

Stepping Stones for Life family governance

We have also contributed to the UnitingCare submission, but would like this supplementary submission to provide a voice for mature age carers.

Stepping Stones for Life is a network of mature carers and people living with disability in Canberra (ACT). Stepping Stones activities provide social support, practical support and pastoral care to families in answering their question of “*what will happen to my son/daughter when I die?*”

Family-governance provides one effective model of support. A family governance coordinator aims to build on the expertise and strength of the family. With the family the coordinator navigates the maze of services and provides counselling through the process of planning and letting go.

Our families speak with a voice of experience. These families have been caring for decades and provide a practical view of disability support. They do not wish to hand over the 168 hour caring work week to another informal carer. They would like to establish a safe and secure life for their family member with the oversight and guidance of the person's network.

For our families a good, safe and secure life means:

- funding for support to replace their role of caring
- accommodation in a good home, with a guarantee the person can stay in that home
- living support that values the person and a community life. This support should maintain links to their social networks and includes 24 hour support

The ACT is struggling with a lack of funding and infrastructure for people with disabilities. The current disability support system is crisis-driven and leaves some families shut out without the funding to enact plans for their family member. In a success story, we have supported a family-governed group home which has provided a pilot for what some of our families seek. This process took seven years from the time of receiving government support to the residents moving in. Our older families are running out of time. We don't envy the government role of having to prioritise which person should receive funding and who is left out.

Stepping Stones for Life supports the National Disability Insurance Scheme (NDIS). This support is about having funding to meet the needs of people with disability across the lifespan.

Our families would like their ideas heard and considered for their family member. Our Mature Age Carers are content with practicalities of a shared home for economic terms, supported by the principles of maintaining individual interests and connections. Stepping Stones families believe the current ideologies are not always realistic and in practical reality do not offer a safe and secure life for their son or daughter. There is not one idea that will be the answer for all people with disability.

Our families speak from a lifetime of caring and building a good life for their family member. They would like to see people with disability receive adequate support. Our families have run out of time and energy. **They want to die in peace knowing their sons and daughters are safe and secure.**

Laura Green (Coordinator – Information Education)

For Stepping Stones for Life family governance (UnitingCare NSW/ACT)