more of a concern than the adult child. In addressing planning needs with older adults, it is important to recognise the journey that they have been on for many years. Developing a relationship with that person is the first step. In order to develop trust, a relationship needs to occur between the person/organisation offering the planning and the person thinking about the planning. Developing this relationship takes special skill and is characterised by:

- Knowledge of available resources
- A holistic perspective about the person in need of support and their environment
- An ability to inspire families to plan for the future
- A genuine interest in people's circumstances

- Positive outlook
- Belief in what CAN happen
- Adequate time to spend with families
- Skill in developing the relationship
- Being clear and articulate
- Showing respect
- An understanding of where people are in life , recognising that there is wisdom in ageing, life experience and valued life roles
- Being a catalyst for change

Services for people with a disability to ensure their quality of life as they and their carers age

It's not difficult to think about what types of services should be available for people with disability to ensure their quality of life as they and their carers age. Help around the house with chores, shopping, cooking, transportation, personal care, helping to develop and sustain relationships with the community and other people are just a few.

Practical support for someone who has a disability or someone who is ageing may not be fundamentally different. There are considerations around the physical dimensions of ageing such as dementia, incontinence, visual difficulty and chronic illness. In some circumstances, both the person with disability and the ageing carer will be going through those at the same time. ¹ For example, adults with Down syndrome tend to age prematurely, developing conditions such as arthritis, osteoporosis and vision loss decades earlier than usual.

What types of support will really make a difference to people with disability and their carers as they age? PHCS suggests that in addition to the traditional (help around the house, cooking, transportation etc.) the types of support that will make a difference to people's lives will include:

- Affordable and appropriate housing- this may be the family home or it may be another home of choice, but it should be within a regular community, ideally local to the area the person is familiar with and not set apart. It should be close to transport, shopping, medical resources and activities in which people can and do participate.
- Community Connection- People are social. Everyone has something to offer. Developing or helping to maintain people's roles in their community is important to the person and the community involved.
- Planning- Support in planning by someone who has the skills, knowledge and time to develop the relationship helps people think about the future and helps us hear what people want to happen to them.

¹ USA Today, 22/03/2010, Down syndrome caregivers face new challenges as they age

Inadequacies in the choice and funding of planning options currently available

It is easier to define the types of support that people may need into the future than it is to find answers for the more difficult questions:

- Who will provide the service
- Who will pay for the service and;
- How much control will the people needing the service have over the service itself

Funding mechanisms for both the aged care and disability sectors are in need of reform. Ageing reform is inexorably linked to the health and hospital systems. Disability reform is also linked with health and hospital systems. The CAP (Combined Application Process) is neither ample nor flexible enough to deal with individual needs and is, in and of itself, not a guarantee of quality support for people with disability. Aged care funding provided to organisations rather than to individuals removes a person's ability to choose whom they want to help them and very much limits their control.

Recognition of people's power in making decisions for themselves is evidenced in established groups in Western Australia such as PiN (Planned Individual Networks) and VMA (Vela Microboards Australia). PHCS supports a model of funding for support which is directed by the person (consumer directed). The TOP (Time off and Planning) program has implemented a support mechanism, albeit small, via small grants which has very successful to date. PHCS work with people who wish to manage their own supports (Shared Management) in the disability sector is a growing area for our organisation.

Issues related to funding for people with disability who are ageing and their carers will take courage and reform to resolve.