

Support for living would save lives from despair

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October 22, 2010 - 7:01AM

On Monday, 150 families of people with a disability will sit down with candidates for next year's NSW election to demand the Minister for Disability Services and the opposition spokesman adopt a plan to reduce the likelihood of family breakdown.

These families believe the crisis-driven allocation of accommodation for people with a disability increases their stress because it reduces their capacity to plan.

They want the state government to implement a preventive approach, widely used overseas, to allow adults with a disability to move into their own homes while their families still have the capacity to support such a transition.

A proposed supported living fund would help families develop informal support among family and friends, complemented by paid support from the fund.

A young man, Jack, shows why we need a supported living fund.

Jack at 17 was capable but frustrated that his autism affected his ability to be understood.

The government provided support in a respite house with other people with disability, but the time Jack spent in this house only increased his anxiety and his challenging behaviour.

Jack was most calm when he was with young people in a church group he attended every Sunday.

Lesley, Jack's mother and a single parent, faced losing her job as she juggled work with Jack's needs.

She contemplated Jack living elsewhere but found that government-funded accommodation was only available when families had collapsed.

Lesley felt increasingly desperate and her powerlessness contributed to her downward spiral.

Two years later, heartbroken, she did not collect Jack from the respite house.

Jack was moved from one respite house to another, treated as a trespasser (a term used in draft government policy during the period), until he finally settled in a group home far from his family and community.

Jack's behaviour deteriorated. He put on 25 kilograms and his life involved a cycle of outbursts and increasing restrictions.

Lesley's life was also hell, as she battled with the service and government to improve Jack's life and move him closer to home.

We should not accept this scenario.

Families are rejecting the role of passive service recipients.

They dream of something more than a life lived in a facility, slotted into a lifestyle chosen for a group.

A supported living fund offers hope because it provides an alternative to crisis and an end to scenarios such as Jack's.

In the future, Jack could live in a two-bedroom unit, allocated through community housing; one bedroom for Jack and the other provided rent-free to a young man from, say, the church group, who provides companionship and support.

Young male support workers, chosen and trained by Lesley and Jack and paid through the fund, would come as required.

Young men could be good role models for Jack, helping him to feel more like one of the blokes when they go out.

Over time, Jack might well need less paid support because he would be more calm.

Some people using a supported living fund could live in a granny flat or use Rent Start assistance on the private rental market.

Others would use services to help them with staffing.

A supported living fund has all the right incentives. Instead of responding to crisis and family breakdown with a bed in a facility, families would be given incentives to plan and develop informal support.

Paid support would also be a more cost-effective way, complementing rather than replacing the freely given support of family and friends.

Importantly, the fund would lead to a clear strategy, rebutting the notion that the only way for people with disability to move out of the family home is to move into a government allocated "place".

The message at this candidates forum will be that the NSW government must actively encourage family initiative if it wants to move from crisis intervention to prevention; from having sole responsibility for long-term support, to being a partner in support.

The time for action is now. Whichever party wins government next year, it must embrace the idea of a supported living fund.

Over time, the fund would have a transformational effect on families and the disability support system.

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This story was found at: <http://www.smh.com.au/opinion/society-and-culture/support-for-living-would-save-lives-from-despair-20101021-16vxxg.html>