

Supported living campaign: Autonomy and control by people with disability and their families

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Abstract

In NSW in October 2010 the Minister, Shadow Minister and the Greens provided political endorsement for a Supported Living Fund – a stream of government funding that builds on family initiative to enable men and women with disability to establish a home of their own. For the first time in more than 20 years, people who were not in crisis would be allocated government funding to assist in their transition to their own home.

This paper describes the campaign run by Family Advocacy that led to this commitment. Insights are described from the early days in which we needed to reframe the demand from ‘supported accommodation’ where people were allocated a bed in a group facility to ‘supported living’ where people had the right to determine how they live, with whom they live, who provides them with help and support and how they live their lives. Through information sessions, teleconferences and workshops Family Advocacy built demand for something different and then built a coalition of families and services to argue for change.

Background

In February 2011, the Australian Productivity Commission described the disability service system as *“under funded, unfair, fragmented, and inefficient, and gives people with disability little choice and no certainty of access to appropriate supports.”* This recognition was critical in bringing State and Federal Governments to the understanding that families of people with disability had known for at least 20 years – that the ‘system’ itself was a major cause of crisis in families, in fact rewarding crisis with a supported accommodation ‘bed’. Yes, the bed was in an outmoded model that research demonstrates leads to poor outcomes, and yes, for most people the bed was far from family and community, but nevertheless, it was thought to provide the lifetime security that parents sought.

The perverse incentives in the system damage families who have been taught to rely on government in a system that provides no reward for family initiative. In addition, because government-funded supported accommodation groups people with disability, families and the community believe group homes and campus style accommodation are what people with disability want and need.

Family Advocacy has very different understandings of how a system could and should work. We recognise that families need to see supported living to know that it is possible for their family member. They need to see people with disability living in their own homes with people without disability and

experience the quality of life that ensues. We know this requires an articulated path to demonstrate how it might happen. We also know that families need support in this endeavour at a time of life when they still have the capacity to support the transition of their family member into a home of their own.

Two significant events gave a focus for our advocacy. From 2006, with the announcement of *Stronger Together*, the NSW 10 year plan for disability services, we knew that the negotiations for the second half of the plan would coincide with a state government election. So we set our sights on the lead up to the state election in March 2011.

Our goal was the establishment of a stream of government funding that builds on family initiative to enable men and women with disability to establish home of their own, arguing that the funds should be used for evidenced based models¹. Our secondary goal was that of family empowerment because we know that the lives of people with disability are always improved when their family is a capable advocate on their behalf.

Critically, however, from our work with families across NSW, we knew that we had to develop awareness among families that there are options other than waiting for government funded places.

The environment

We recognised that we could take nothing for granted. Many families had become passive recipients of services and we had to inspire them with a realistic belief that they could become agents of positive social change – that collectively they could influence the system. We also had to reframe demand – from supported accommodation² where people were allocated a bed in a group facility to supported living³ in which people had the right to determine how they live, with whom they live, who provides them with help and support and how they live their lives.

We needed to create a social movement to promote a long term process of change in which people with disability would be valued as contributing citizens who have a right to and can be supported to live in

¹ *Effectiveness of Supported Living in Relation to Shared Accommodation* (SPRC:2007) for people requiring 24 hour care found a range of approaches that are effective in terms of quality of life of people with disability and cost. ALL had moved away from providing 24 hour care because when the right elements of formal and informal supports were put into place, 24 hour care was not needed. Key elements of the most effective models are:

- separation of housing and support;
- support tailored to each person with a notional budget upon which they could call;
- support provided through a mix of formal and informal support with an investment in developing informal support.

² Supported accommodation refers to accommodation for people with disability usually in shared housing with up to 5 other people with disability. In general, the person with disability lives with strangers for whom the commonality was disability, in places that were far distant from family and community.

³ Supported living is an approach in which people with disability live with people without disability or by themselves. There is a separation of housing and support and support is provided through a combination of paid and informal support with intentional strategies used to develop informal support.

their own homes. Bill Moyer's Movement Action Plan⁴, a framework to understand successful social change movements, argues that social change groups should focus their energies on highlighting the problem in order to alert, educate, win over, inspire and involve the general public in advocating for social change.

Families are divided on this issue. Many families dream of supported living but don't know how to 'do it'. Other families feel threatened by the ordinary, inclusive nature of supported living believing that only grouped accommodation fully funded by government can work.

Many factors had the potential to hinder the achievement of our goals. There was a perception that high cost supported accommodation should be left for a National Disability Insurance Scheme and that it was 'unfair' to allocate funds to people not in crisis. The Australian Government was moving toward such a scheme, which meant the state government might respond that this was not their problem – that we should be targeting the national government. In addition, the lack of affordable housing and the lack experience of non government service providers in facilitating supported living and developing and utilising informal support were real impediments.

On the positive side, there were many factors likely to help us achieve our campaign objectives. All stakeholders acknowledged that the current system has serious problems. People with disability and families do not get what they want and need; services have little choice of who comes into their houses and are aware many residents want something different; government acknowledges that the system is always at boiling point with many unhappy customers.

In addition, there was widespread recognition that an accommodation system totally reliant on government resources is unsustainable. Some senior people understood the 'value added' when people with disability and families are given more control of the resources targeted to their benefit. Many people understood that despite widespread dissatisfaction, the system was maintained because of lack of vision of something different.

What did we do?

This analysis uses Bill Moyer's *Movement Action Plan* as the framework for reporting.

The hidden problem

In 2005, when the NSW government decided to redevelop rather than close institutions for people with disability, Family Advocacy ran the *Think Again* campaign arguing that size of accommodation does make a difference to the lives of people with disability. We argued that the community and government should 'think again' about their move away from closure of institutions. The campaign was a resounding failure. Sources inside government informed us that for every letter sent to the Minister by campaign supporters, there were ten letters arguing for keeping institutions open.

⁴ Moyer, B, *The Movement Action Plan*, http://thechangeagency.org/dbase_upl/movement_action_plan.pdf

From the *Think Again* campaign, we learnt valuable lessons. We learnt that most people had no idea about supported living – about approaches to supported accommodation that did not segregate people and segregate them from the community. We learnt that when you argue against something, you bring out the ferocity of opponents. Perhaps their anger would not be so virulent if we built a solutions-oriented campaign that argued for something.

We realised we needed to build a vision and a strategy. We had been good at documenting problems but not at identifying solutions. We needed to share our vision for the future. In mid 2007, Family Advocacy committed to a long-term strategy to secure a Supported Living Fund for NSW. We would use the confluence of the next state election and the second stage of the 10 year plan to launch and run a four year campaign for a Supported Living Fund for NSW.

As a first step in sharing the vision of supported living, we worked together with the Multicultural Cultural Disability Advocacy Association that generously sponsored the development of the supported living website, <http://www.supportedliving.org.au> so that people with disability, families, supporters, services and government could learn more about a way of life experienced by many people with disability.

Increasing the tension

We needed to build and communicate our evidence base. Unmet demand and its negative impact on people with disability and families were already clear. When in 2006, the NSW Government published the *Accommodation and Support Paper* that misrepresented research evidence to argue for cluster housing⁵, Family Advocacy developed a paper, *Presenting the Evidence*, to accurately disseminate the evidence about different approaches to housing and support for people with disability.

Family Advocacy made a strong organisational commitment to the campaign. New information sessions, teleconferences and a new workshop were developed that reached hundreds of families sharing new possibilities. We canvassed the possibility of a DVD about supported living but settled for developing a NSW edition of *A Home of My Own*, an excellent Queensland publication developed by the Queensland Disability Housing Coalition that provided information to assist families with housing and support.

Our interest in supported living as a real possibility was enhanced by the West Australian Government moves in 2008 to establish their Community Living initiative which created supported living opportunities for people with disability in that state. We read as widely as possible and talked to people involved, seeing it as a possible model for replication.

⁵ The Accommodation and Support Paper quotes Felce and Emerson (in Stancliffe & Lakin 2005:152) to report, accurately, that a number of jurisdictions have developed new campus-style accommodation. What is not acknowledged, however, is that the statement is taken from the introduction to a number of large scale evaluative studies undertaken by Felce and Emerson that conclude: “Across a range of measures of resource inputs (eg staffing ratios, buildings), non resource inputs (eg social environment) and process and service recipient outcomes (eg choice, activity, social networks, social integration, medical usage), residential campuses offered significantly poorer quality of life than dispersed housing schemes (Emerson:2005 in Stancliffe & Lakin:2005:168)”

Finally, in 2008, Family Advocacy joined with individuals and a number of advocacy organisations to establish In- Control Australia, an unfunded organisation committed to bringing about systemic policy change to enable individuals living with disability and their families to be able to direct their own support. Modelled on In-Control UK, In- Control Australia sought to provide a point of reference, information and awareness, dialogue and exchange, critical inquiry and leadership and influence on the issue of giving people with disability control over their publicly funded supports. As an active member of In Control, Family Advocacy was hosted four In- Control events, building the knowledge base of people with disability, families, service providers and government about self directed support. We showcased supported living as an example of self directed support at Parliament House to 200 people.

Ripening conditions

In February 2010, Family Advocacy used its journal to disseminate a concept paper on the Supported Living Fund to encourage active discussion in the sector. The paper was sent to the Minister, Peter Primrose, the Shadow Minister, Andrew Constance and the Chief Executive of Ageing Disability and Home Care, the responsible state government agency. All were keen to meet because our paper seemed to tick many of the boxes of their thinking.

Our paper argued that the NSW Disability service system is not effective in preventing crises and fostering family initiative. The fact that government provides accommodation for people with disability when families are in crisis and the person about to be homeless sends the wrong message across whole disability service system. We argued that demographic factors make it imperative for our system to change particularly in the context that most accommodation delivered with government resources are expensive and are not evidence based. We concluded that if the NSW Government wants to move from crisis intervention to prevention, from having sole responsibility for long term care and support to being a partner in care and support, it must encourage and support family initiative while families still have the capacity to partner.

We had the opportunity to meet a senior Treasury official and developed a business case for the Supported Living Fund.

We argued that a stream of government funding that would enable men and women with disability to move into a home of their own in a planned and timely way would create a shift to more evidence based approaches that lead to good outcomes for people with disability and are cost effective for government. In addition, such an approach would strengthen prevention and early intervention strategies in disability service provision to minimize the need for high cost intensive supports.

In April 2010, we began to work with The Change Agency to assist us with the campaign and to push us beyond the comfort zone of our usual advocacy strategies. We brought together a planning group to guide our path. Our intention was to include a combination of long term allies who knew our issues and the Family Advocacy perspective well, together with advocates from other sectors who had experience in social change and some connection to people with disability. Our invitees included a senior unionist, a health advocate, an anti poverty campaigner and a former political staffer. Whilst all showed interest, only the political staffer actually attended our planning day in June 2010. We engaged a final placement social work student to provide support for the campaign.

An important strategy that emerged from our planning day was the need for a coalition of organisations who would endorse the Supported Living Fund both to government and to their constituents. We recognized that endorsement by key advocacy and service provider organizations would build the base of people knowledgeable about and advocating for supported living as well as deepening the legitimacy of our claims to Government. We approached 17 organisations and 16 came on board in support of our campaign.

Take – off and waging the movement

In July 2010, we started to make contact with the 3,200 families on the Family Advocacy database, providing information about our campaign and urging them to become involved. We offered to assist families to write letters at various stages to the Premier, Opposition Leader, Minister and Shadow Minister. Since we did not want form letters that seemed easy to discard, we had lengthy conversations with several hundred family members, helping to turn their personal story into a powerful letter written in their voice and used a regular campaign update to keep everyone informed of responses sent to individual families. We also developed a campaign Facebook page to further spread our message and it quickly enabled two-way communication with a growing support base.

We used the endorsement from major disability organisations to demonstrate to the same targets that the concept of a Supported Living Fund had wide organisational as well as parental support and this helped us to get a second round of meetings with the Minister, Shadow Minister and Greens' spokesperson, Ian Cohen.

In September, Ian Cohen made a speech in Parliament endorsing the Supported Living Fund. Although the Greens were a minority party in the NSW Parliament, Ian's endorsement meant that the policy we were advocating was on the political agenda. We used this commitment to invite the Minister and Shadow Minister to a Political Candidate's Forum to inform the public about their real level of commitment. We reasoned that disability tends to be peripheral to mainstream issues in state or federal elections and so it was critical that we confirmed support prior to the election. We tightened our campaign 'ask' so that we could be clear about what we expected in relation to the Supported Living Fund. Consequently we indicated a commitment to the Supported Living Fund would involve:

- Providing new money

- Extending the target group to include families **not** in crisis

- Enabling people with disability to have a home of their own, using a combination of paid and unpaid/informal support

- Enabling families and people with disability to direct their own support

We made our demands clear in our letter of invitation to the Political Candidates' Forum and offered the politicians the opportunity to also talk about other policies they would take to the election. Our invitation was confident and bold. We did not chase diary secretaries to coordinate dates. We just made the decision, set the date and indicated, politely, that it was the place to be. Interestingly, the politicians seemed to dismiss the invitation for a while and did not respond. We had the confidence to believe that our meeting was capturing the agenda and that if one of them didn't come, that would be news too!

Ultimately, all three were very keen to participate and the date had to be changed to fit in with their pressing previous commitments out of Sydney.

The Political Candidates Forum was held on Monday 25 October 2010. On the previous Friday, we had an opinion piece published in the *Sydney Morning Herald* entitled 'Support for the living would save lives from despair'. We sent out media releases in an attempt to get media to cover the meeting but ultimately no media attended the event or reported on its commitments.

The Political Candidates' Forum was a great evening for the people present. We scored the politicians as they spoke using a scorecard based on the [Midwest Academy's](#) structured approach to 'accountability sessions'. This provided a light touch in what at the beginning was a tense mood. And ultimately, the Minister, Shadow Minister and Green's spokesperson all endorsed our four requirements and we felt a new era was upon us.

The long haul

The campaign analysis thus far has found Moyer's Movement Action Plan to be a useful framework. Moyer however describes the final stage as 'Majority public opinion' which does not yet feel like reality. As the campaign update on the morning after the Political Candidates' Forum reported:

"A verbal commitment is one thing...implementation is another. We will continue to work with both major parties in the lead up to the state election to bed down the next steps."

We needed to let the people whose involvement in the campaign had brought us this far that there was more work ahead. And we continue to work with government in an effort to ensure that which is implemented reflects the spirit of the concept of a Supported Living Fund and the dreams of its supporters.

What have we learnt?

Family Advocacy has learnt many lessons in securing the Supported Living Fund.

We learnt that it's about the long haul. A social change movement, grounded in fundamental values of justice, democracy and rights is only as strong as its grass roots support. Our recognition of the critical importance of winning the hearts and minds of families was pivotal if ultimately we were to change the minds and policies of political and bureaucratic decision makers.

We learnt that we could build a base through information sessions, teleconferences and workshops that helped families to envisage something different. Once we had 'created demand' we could use that demand to gain political commitments; and that when you offer assistance, families are happy to tell their stories in the hope of gaining an important commitment.

Finally, we learnt the value of concerted effort emanating from a campaign plan and strategy. Taking the time to think through the issues, bring together people to lend their ideas and their skills, write it down in a form that allows you to amend strategy in the light of tracked progress allowed us to stay focused to achieve our goals.