

Senator Sue Boyce

Senator for Queensland

Title : **Positive Futures Program**

Event : **Launch of Positive Futures Program**

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Location : **Mount Gravatt Showgrounds**

Contact : **FSG**

Good Morning, and thank you to Diane Perrin and Vicki Batten. It is good to be here as Senator Sue Boyce this morning, as usually I am here representing a Minister. Today I am here as a Senator for Queensland, and as the mother of a young woman with Down syndrome. The Positive Futures Program is something that I personally have an interest in, and support.

Many older parents of people with a disability unfortunately do not make plans, or die before they can make plans, making a decent life problematic for the person they have cared for. It is vitally important that programs like the Positive Futures Education Resource is out in the community and that succession planning is discussed openly, within the family and within the community.

Recently much was made of a radio interview given to the ABC by a well known Rugby League coach. It wasn't about his team's ability, or how they were travelling in the competition, but rather that this highly successful sports leader became quite emotional when asked about his two disabled children and their future.

Almost in tears, he said it was something that he lived with each day, and it was not going to go away. He hoped that he had prepared for their future as best as he could and that the family would be there to pick up the pieces when he wasn't.

His two children will no doubt be physically cared for in the future, but this same question sits uneasily with many thousands of families around Australia as they face the dilemma of getting older...and trying to secure the future of their adult child with a disability. What happens to those they care for when they are no longer around or are unable to care?

A recent FACSIA report, Succession Planning for Carers: Summary Report on Consultations, stated "evidence is emerging in Australia and other countries that indicates few parents and carers have made comprehensive plans for future care,

accommodation and support, and that they are reluctant to engage in such planning. The reasons for this reluctance and/or lack of planning are varied. Some carers report that 'coping with the present' is difficult enough; others believe they are going to live longer than their children; and a number of carers experience frustration and confusion about the lack of information and services when trying to undertake planning; whereas others are willing to contribute financially but don't know how to start to plan, or are discouraged by complexities in the social security and taxation systems."

Getting started was identified as one of the most difficult problems for families trying to plan for the future.

Families are desperately looking for a 'how to plan' plan. Not only is it technically complicated—with financial, tax, legal, state & Federal government legislation to be considered but it's also emotionally tricky.

On International Day for People with a Disability on Monday, one organization recalled a 95-year-old mother who rang seeking advice about the future "if I die".

Well, we are all going to die. Acknowledging this is one step but then acting as though you believe it is another.

And planning may seem pointless if the family has little money and sees little prospect of adequate services, let alone the right services, being available when needed.

Indeed, one very disturbing fact that emerged from Monday's forum is that, despite Disability Services Queensland rhetoric about options, people with a disability are being coerced into taking unsuitable housing options.

Some elderly parents, in particular, have dealt for their whole lives with an inflexible and under-funded welfare system that told them what they could have, rather than asking about their needs.

In numerous workshops, when parents were asked about their "dream" for the future of their child with a disability, they spoke instead of what "they" (a nebulous grouping of government and non-government service providers) would NOT do.

It takes a considerable time for some parents to think in terms of an ideal plan which may rely for some of its inputs on resources not currently available within the formal service delivery system. Again, seeing and hearing of the "dreams" of peers assists parents to think more positively.

This program, and others like it, had its genesis in government thinking spearheaded by the then Minister, Senator Kay Patterson, who recognised that putting the individual and their family at the centre of government planning was a very large part of the solution. I believe that the Federal Government has done a better job of listening in the past few years and certainly a lot more funding has been provided.

In this budgetary year, the Federal Government has allocated more than \$1billion to HACC services and \$1.8billion to a national Disability Assistance Package.

Unfortunately the Queensland Government has talked the talk, but lagged behind in provision of services and in recognising the extent of unmet need.

If only the State Government would reconsider their commitment to Disability Services.

The Positive Futures Education Resource is an innovative step by step approach to succession planning, and I welcome the opportunity to launch it here today. I commend the FSG on taking this initiative, and I look forward to

hearing some of the personal stories later on this morning. I believe that this program will enable families, carers and service providers to look at this complex issue more objectively and in a manner that is more conducive to taking siblings, friends and the community on the journey with them.

As a carer myself, I have begun to put in place a plan for my daughter, and I realise how difficult getting started and staying started can be. One of the great benefits I see in the step-by-step approach of this Resource is that it will assist more carers to systematically tackle this subject with some assurance and calm.

I wish you all the best and it is my great pleasure to officially launch FSG's Positive Futures Education Resource.

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