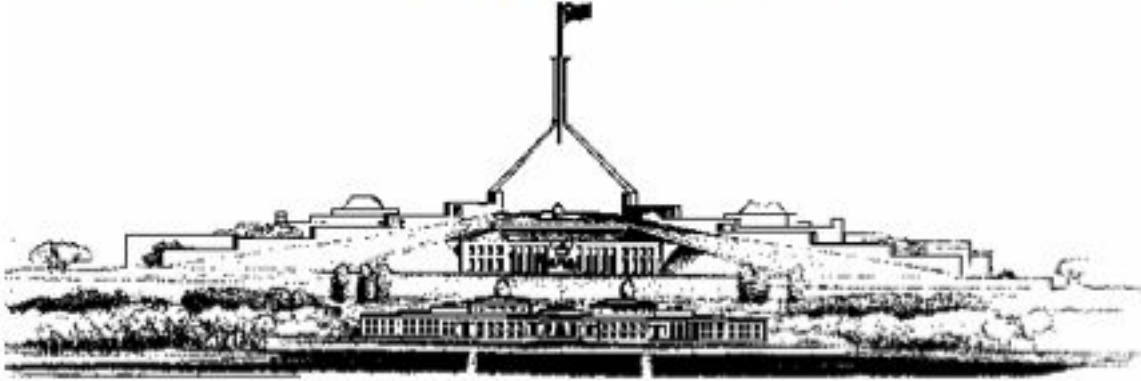




COMMONWEALTH OF AUSTRALIA

PARLIAMENTARY DEBATES



THE SENATE

MATTERS OF PUBLIC INTEREST

Ageing Parents of Children with a Disability

SPEECH

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Senator BOYCE (Queensland) (12.45 pm)—I would like to speak today about an ongoing and serious issue for parents of children with a disability. The issue actually hinges on the very poignant question: what happens when we are too old or are no longer able to care for our children with a disability? This issue came to the fore again recently in Brisbane, in a radio interview given to the ABC by a very well-known rugby league coach. The interview started out being about his team's ability and position on the ladder, but what caused a fuss about this interview was that this very controlled, very strong man became very emotional—with his voice actually breaking—when he was asked about the future for two of his children who have a disability. The question that was asked was: what about their long-term future? He answered that it was something that he lived with each day and it was not going to go away. He hoped that he and his wife had prepared for their future as best they could and that the family would be there to pick up the pieces when he and his wife were no longer around. His two children will no doubt have their physical needs met in the future. But as to their happiness, their sense of contentment with life, this planner and motivator extraordinaire could simply say that he would do his best and hope everything would be all right.

This same question and this same hope, rather than certainty, about the future confronts many thousands of families around Australia—families that have an adult child or a growing child with a disability. Many of these families have a far lesser ability to plan and to carry through their plans than the well-known Brisbane coach as they face this dilemma of getting older and continuing to look after their adult children with a disability. What happens to those we care for when we are no longer around or no longer able to care for them? The size of this problem within Australia is in fact relatively new. Firstly, advances in medical treatment mean that people with disabilities are, on average, living much longer lives—in many cases, with life spans close to the average Australian life span. In the 1960s, the life expectancy for a person with down syndrome was about 32 years. I now know a number of adults with down syndrome who are well into their sixties and living active, productive lives. I know young men with muscular dystrophy who are living

well past the life expectancy for people with this disability. So there are more older people who have a disability than in previous generations, and we have the right to have every expectation that, in many cases, these people will outlive their parents. This is a relatively new phenomenon.

Secondly, the great majority of people with a disability now live in the community, either with or near their families. They do not spend their lives from birth to death in institutions, as happened in previous generations. But their ability to live functional lives within the community is often very dependent on the little things that their family do to assist them. I am speaking here not of paid services that are often provided by professional organisations but of the smaller things that keep life ticking along. Without that sort of planning and help from their families, there is a very real risk that, at their parents' death, these adult children will lose not just their parents but also their home as they struggle to cope without a caring monitor of the quality of their lives. The medical and social advances that I have mentioned that have led to this increasing longevity and community inclusion for people with disabilities are to be very loudly applauded. But these advances have created, on a larger scale than we have ever seen before, a new and urgent need for long-term planning by parents and by siblings of people with a disability. Carers Australia has in fact described this need as a policy crisis.

I would like to flesh out a little for senators this dilemma being faced by thousands and thousands of Australian parents. In the majority of cases, these people with a disability will have their physical needs taken care of by others when their parents have gone. They will most likely be adequately fed, clothed and housed. But I ask any parent in this place to think about whether that would be their idea of enough for their child or for any vulnerable person they know. In fact, in contemporary Australia, our idea of an adequate or a good life includes a very high social component. In terms of a hierarchy of needs, an adequate or a good life includes living somewhere that is genuinely your home, not just a roof over your head controlled by others where you can sleep. A good and adequate life includes spending time with people you like and/or love—people who care about you because

of you, not because they are paid to do so. It includes spending your time involved in activities that you actually enjoy, not just filling in the days going to functions and on outings that someone else thought might be a nice idea for you. Most crucially, a good or an adequate life within contemporary Australia involves having people who care about you and about the sort of life you are leading.

In many cases, when parents die, the siblings will take up this monitoring role for adults with a disability. But I hope that we as a society have already recognised that we ask far too much of many parent carers, ignoring their needs until they are at crisis point. To expect siblings—who probably have their own families, life issues and problems—to replace the parent completely in that role is, in my view, unrealistic and unreasonable. Most parents of people with a disability whom I know do not have an expectation that a sibling would completely replace them. They expect the siblings to be involved in the life of their brother or sister but they do not expect them to be the provider of all things in the way a parent might happily be.

I would briefly like to mention those who will not even get the basics of adequate minimum care that we are talking about—basic food, shelter and clothing. Many of the homeless people in our cities and those living in boarding houses and hostels are people with psychiatric and intellectual disabilities. They are very vulnerable people who have fallen through the cracks. None of us, least of all the state governments, can be proud of our lack of support for homeless people.

For the past few years, I have been involved with a Queensland organisation called Lifeways. I want to speak briefly about the purpose of Lifeways, as it relates to planning. The basic premise of the Lifeways organisation is that good housing, good support services and adequate financial resources are very important in the lives of adults with a disability but it is even more important for vulnerable people to be cared about—that is the critical need. What keeps vulnerable people safe is not a good house, a good car, a good bank account or a good service provider but having someone—and preferably lots of people—in their lives to ensure that they are not being exploited, abused or neglected.

The Lifeways solution to this problem would be to have paid facilitators to help families, including the person with a disability, to develop a long-term plan and a personal support network that would gradually replace the parents in caring about the individual at the centre of the plan. There is some good Canadian research on the establishment of networks. It would certainly involve siblings, if there are siblings around, but often people who are keen to be involved in the life of a person with a disability are not recognised by parents. Parents of children with a disability, particularly a psychiatric disability, often experience a lot of

negativity from others and they are very reluctant to ask for help. So the idea of having an independent facilitator who would locate people to be part of a network, and maintain that network as it inevitably goes through the waves and troughs that any organisation established by people will do, is very important to this plan.

It is also very important for helping people in more remote areas where there simply may not be enough people to establish a support network of known volunteers within the social networks of the family. It would be thought that, in situations like that, you would have people from community organisations and church groups involved in assisting perhaps more than one person with a disability so that, in the long run, when parents are no longer there, there is a group of people who care about the person with a disability and care about continuing to ensure that there is a group who will monitor the quality of the services that are being offered to these people not just for their adequacy but for their suitability for the particular individual.

I think it is important to note that succession planning services should not be provided by current service providers. By that I mean that the organisation that is currently providing accommodation or employment or assisting with personal hygiene and health issues should not also be the organisation that is doing the planning for those things. It seems to me and Lifeways that there is an unacceptable conflict of interest if organisations that are providing accommodation and other services are also assisting families to plan for the provision of services and for monitoring the quality of those services.

Late last year the Department of Families, Community Services and Indigenous Affairs responded to this planning crisis by producing two very useful booklets on succession planning for families. This followed quite wide consultation throughout Queensland. This parliament also passed legislation, initially developed by Senator Patterson when she was the Minister for Family and Community Services, to enable families to establish special disability trusts. I think special disability trusts deserve wider publicity and recognition than they are currently getting. There was a catch 22 for parents who were trying to provide for an adult child with a disability in that if they managed to save any significant amounts of money to help that person it affected their pension entitlements. Special disability trusts allow families to have funds of up to half a million dollars and a principal place of residence for the use of the adult with a disability before pension entitlements and other government benefits are affected. This gives people a very strong impetus to save to underpin that planning for the future.

It is also worth mentioning that in recent weeks Minister Brough has announced a \$1.8 billion disability assistance package of supported accommodation

and respite services. Information sessions on this will be held throughout Australia in the coming weeks.

What are the state governments doing? In most cases, it is very little. There is one good planning organisation in Queensland, called Pave the Way, but it is only able to assist a very small proportion of those families wanting help. Across the board, most state governments are failing their disability communities. Queensland, New South Wales, Victoria and Tasmania apparently cannot even manage to develop lists of the known unmet needs in the disability area in their states. They cannot meet even the most basic governance requirements in relation to the Commonwealth funding— (*Time expired*)