



Bronwyn Moloney started work in the late 70s at an institution which had just changed from a medical model to a residential model. Bronwyn has been fortunate to be involved in creating different living options for people with disabilities. She has particularly worked with people leaving institutions to return to the community, and families wanting something other than congregate care for their adult children with disability, knowing that group homes are not the answer.

Home Soon: Successfully transitioning from unsuitable accommodation to a better life

One of the greatest joys to me as a worker has been seeing someone take ownership over their home. It can be simple things like accompanying someone to go shopping for things for their new home, having them come to the door of their home to let me in, seeing someone sitting or lying relaxed in their living room or simply seeing someone with the freedom to access all the rooms and garden spaces in safety. It can also be seeing people grow into their new lives. This could be listening to music they enjoy, watching TV shows of their choice, having food they like in the fridge and pantry, having space for all their clothes and knick-knacks, putting their art and photos on the walls or having a pet to share their home with.

During my career I have been particularly interested and involved in assisting people described as having high and complex support needs in achieving their own home. I am talking about people who are very vulnerable due to dangerous behaviour, or because they are immobile and require assistance in every aspect of their day to day living, or who live with life-threatening health issues. I often had people say to me, 'this person will never be able to live in his or her home' but my experience has shown me this is not the case.

When I talk about home I am talking about a place that is dynamic and changes as we do over our lives. I'm talking about the many different places we get to call home throughout our lives as not many of us remain in our childhood home or in the first home we move into after leaving the parental nest. I have lived in different states, different countries and have shared my homes with different combinations of other people.

Some adults with disability remain living with their parents or other family members until death changes this. Other people who were institutionalised as children may in turn spend the remainder of their life in institutional settings such as group homes or aged care facilities. Living this way means they may never have had much they could call their own.

Living in group homes or nursing homes usually means a person has little say in where they live or with whom they live. They are also limited in their options for decision making, not only the more trivial day to day decisions of what to eat, wear, when to do things but also those bigger decisions about where to live, who they have to support them, what activities they want to do, with whom they want to spend time, and when they want to be left alone. This lifestyle also limits



opportunities to try new things, gain experience and learn from a variety of experiences (both positive and negative).

When thinking of people who require a lot of support, it is easy to say 'way too hard, we can't go there! Stick with what we've got even when it is bad, sad and lonely.' This thinking needs to be challenged and there is so much to gain when it is.

Creating something tailor-made is not always easy, but it **can** and **should** be an option. This is where the person with disability needs many 'believers' around them. One parent or one brother, sister, or committed worker will not be able to do this on their own. There must be a dedicated network of supports who will work collaboratively, intentionally and probably for a long time to ensure that the person with disability is afforded this right to have a home they can call their own. Strong leadership in organisations has been essential in supporting some of the people I have worked with to gather a network of committed people around them when there have been few or no people in their lives.

I have seen how having a home of their own has been so significant that it has not only been life changing but in some cases even life-saving. Ironically a lot of opposition to a person moving out of their family home or out of a disability group living situation is often related to concerns for a person's safety and well-being, but I have seen first-hand that it is actually the opposite. I have worked with adults with disability whose lives have been restrictive, abusive and life-wasting. I have known families who have felt deep sadness and at a loss to change this situation.

While the good news is a real home is possible, it is important we respect how big a change this can be for people. What I have witnessed is that a person with disability who has experienced no power, and has been abused perhaps for decades, is suddenly told 'this is your home, no one can tell you what to do now'. For a person with intellectual disability, and I am thinking specifically of a friend of mine, this is extremely confusing.

My friend Martin is one person who was helped to leave a large institution and move into a home of his own in the community. I have been involved with his journey for over 19 years, initially through a request to be on a 'circle of friends' to assist him with a very difficult transition to the community, but then over time he has formed a lasting friendship with myself and my extended family.

Martin totally relies on other people - family, friends, and paid support to provide ongoing support for him day to day and into the future. When Martin was assisted to move into a home on his own, he focussed on this total freedom of being able to assert his rights to do what he wanted after years of control and abuse.

Martin was abusive to all workers who tried to help him do things in the home, including things that would

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be in his best interest, such as personal cleanliness and wellbeing, safety, and household tasks such as cleaning, cooking, washing and so on.

Workers also found this transition difficult. They wanted to help Martin in his new roles as a homeowner, neighbour and community member, however the tendency to make decisions and take over tasks required in day to day living enraged Martin, who saw this as taking away his rights to do anything he wanted now. In Martin's case, his workers were used to seeing Martin's home as a 'workplace' not his home, and it still looked and felt a lot like an institution.

This was not helpful in terms of keeping him safe and healthy and in forming helpful relationships with others. There were many people, in his service and in his family and the community who were quick to say that this 'own home experience' was not the answer for Martin.

What emerged was a revolving door of workers passing through his home and crisis management by those trying to make this new, wonderful home ownership work. This has been a common pattern for people I have worked with, but there are safeguards we can put in place to support the person to remain in their own home.

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It is crucial that we assist people with disability to have more than just shelter and to create possibilities for residential structures to become 'homes'. It will not happen without changes to the way we provide support to people and as Martin's experience shows, having a roof over your head is not the end goal. Providing a house for a person with disability will not prevent loneliness and abuse.

Recruitment and selection of workers who are aware of their role in supporting a person to create a meaningful home and lifestyle is a key step. I encourage workers to get to know the person they are employed to work with, not just fulfil the tasks that are required to ensure health and safety. This process can be assisted by good documentation about the person's history, family, likes and dislikes, which has been compiled by family, friends and others who already know and appreciate them as an individual, not through service and medical/therapy reports!

It is also vital that workers learn to work in right relationship with the person with disability. One of the most difficult hurdles can be assisting the person to get used to an environment where they share the balance of control with the people who are supporting them. Traditionally, there has been a huge power imbalance and that model of support does not work. Behaviour change occurs when the person with disability is able to take back some power and control but is also safeguarded from neglect and abuse.

Martin continues to be a vulnerable person and it has not been an easy 19 years, but he has remained living on his own in a house he calls home. Martin and many of the other people I have known and worked with require people around them who can think differently from the traditional responses to 'managing' complex behaviours.

Finding a house can be what many see as the primary hurdle. People get very motivated to get the 'right house' and can put an incredible amount of time and energy into this. However, despite how suitable the home may look, it is just the first step of many in making a successful transition from unsuitable accommodation to a better life for the person with disability.

Fortunately for us in Queensland, we have advocacy and capacity building organisations who have shown substandard options do not have to be accepted, and have assisted people with disability, their families and friends to work towards models of support that can provide what we call a 'good life'

In 2002, a small group of people were brought together by SUFY (Speaking Up For You) and CRU to look at the development of a different model of support because the current service models, where the power resided with the organisation and not the person (and their family/friends), were putting people at great risk of living isolated and abusive lives. This particular model, which I have been fortunate enough to be part of, became Kalpana.

Kalpana became one of a small number of forward thinking organisations who recognised the need to return power and control to people with disabilities through embracing self-direction. Back then, returning control and choice to disempowered people was seen as a whole new way of thinking but now, with the NDIS, this opportunity is being offered to many more people. Nonetheless, it still will take dedication and collaboration to turn this opportunity for something better into reality.

Fortunately, bringing people along and making sure they understand the nuances of 'home' for the person is very possible and the outcomes are amazing for all who are involved. Walk into anyone's living environment and you get some indication of the person who lives there. Everyone can reflect on what home means to them and how different this is for them as an individual. This is no different for the person with disability, and their workers will have a role in making this a lived reality with (and not for) them.

The practical tasks of finding and furnishing a home can be achieved with proactive service providers, advocates, families, and circles of support. What is harder is putting in place the essential day to day support. Not only are there the constraints of funding, the bigger issue is really knowing what is going to work for a person who has not experienced living in their own home, which can take a while to suss out.

When I think back to when my own children left the safety and security of the childhood home, it was an emotional and busy time. The planning, the excitement, the packing of valued possessions, not to mention the practical things like gathering essential household items like furniture and cleaning items. These were far bigger jobs than any one young adult or parent could handle and time and time again it would be friends and family to the rescue. We all need help and support at times like these. Whether from my children, friends or people I have worked with, it is a wonderful feeling to be welcomed into a cherished home, and to be part of the supportive network around a person as they undertake the rite of passage of establishing their own home in their own way.



RESOURCES FOR INCLUSIVE EDUCATION & LIFE

Inclusive education can be a strong foundation for a life in community.

It is never too early to be talking about and starting to plan for when you grow up - a home, a job and a life in community.

CRU's Families for Inclusive Education Project has resources for parents of school aged children about creating a vision & how to pursue the inclusive path at school, with a focus on classroom learning, friendships & belonging, and the advocacy skills families need to maintain that path.

For more information visit our website at :-
<https://cru.org.au/families-for-inclusive-education/resources/>



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