

## Creating Homes: One Person at a Time.

The last edition of CRUCIAL Times explored what it takes to create a genuine home for people who live with disability. We looked past the securing of the house itself and reflected on how a home can be an important launch pad to a rich life in community. We thought this rich and vital topic of creating a home would benefit from further exploration and so in this edition we have focused on how we might assist people to achieve this 'one person at a time' without compromising the supports they might need to take up their role as head of their home. While there are new opportunities for people in Australia to achieve this goal there are still strong defaults to grouping people with disability without any dedicated exploration of what would best suit the person themselves. There can be an assumption that if people require assistance or company throughout the day and overnight that the only way to achieve that is by living with other people with disability and engaging paid staff. In this edition, our authors describe some different options and how families and paid workers can support this to happen. These articles also illustrate the role that friends and housemates can play in supporting the person to thrive in a home of their own.

A number of these articles have been gathered from other publications and are being republished in this edition. We have chosen these because we think they have important messages that have stood the test of time. We have republished an article by Patricia Fratangelo from the United States, written when she was Executive Director of Onondaga Community Living in Syracuse N.Y. While in that role, Pat supported many people with disabilities to share their homes with people who don't have disability. Pat has a wealth of knowledge and valuable insights on this topic of life sharing.

**A 'real' home is not solely one's dwelling place, but rather a key crucible in life that helps sustain & uphold much that is deeply personal, private & intimate about us...**

**...individuals should have the opportunity to explore & pursue all of the rich & diverse options for what home life can be, so that their eventual 'home' is as fully developed as it could be.**

**Dr Michael Kendrick**  
CRUCIAL Times 40



Deb Rouget and Cameron Skinner from Victoria have co-written an article about Cameron's experience of leaving his parents' home in regional Victoria and sharing his own home with flatmates in a regional town.

We have included a short extract from *The Shouted Goodbye* written by Jeremy Ward. His daughter Mena revelled in having her own place and Jeremy shares some of the strategies that made that possible despite limited funding at the time. Another parent, Sue Boyce has contributed a thoughtful article on assisting her

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daughter Jo to move into her own home. Sue's story is a great illustration of the thinking and planning that can be going on long before the person actually makes the move.

This blend of local, national and international articles, I think highlights that creating a home and lifestyle is a long lasting and universal topic. It does not change with state borders or changing funding programs. Those things may determine how you secure the house or even how you pay for some of your support. They can be critical when physical and financial access is an otherwise insurmountable barrier. However, once the shelter is secured, the things that most determine the quality of the life you live within your home are more likely to come from your level of choice and control; freedom and spontaneity; the presence of family and friends and just enough balance between risk and safety.

One of the recurring messages through these articles is that ensuring the support is sustainable and can grow and evolve with the person is critical and requires thoughtful work with the person and their supporters. Ensuring there are adequate safeguards and succession plans also needs to be paramount as we provide for people who are vulnerable and may need to depend on others. Abuse and neglect of people with disabilities can and does happen, and we have seen this recently in media reports. For people and their families this is the stuff of nightmares and while the natural instinct may be to hold people close to protect them, our authors talk about safety coming from a life in community where the person is known, visible and valued.

Bronwyn Moloney has had the privilege of walking with many people as they have had the opportunity to venture into a home of their own. Bronwyn has worked in the sector for a number of decades and has witnessed the transformation of people's lives as they have been given the opportunity to move from unsuitable accommodation to their own place. Bronwyn reinforces that it is never too late to work for something better.

And finally, to assist us to explore how some of these options may be possible, we have included an article by Bronia Holyoak who describes a pilot project, Individual Living Options that started in Western Australia and is now being



gradually offered as part of the National Disability Insurance Scheme. This funding mechanism provides flexibility to accommodate support arrangements that don't fit neatly into typical support categories. The article also illustrates the ability of people to influence policy which is an important message as we try to change the opportunities for people with disability to live in homes of their own.

**Margaret Rodgers**  
Chief Executive Officer



The **National Alliance of Capacity Building Organisations** (NACBO) is a national network of values-based, capacity building organisations.

NACBO has a new statement featuring 23 stories of people living in homes of their own.

***Meaning of Home***  
***best practice for people with disability***  
***in home & community living***



Read NACBO's statement at  
[nacbo.org.au](http://nacbo.org.au)



## Home

Home is a central part of your community. At CRU we often speak of belonging to our community, and the ideas of building community and intentional communities, and the L'Arche community is an example of this. Home conjures many different meanings for each of us, and we all need the freedom to explore and express what that meaning is.

I see my home as one of the communities I have created and belong to. I live with my husband and a friend and we have lived together in this arrangement for over 20 years. For half of that time my husband's father has also lived on the same property in a daddy flat. He's not a granny so we can't really call it a granny flat. We share a meal each Sunday evening and have other family members join us.

Home is my sanctuary and a place of security, both physically and emotionally. It is a place to sleep, to practise my spirituality, to store my personal belongings, somewhere to create and share meals with family and friends. It's a place where I feel love and safety and can also freely express my vulnerabilities.

This may be the same for most of us but not all of us. While I have a real sense that my home is contained within a community, so often we see fragmented variations of this connection for people with disabilities. Without connection with others in community, what keeps people safe?

We have seen most recently that for people with disabilities even an ordinary house can become an institution - a place that becomes their everything, yet is completely outside their control. Services effectively taking over their home, and sending strangers in to provide support.

As a sister, I have recently supported my sister to reclaim her home. She is supported to live in her home, a private rental townhouse, each day and evening. She lived for many years with her best friend and together they shared their lives, as well as morning and evening supports. Her friend moved out recently and it has been an opportunity to reflect on what a home is for my sister and to support her to create that again.

It is the same for her as it is me. A place where she feels safe, can store and enjoy her favourite possessions, and be vulnerable.

She and I are the only people who have a key to her home. She chooses who comes into her home. She does her own shopping, with support, not the other way round. She goes to her bedroom to sleep when she is ready not when the worker's awake shift finishes. These little things that mean so much can be taken away with little thought.

It is our role as supporters to make sure they are not, especially with changing circumstances or unexpected events like COVID-19 which can unintentionally threaten the ordinariness of home.



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**Patricia Fratangelo** was the Executive Director of Onondaga Community Living in Syracuse, New York until her retirement in 2016. She had worked in the field of developmental disabilities for decades, beginning as a direct care worker. Her book *One Person at a Time: How one agency changed from group to individualised services for people with disabilities* was written with Marjorie Olney and Sue Lehr in 2001. Patricia has written previously for CRUCIAL Times in 2004 on 'Listening Differently'.

This article was first published in *TASH Connections*, vol.32, Issue 9/10, September/October (2006), Pages 7 to 8.

## Sharing Lives

*"All men are caught in an inescapable network of mutuality, tied in a single garment of destiny. What ever affects one directly affects all indirectly. I can never be what I ought to be until you are what you ought to be, and you can never be what you ought to be until I am what I ought to be."*

*Martin Luther King*

Living and sharing life together is part of what makes each of us whole. Learning from, and taking care of another person through the triumphs and struggles of life is part of what helps to bind us together as we grow in relationships with one another. Life sharing is a term that is arising in our field and it is time to now begin to realise what this can mean for a person with a disability. People with disabilities have typically not had the opportunity to choose their home or lifestyle and often times have been placed into a living arrangement with other people who they do not know, nor do they care to live with. The system has traditionally offered only what was available, with little or no opportunity for another type of arrangement that is out of the norm.

As we begin to listen differently to what people actually want, we find that often times those coming for services do not want what has been normally offered. People are beginning to ask more and more for ordinary and regular lives in partnership with other community members. It is not that the person miraculously needs less support and that the human service system is not necessary, the support just needs to be delivered in a very different manner, more creatively with community citizens in partnership in integral roles with those you are paid to support. It is this combination of supports and services that will enable the person to live more effectively and contently in the long haul.

*This necessity of becoming a learner as well as a teacher has enabled the life sharing partners to grow together.*

Several years ago I was planning for a man who was not happy with his current life. He was living with a group of people that he called 'sick' and he was supported by 24 hour staffing that he did not like.

As we began to plan with him more deeply, we knew that what we were currently providing for him was not working. We needed to find another way. What we learned from him is that he did much better when he was with typical community people and that he had no desire to live with any person who he deemed to be 'sick'. Because he was so distraught living within the group setting, staff often times needed to intervene, setting him up to be at odds with staff. As we began to walk further down this path of understanding, it was clear that he would need a lot of support but that it needed to be delivered in an entirely different manner. He wanted a more normal and ordinary life. He wanted to share his home and his life with people that he valued and who would value him in return. He wanted to be seen as a regular guy, to live with a regular guy and to do the things that regular guys do. He wanted what each of us wants. He deserved to live a gratifying life co-connected with others who he could share in mutual enjoyment with. We needed to open our minds and our hearts to another way of providing support to him. This led us down a different path as we began to recognise community people that he valued as regular guys who could enter into honest and valued relationships with this man.

*The more we see those with disabilities as dissimilar from those in society, the farther away their service and lifestyle will be from that of the general population.*

What this man was teaching us was that there are many unique ways of providing services. He was pushing us towards a new path for how services could be delivered, helping us to realise our weakness; the facilitation of connections of the people we serve with typical community members in honest and productive relationships based upon each of their personal interests and aspirations. We were also caught up in delivering only what we had available and not necessarily what someone needed. He was helping us to fully realise the deep fundamental needs that were being neglected in the service delivery of the past, the profound importance of honest and fulfilling relationships between people. Our new focus was how to support a person to join in partnership with members from his or her community in honest and valuing ways.

The first of the essential tenets that we all must believe in, is that every person we support has an inner spirit core, although it may have never been recognised previously, it lies within. It is the task of each of us to discover what that inner core is all about and where that contribution may lie, even if it is not readily apparent. If we are successful with this then we will see the beauty of each person, allowing us to assist them in finding others who can enjoy that exquisiteness while working to nurture and enhance the magnificence that the person shares.

As we continued down the path of learning more about this man, we found many interests that he had while growing up, that were now lost with

his life within the system. We also realised more and more the importance of many of these experiences for this man. He truly valued working men and saw himself as a working man, not a client of the system. Although people say he cannot read, he could identify all construction trucks by company names. We knew he would not succeed in another traditionally staffed arrangement, so we looked to the community to find a man out there who could share this man's love of work and construction. Our goal was to look for a man who could enter into a potential life sharing role, sharing this man's dreams, his home and his life in a meaningful way. Such a man was found and they have been sharing their lives together now for over 12 years.

As I look back on the many people who have entered into the life sharing role with a person with a disability, I have found that they originally saw themselves as a teacher. Various people have entered into this role believing that they could give something to a person. They could teach, they could support, and they could model. But as they take on the role of a true life sharing companion, living life day to day alongside of someone (who was at first seen to be the person in need) they begin to realise that as a life sharing companion they are also being taught. They are being taught about their own humanity and their own humility; their personal failings and inhibitions, their capacities and weaknesses. As people grow in this role as a sharer of life and all that comes with it, they begin to realise the depth of the experience that they entered into. This necessity of becoming a learner as well as a teacher has enabled the life sharing partners to grow together. I have spoken with many of the community people, who have entered into life sharing roles with someone with a disability, and it seems when they meet with this awareness then life becomes more settled. The inner development of both people is now the work, as together they continue to share their lives with one another. No one is the burden to the other. I have seen this deep personal attachment; mutual growth and awareness go on between people for years upon years as they surmount the triumphs and struggles that each new day gives to them.

*"The healthy social life is found when in the mirror of each human soul the whole community finds its reflection and when in the community the strength of each one is living."*

*Rudolf Steiner*

A critical tenet to enable those with and without disabilities to share life and enter into honest and caring relationships with one another is that the service system must allow the creation of conditions that permit such meaningful and important relationships to unfold. The more we see those with disabilities as dissimilar from those in society, the farther away their service and lifestyle will be from that of the general population. It is when we begin to understand fundamentally the needs of all people to be in valued, honest and ordinary relationships with others that the possibility of community members sharing life in straightforward and personally rewarding ways will occur. We must give up the mindset of the service system being all knowledgeable and the inimitable protector over people who are deemed to be different. We need to listen more carefully to those who come

*She realises now that her perceived role as this woman's protector and teacher has changed, as she learns more and more each day with the person she thought could not teach her in return*

to us for support and we need to support them in becoming involved in valued and honoured roles with others. We need to support the development of ordinary relationships between those with and without disabilities. We need to recognise the growing relationships for what they are, friends and companions and not lump them into a human service category. If we can begin to do this, we will begin to experience the wonder and excitement of people who are choosing to share their lives with one another in some very honest and real ways.

I was talking with a woman who is the non disabled housemate to someone that we support. She lives there freely as a companion and friend and is not in any paid or volunteer role. These two women have lived together over the last few years. Her housemate had been institutionalised and always supported through the system in very traditional services. Although her housemate is classified as severely intellectually disabled, this woman has come to know her as a very intelligent peer. They have a wonderful home and work together to share the responsibilities of not only their home but also their interdependent lives. As I was on the phone with her the other day, I realised that her role had shifted from teacher to learner. She tells me of the times they share in the gardening that they do and how much they both enjoy it. She also shared with me the times that they have had in growing together through times of struggle. She realises now that her perceived role as this woman's protector and teacher has changed, as she learns more and more each day with the person she thought could not teach her in return. As she has gotten to know her life sharing partner more fully she has learned much about her own self along the way. She remarked that she felt she was a part of such a wonderful arrangement, that her housemate was

*Sharing a life with someone you value and respect should not be by chance or luck, it should be the norm.*

such a lovely person and that she felt so fortunate to have been brought together.

Stories like these should not be the exception. We had a state official come to visit us recently and she met these two particular women. When this state official came back to talk with me she said, 'She is a very lucky woman.' Sharing a life with someone you value and respect should not be by chance or luck, it should be the norm. Just because you have a disability does not mean that you do not aspire to all the ordinary lifestyles and experiences that each of us take for granted. How did we get so far from normal and ordinary lives and relationships for people with disabilities?

We need to look at the changing role of the human service system as we begin to facilitate and support more honest and valued roles between the people we are paid to support and common community citizens. It is all very possible, we just need to change our mindsets and our hearts, and find the inner core of each person that we support.



**Jo and Justin answered the question themselves of who would share Jo's home.**



**Sue Boyce** is a former Queensland senator and journalist. She's currently Chair of her family's company, Everhard Industries. She has three adult children and five extremely gorgeous granddaughters. Her younger daughter, Joanna, has Down syndrome. Jo and Sue are still working on what self-managing under the NDIS actually looks like.

## How Jo Moved Out

Joanna is a daughter, a sister and sister-in-law, and more interestingly, in her view, an aunt. Most exciting of all, she recently became a WIFE. She's 36 and has Down syndrome.

I've always been very jealous of people who say their child with a disability decided to move out when the older siblings did. Jo has a big brother and sister, but she loathes most change and moving out was never on her agenda.

Plus Jo shared her time—every two weeks or so—between my house and her father's. In retrospect, I realised that this might have been one of the reasons she didn't feel the need to move out—we didn't have time to become as 'irritating' as the parents of young adults are well-known to be.

I first seriously broached the topic of moving out with her when she was 25. One of the biggest problems I encountered was trying to explain the abstract. Jo wanted to know exactly which house with exactly which friends whilst I was talking about 'a' house and as-yet-unknown friends.

So moving out at 25 was an abject failure, but I kept working on her cooking and organising skills. And I was determined when she turned 30 that we were going to DO IT.

My main motivation for wanting Jo to move out was the stories I had heard over the years of people with an intellectual disability left bereft of not only family, but community, when their aged parent died. I still can't forget the horror story of a woman who left her home to a service provider in her Will on the proviso that her 50 plus year old daughter with Down syndrome would continue to live in the house with others. Within two years, the house had been sold and the daughter who had lived alone with her mother within a friendly community she knew very well was moved into a new group home in a new city four hours drive away. Unsurprisingly she developed "behaviour problems"—for which she was medicated! I know that in terms of disability horror stories this is mild, but it's still a horror story to me.

I spent a lot of time in the 1990s looking at how the quality of Jo's life could be protected long-term and what a 'good life' with as much independence as possible looked like. I was initially very motivated by the writings of a Canadian parent and academic Al Etmanski and his early book *A Good Life*. He set up an organisation called Plan Institute. Some have the view that the NDIS funding has superseded the need for such organisations. I don't agree.

We were very lucky that my mother left enough money for a Trust for Jo to buy a house. So when Jo turned 30, I sought approval from Centrelink to set up a Special Disability Trust (SDT) for her. Special Disability Trusts are still one



of Centrelink's best-kept secrets but the information is on the Department of Social Services website. There are a range of benefits including that an SDT can own a home and have about \$680,000 in assets before it affects the beneficiary's eligibility for the pension etc. The SDT can only be used for care and accommodation costs related to the disability, so it could pay for someone to accompany her on a holiday but not her personal costs. Jo already had a discretionary Trust, so I've kept that going.

I had a long list of criteria for Jo's home: not too far from my place, low maintenance, secure, layout that meant a 'supervisor' could live there without being on top of Jo and the 'friend/s', easy access to bus and shops. Jo was fairly reluctant but nevertheless we went house-hunting, so I could turn the abstract 'house' into something she could see. I think we drove real estate agents nuts taking huge amounts of time to 'play act' how she would do things if she lived in each house or unit. Jo became more accepting as she saw how it would play out.

The almost-perfect house became available near me—it's bigger than Jo needed but I thought that was

the least-worst problem we could have. It's solid concrete with very little garden, good security and a downstairs bedroom and bathroom for a housemate.

I'd remembered advice from Dr Tony Attwood years earlier and all the appliances we bought were the same or similar to those she'd been used to using at my place. Jo chose the furniture, with lots of price and colour guidance.

In the meantime I talked to dozens of parents and organisations that shared my values such as CRU, Bespoke Lifestyles, and Community Living Association (CLA).

Jo and I spent six months practising living at the house one or two nights a week, but I still hadn't solved the problem of the "friend" who would occupy the second upstairs bedroom, when Jo solved it herself by telling me her long-term boyfriend Justin would like to move in with her.

So in February 2017, Jo (along with Justin) was finally installed full-time in her own home just down the road from me.

Initially, it was just the two of them with Justin's support worker twice a week but it became obvious pretty quickly that they needed help on a more regular basis with the small things, like the kettle isn't working, and the slightly bigger things, like it's 8pm and we haven't thought about dinner.

There was a lot of parent visiting from me and Justin's parents during that time. To find that extra on-site support, we used a concept from the CLA for 'housemates' who live rent-free in exchange for a certain level of help.

It took a while and several false starts until a friend of a friend expressed interest. The arrangement suited her perfectly because her adult son was very keen to live on his own and this was an affordable way for her to achieve that.

We developed a written agreement with her, based on a template provided

by CLA, which we review annually to see everyone is still happy. She provides evidence of her Blue Card every year and I have worker's compensation and insurance cover for her being there.

Kelly is contracted to be at the house overnight unless she gives us notice, to prepare dinner once a week and some other ad hoc help. She contributes to the cost of utilities.

At first we had some issues with Jo and Justin treating Kelly as the full-time taxi service but she's good at saying "No" and does some driving for them when she has the time. Kelly comes upstairs to use the kitchen and laundry, sometimes reminds them about their jobs, has dinner with them at least once a week, watches some footy matches and helps them choose when they've double or treble-booked themselves. She gets asked about the small...and big things, but they also live separate lives.

In addition to the written agreement, I developed a plain English 'code for the house' so they respected each other's privacy.

Meal prep has been an area that needed some creative thinking. If they prepared their own meals, it would take from the minute they arrived home from work until dinnertime...with supervision needed around cooking times. Instead they currently work with the support worker one day a week to prepare home-cooked meals for two or three nights, Kelly cooks one night a week and they use a meal delivery service for the rest of the week.

Day to day, they are going brilliantly but the COVID shutdown demonstrated how vulnerable they were if the routines changed. Setting them up for Zoom meetings and thinking of things for them to do when work and all sport were cancelled took a lot more parental involvement and organisation.

This has been a great start but there is more to do. The next step I see is finding a person to take over the organisational and financial administration of their home and their activities. Currently the administrative side of having a cleaner, gardener, support workers, house maintenance, travel, bills paid are handled by me and Justin's parents. I'm keen now to explore how these can still be very high quality but not so dependent on us.

### **HOMESHARE – CODE FOR THE HOUSE**

Jo and Justin are very pleased to have KellyB living in their house but they are worried about a few things and they think KellyB might be too.

- KellyB will not go into Jo and Justin's rooms unless they ask her.
- Jo and Justin will not go into KellyB's room unless she asks them.
- KellyB will not talk to other people about Jo's and Justin's private business, unless she thinks they are doing something dangerous. If she thinks they are doing something dangerous, she will tell a parent.
- Jo and Justin will not talk to other people about KellyB's private business.
- KellyB will not tell Jo and Justin what to do, unless they ask for help.
- Jo and Justin will not tell KellyB what to do.
- If Jo and Justin do not like something that KellyB is doing, they will talk to her about it. If that doesn't fix it, they will talk to a parent.
- If KellyB does not like something that Jo and Justin are doing, she will talk to them about it. If that doesn't fix it, she will talk to a parent.
- Jo and Justin will not ask KellyB to do their jobs (dishwasher, bins, laundry and so on) for them. If they need help, they can ask KellyB to show them what to do or to help them decide who to ask.
- KellyB will not ask Jo and Justin to do her jobs for her.



**Cameron Skinner** lives in Warragul, Victoria. He is a receptionist for the Jeremiah Business Group, lives in his own home and believes in the importance of giving back to community through volunteering and sharing.

**Deb Rouget** has been involved in the lives of people with a disability and families for nearly 30 years.

She has been the Chief Executive Officer of Belonging Matters since its inception in 2003. Belonging Matters is an education, capacity building and advisory service in Melbourne focused on assisting individuals with disabilities and their families to imagine and pursue lifestyles that are authentically enriched with community and belonging.

This article was first published in *Parity*, vol.31 / October (2018), pages 61-63.

## A Home of My Own

### Deb Rouget

When I first met Cameron in 2003, he was not in a great place. He was very lonely and isolated and had very few roles. However, Cameron's vision for his life was quite clear and quite typical. He wanted to move out of home and get a job! However, because of his mental health needs, intellectual disability and Cerebral Palsy, the system had a very narrow view of his possible life path. It was restricted to day programs and potentially group home living. The future seemed bleak but with a belief in Cameron's potential and a vision for a typical and inclusive life, we began to craft a very different version of the future!

### Cameron Skinner

Prior to 2004, I was living in Neerim South with my parents. I was isolated and lonely spending most days by myself. Mum and Dad built a small unit on their farm where I lived. I got sick and moved back into the house with Mum and Dad. After a while my health improved a bit and Mum and Dad asked me if I would like to move out of home. We had a meeting with Deb Rouget from Belonging Matters.

I told Deb about what I wanted to do. I really wanted a job and to move to Warragul because there was nothing to do in Neerim South. I also spoke about the things I liked to do.

We did some planning and applied to get funding. I didn't think I would get the funding but I did. This was great! We then looked for a house in Warragul and looked for a housemate. When I first moved into my own place it was a bit weird as I had never really been away from Mum and Dad before. It took me a while to settle in but I got used to it. I love living in Warragul because everything is close. I can walk to shops, cafes and the movies.



Since moving out of home I have rented three different houses. I had to move as the landlord needed or sold the house. One year after I moved into my first home, Denise my support worker helped me to get a part time job as a receptionist. Work has been great. I get paid and I have grown as a human being. I get on well with my workmates and have made lots of friends at work. My boss Gerrard is great. I have met some of his friends and went away to watch the cricket with them.

I have had a few housemates over the years. Caroline moved out and Brian and Lincoln both got married. I still see them and we spend time visiting each other or catching up down the street. It was important to me that I got on well with my housemates. They needed to be smart, have a good sense of humour and like spending time together. Often, we would kick the footy, go to the movies or share a meal.

If I felt down I could talk to them. I didn't want to live with someone who was demanding or pushy. My housemates helped me learn things. For example, cooking, doing the chores and making my bed. They got free rent and we split the bills down the middle. My last housemate didn't work out so well. At the moment, I'm living by myself!

My neighbours have been important. Sometimes I have helped with the street working bee. I don't really like gardening but it's good to help out trimming other people's hedges. Fay and Ron say I'm the best neighbour they have ever had! Sally and Pete were also my neighbours. They have moved but I still see them down the street. They reckon I'm a legend!

Having my own place is great because I can do what I want. I have come a long way and it has given me independence. I have learnt how to run my house, pay the bills and look after myself. I love it. I'm so happy and content with my life. I wouldn't want to change a thing. I've got the best life!

### Deb Rouget

Home is not merely a roof over one's head. It is often our sanctuary and it's very personal and private. Yet, often people with intellectual and developmental disabilities are predominantly marginalised and socially excluded and do not experience the same rights and opportunities as other citizens.<sup>1</sup>

The report *Shut Out*, 2009 states that 'Once shut in, many people with disabilities now find themselves shut out. People with disabilities may be present in our community, but too few are part of it. Many live desperate and lonely lives of exclusion and isolation'.<sup>2</sup> Although large institutions have largely closed, the current group home models offered to people with intellectual disabilities still congregate and separate people from their communities. Such models offer little choice to people as to where or with whom they would like to live with, are characterised by paid staff, established routines and ownership resides with government or non-government organisations with no guarantee of continuity.<sup>3, 4</sup>

To explore the learnings from Cameron's story I have used the themes and attributes of the Individualised Supported Living Framework.<sup>5</sup> This framework was a three-stage research project aimed at examining the 'characteristics and outcomes achieved when adults with intellectual and developmental disabilities were provided with necessary support to enable them to live in their own homes'.

### Leadership

The initial impetus for Cameron to move into his own home came in 2001 when his mum, Maggie was invited to a presentation hosted by the Department of Health and Human Services in Gippsland, Victoria. Dr Michael Kendrick, a parent and myself spoke about personalised supports, self and family directed supports and social inclusion.

'This is a day I will never forget because it resulted in the most significant change in my thinking, which was to result in a huge transformation in Cameron's life. They told us stories about people with disability getting a more meaningful life and following typical pathways. We learned about young people getting jobs that they liked and enjoyed doing. Planning to move into their own homes and follow their interests...

On that day I learned that it was possible, to turn your dreams into reality. With planning and vision

Cameron could have a good life. This was the beginning of a very exciting, and at times stressful period for my family... Shortly after this meeting I invited Deb Rouget to come and talk to us as a family. We sat around our kitchen table and shared what we thought were the possibilities for Cam. I was thinking an option would be to share a house with another person with a disability. Deb helped us identify some of the pitfalls that this type of arrangement could have on Cameron, looking at the pros and cons. We then explored options that Deb suggested that could be possible for Cam and she started helping us to think beyond what our previous blinkered vision of his future'.<sup>6</sup>

By being exposed to other innovative options, leadership examples and having access to capacity enhancing support, Cameron and his family were given permission to dream and create something that was uniquely Cameron and typical of what most home leavers experience. In 2004, we established a clear vision which has anchored Cameron's life in his own home and community.

The significance of clear vision, sharing examples and leadership should not be underestimated. It is the spark and the glue that can make things happen and avoid a life of homelessness and dependence on traditional models. 'Prior to this time, we had wrongly pigeonholed Cam into something that he did not want to be — a dependent person, a client, a service user, an unemployed person. Now he is an employee, a housemate, a tenant, taxpayer, consumer, friend, colleague and much, much more'.<sup>7</sup> Cameron, Maggie and Greg now provide leadership to others through sharing their story.

## My Home

Cameron's home is in a typical neighbourhood and typical street. If you were to ask neighbours 'who lives over the road' they would say, 'That's Cameron's house'! Cameron's home reflects his personality — Collingwood picture adorn the walls, there's a big screen TV for Foxtel and up until recently a home for his much beloved dog Monte. The rituals and routines are uniquely Cameron's. Like all young people when first moving out of the family home he had to learn skills and set up his own routines. Living with a housemate made this possible. Interestingly, although Cameron had support from a housemate, there wasn't a 'staff' room, rosters on the wall, sprinkler systems, shift change overs, a white bus in the drive way etc. His home is not a workplace or owned by a service — the lease is in Cameron's name. Thus, he has secure tenure even when housemates leave.

## One Person at a Time

Cameron's home has been developed around his aspirations and needs. He wanted to live in his own home and move closer to employment opportunities. As with many parents, originally Maggie and Greg thought Cameron should live with another person with a disability. During discussion, they identified the difficulties and compromises that might have been necessary if Cameron was to live with another person with a disability. As Greg suggested in the video *Home and Belonging* '...the main reason why we wanted Cameron to have a housemate who did not have a disability was the fact that it would be who would be supporting who...We wanted it to be Cameron's house, and for him to be able to learn from a housemate....'<sup>8</sup>

## Planning Focuses on the Person

Focusing planning on Cameron as an individual, not as a person with a disability was central to the process. The planning and strategy were prioritised into five key areas: Cam would live in his own home close to work; have a housemate for support; employ a support worker who could assist him to find paid employment; initiate a Circle of Support and develop social opportunities in his local community.<sup>9</sup> 'We worked through the priorities and...Cameron moved into his own place in June 2004'.<sup>10</sup>

## Control

Cameron and the people closest to him have control over his life, rather than an agency or service. Although Cameron needs some support and guidance, he determines where he lives, who he lives with, the decor, his routines, what he does in his spare time and all other aspects of daily living. He also chooses and directs his own support workers. This was possible by choosing to self-direct Cameron's funding package. 'As parents, this process felt that we were taking charge with Cameron and that it was his dreams and hopes that were the driving force. We all felt empowered, particularly Cameron'.<sup>11</sup>

*Cameron's home reflects his personality.  
The rituals and routines are uniquely Cameron's.*

## Support

An important part of Cameron's life, like all people, is to have support. A lot of Cameron's supports these days are naturally occurring as a result of increasing his roles in the community, for example, neighbour, employee, friend and community member. Cameron's housemates receive free rent in lieu of support. His housemates have assisted Cameron to learn all the aspects of living in his own home. This enabled a much more natural and equal relationship, rather than having high degrees of paid support.

Through Cameron's Individualised Support Package (ISP) and a self-directed funding arrangement, support workers have been recruited for specific roles over the years. Denise, for example was specifically recruited to assist Cameron to find paid employment. Given Cameron loves people, she was able to secure a job as a receptionist at a local business. Her role was then to focus on building Cameron's skills in the role in a very personalised manner. Over time this was replaced with naturally occurring supports in the workplace.

At the moment Cameron is not living with a housemate however, they have been a vital and crucial component of Cameron learning to manage his own home. He also receives a few hours support each week from Steve, his support worker who teaches him new recipes and helps with cleaning. Cameron also employs a gardener to do the lawns and garden. Through a self-directed funding arrangement, Cameron together with his family are able to choose and direct support workers. This has also been crucial as it has enabled the right match in support worker in regard to task and for his personality.

## Thriving

Cameron has thrived over the years because he has a typical and inclusive living arrangement that has been specifically designed and tailored to his needs. As he states above 'I'm so happy, I'm so content with my own life — I wouldn't change a thing'. This is a long way from the isolated and lonely person I met in 2003. Cameron now has many valued roles in the community. He is a tenant, neighbour, employee, volunteer, friend, housemate, sports fan and customer. He is also a well-known and respected community identity. Through these roles Cameron has had many opportunities for growth and development such as learning the roles and responsibilities of living in your own home, solving problems, getting to know new people, volunteering at the local market, being a good neighbour and friend. His role as a receptionist has taught him many nuanced skills such as doing the banking, greeting business people, administration duties, answering phones, time management, data entry and going to the post office.

**'...the main reason why we wanted Cameron to have a housemate who did not have a disability was the fact that it would be who would be supporting who... We wanted it to be Cameron's house, and for him to be able to learn from a housemate....'**

## Social Inclusion

Moving from his parents' small farm to Warragul has made a huge difference to Cameron's community inclusion and contribution. He has strong relationships with his work mates and has been away to watch the cricket interstate with his boss! His neighbours, Fay and Ron say he's the best neighbour they have ever had! Cameron has volunteered at the farmers market and at neighbourhood working bees. He can walk to the shops and knows everyone in town! As seen in the video *The Receptionist*<sup>12</sup> he will be walking down the street and someone will greet him with a handshake or smile and call him a legend! His previous housemates have a lasting bond with Cameron. They visit each other and Cameron enjoys spending time with Brian's children. Although Lincoln has moved to Melbourne, he catches up with Cameron when he's in town!

## Summary

Cameron's story has many lessons about assisting people to develop a much deeper sense of home rather than having merely a roof over one's head or being 'accommodated'. Home was developed intentionally with Cameron as a unique individual — not only in regard to his 'home life' but in relation to his support, connection to community, economic contribution and life purpose. If all of these aspects had not been adequately developed, Cameron could have been at risk of continued isolation, dependence, poverty and loneliness within his own home!

## Endnotes

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6. Skinner M 2010, Thinking About More than Accommodation, *Belonging Matters*, Issue 3, pp. 10–11, Melbourne.
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9. Skinner M 2010, op cit.
10. Ibid, p. 11.
11. Ibid p. 10.
12. <https://www.youtube.com/watch?v=vR8wJQfSGxU>



**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

***What I have learnt is that it takes a lot more than just bricks and mortar to make a place a home. It takes a lot of time, a lot of intentional thought and action and good people who want the lives of people with disability to resemble that of others who thrive from having a place to call their own.***

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.

What I have learnt is that it takes a lot more than just bricks and mortar to make a place a home. It takes a lot of time, a lot of intentional thought and action and good people who want the lives of people with disability to resemble that of others who thrive from having a place to call their own.

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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**Jeremy Ward** is a parent whose eldest daughter, Mena, lived with disability and required support to live in her own home, which she did successfully for over 10 years. Jeremy's older sister also lived with a significant disability all her life. He has many years experience in disability advocacy, in the law as it relates to people with disabilities, and in assisting families to plan for the future. *The Shouted Goodbye*, Jeremy's account of Mena's life, was published in 2015.

In this edited excerpt from his book, we see how Mena's parents, Jeremy and Margaret, supported her to live in her own home.

## The Shouted Goodbye (excerpts)

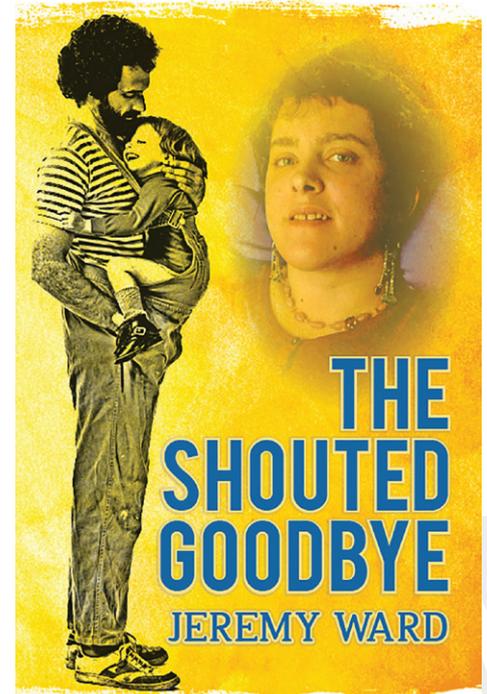
When Mena was fourteen, we had an opportunity to buy a small two-bedroom, low-set house near us in Corinda which, with simple modifications, we knew would work for her. We had ten years, or such was our plan. It turned out not to be Mena's plan. Not long after she left school she announced she was moving out of our family home on her nineteenth birthday. It might be that we contributed to her sense of urgency. After we bought the nearby house we often took Mena for walks to see it, or drove past on our way home from school, telling her that one day it would be hers to live in.

Mena moved into her new home on her nineteenth birthday. The move was successful, but far from ideal, and we decided to accept an offer from the department of housing for Mena to move into public housing. She moved into her department of housing cottage less than two years after her initial move from the family home. We had specifically bought the first house as a future home for Mena, yet it had been occupied by her for less than two years.

Margaret claims she began thinking about independent living for Mena when Mena was eighteen months old. Perhaps it was her architectural training and love of housing. I certainly don't remember those conversations. I was too consumed by the everyday reality of parenthood to be thinking that far ahead. But once we began serious planning, independent living for Mena was certainly a priority.

Mena required support twenty-four hours a day, seven days a week. Her level of disability required her to have someone with her at all times, including overnight. They did not need to be paid support workers, and certainly did not need formal training, but Mena's lack of capacity, both physical and cognitive, meant she was very vulnerable in a number of ways. Mena was a delight to spend time with, had a wicked sense of humour, was friendly and affable and always positive. She had highly attuned emotional intelligence. Yet the reality was that she could not roll over in bed, get out of bed, get into her wheelchair, bathe, toilet or dress

*Margaret and I saw the need to fill Mena's life with unpaid support as a welcome challenge, an exciting opportunity, an important safeguard, rather than an insurmountable obstacle.*



herself, prepare food or undertake any tasks other than very basic ones, without support. She had a poor sense of danger and a lack of discernment when it came to strangers. In her house by herself, she would have no way of saving herself from a fire, especially if in bed.

Margaret and I never wanted Mena to be supported only by paid workers, even if we'd had sufficient government funding or private funds to make that possible. Our vision, that Mena would be a valued citizen in her community, could never be realised if she was surrounded only by paid people. Nor would she be safe in the long term if she had only paid workers in her life. Paid support workers come and go, the quality varies. That is not to say that they have no commitment or that they cannot become close friends. Many did in Mena's case, some remaining in her life long after they moved on from their paid role. But while working for Mena they were, first and foremost, in a paid role. They were not there primarily because of a deep, personal commitment.

Margaret and I saw the need to fill Mena's life with unpaid support as a welcome challenge, an exciting opportunity, an important safeguard, rather than an insurmountable obstacle. When it came to working out how to build the network of unpaid support, it was the coordinator of our local association who came up with the primary strategy.

The plan was to generate a guest list of approximately twenty-five people who would dine with Mena one evening a month. A meal would be prepared and each dinner guest would be with Mena alone for two hours dining with her and helping her with her meal. We talked to Mena's paid workers to clarify the dinner guest's role. We set out some rules: the dinner guest could do no wrong; Mena's workers were to treat guests as they would any guest invited to their own homes.

Margaret did all the work of setting up the roster. She made contact with each person by phone, discussed the idea and what was being asked of them and planned a schedule, initially for three months. She mailed each person a copy of the schedule, with their agreed dates highlighted. Guests could also see who else was on the list and when they were scheduled, in case they wanted to swap. Seeing who was involved allowed people to feel part of something creative, something exciting. Each Sunday evening, Margaret would phone those coming during the following week to remind them.

**The dinner roster also gave Mena a way of bringing people she wanted into her life, saying *I want you to come to dinner.***

The beauty of the roster arrangement was that it provided opportunities for people to maintain contact with Mena, such as paid workers who had moved to other jobs. The dinner roster also gave Mena a way of bringing people she wanted into her life, saying *I want you to come to dinner.*

About two years after Mena moved to her cottage, one of her support workers announced she was leaving to take another job. We were disappointed, but knew all Mena's workers would move on at some stage, particularly as many of them were students. She asked to become part of Mena's dinner roster and over the course of discussions about her leaving she revealed she was looking for somewhere to live. Margaret and I had been thinking for some time about Mena having a housemate. Our idea was to find someone who would agree to be with Mena for a number of nights a week in return for paying no rent. Ideally we would have liked Mena to have a housemate who shared her cottage on equal terms, but the reality of our funding situation, and the size of the cottage, did not really make that possible. But if a housemate was able to cover four nights a week, paid workers could cover two, and Margaret and I would cover one night. That would free up some funding for the daytime and make life easier for us. We also thought Mena would love it. We wanted her to have the experience of house sharing, just as most young people do in the years directly after moving out of the family home. Mena would learn about sharing the private space of others. We thought the young woman now leaving would be ideal in the role of housemate. She knew and liked Mena and they got on well. She knew the routine of Mena's house, with paid staff coming and going, and the dinner roster. She understood and respected our family values and the values we expected in Mena's house. We trusted her and knew she would keep a watch on things and come to us with any concerns.

We talked to Mena about the idea of someone living with her. We pointed out that her housemate would use the spare room, share the kitchen and bathroom, and be with her on some nights instead of a support worker, or better still, instead of one of us. We emphasised that it would not mean the house stopped being her house; she would just be sharing it with someone else. Mena was keen, ever open to something new, and her former support worker accepted our offer, agreeing to commit to four nights a week. She agreed to be home by nine on the four nights and to let us know if she was going to be late. She would not leave in the morning before Mena's worker arrived at seven. The spare room would be her private space and we asked that she be strict in policing that with Mena, so she would learn not to go in unless invited.

Mena and her housemate became very close through sharing the house. Her housemate sometimes joined in with dinner guests, most of whom she knew from her time as a support worker, but she did so without forgetting the importance of Mena being able to connect with her guests. To Mena's delight she kept her surfboard in her room and, if home on weekends, calmly closed her door to whatever else was happening when she needed some peace.

Sometimes, when we were scheduled to sleep over and there was no dinner guest, Mena's housemate would suggest that she and Mena have a 'girls night in' and offer to put Mena to bed and be there for her overnight. They were lovely, freely given times when she and Mena hung out like any other twenty-two year-olds. She would do Mena's nails and they would eat chips and watch movies together. Occasionally she would have to remind Mena that she was

**Mena's two experiences of sharing her house were extremely positive. She learnt about living closely with someone who was not an immediate member of her family.**

no longer her paid support worker, but her friend and housemate, whose only support role was to assist Mena to roll over in bed that night. When she moved on after nearly a year she remained firmly in Mena's life, becoming a regular dinner guest. She remains part of our extended family.

We learnt a lot from the house-sharing experience and were keen to replicate it. There was no obvious support worker that we could ask. Around that time, a small group of women around Mena's age had begun meeting with her to plan social outings. When we asked that group to think about how another housemate might be found, they suggested seeking young women from regional south-east Queensland who came to Brisbane to study. They drafted a flier and we sent them to all the local service clubs in towns within a two-hour radius of Brisbane, asking them to circulate it. Despite the brilliance we saw in the idea, we received no response.

With our brilliant strategy a failure, we went back to a more conventional approach and advertised on university accommodation sites. Almost immediately we received a response from a young Indian woman who was living with relatives while studying for a master's degree. She had no experience of supporting someone like Mena, which was a good start, and was keen to move from where she was living. When we met to talk about the proposal, she and Mena seemed to connect.

The young Indian woman was aged in her mid-twenties and had been living in Australia for some time. We knew she would need to study, and we understood that her family would want to know where she was living, but we hadn't reckoned on being subjected to scrutiny by an Indian mother. Emails passed back and forth. Would there be parties? Would there be boys in Mena's house? The family was from a four hundred year-old Indian Catholic community and her mother was not about to let her daughter be led astray. With her mother satisfied, Mena's new housemate moved in. As with the previous arrangement, we asked her to sign a simple agreement, setting out the same terms, conditions and expectations. Margaret told her about Mena, about the culture of the house, and that she would need to learn about Mena's routines and how to support her overnight, as well as accepting friends, workers and family members coming and going every day and, of course, know about the dinner roster. She readily accepted all those requirements, but had one request. She needed a pressure cooker. I had assumed all curries were cooked slowly over low heat and it had not occurred to me that whipping up a quick curry or dhal in a pressure cooker, after a long day at work or university was, for someone like Mena's new housemate, as commonplace as throwing a frozen meal into a microwave.

Over the next eighteen months the pressure cooker never had a day off. Mena's house filled with the aromas of southern India as she tried everything put in front of her. With such cultural differences it was remarkable how quickly the young woman fitted in to Mena's house. She became a loving friend and fierce advocate for Mena. She engaged with Mena's dinner guests and politely told support workers what she thought Mena needed. She came to staff meetings.

In the house she quickly learnt how to turn Mena during the night. She became used to people sleeping on the living room couch, including me. If that stretched her cultural boundaries, she never showed it.

Mena's two experiences of sharing her house were extremely positive. She learnt about living closely with someone who was not an immediate member of her family. She loved the experience of having young women in her house, who laughed and played and looked out for her. She enjoyed the freely given aspects of those periods in her life, the times when she and her housemates did girly things together, playing music, eating chips and watching movies.

Mena lived by herself, in her own home, for most of her adult life until she died in 2009, albeit with someone always present to provide support. Sometimes people say they do not want their family member with disability to live alone, offering it as a reason to opt for a group home or institutional living. But that is living with others who are not chosen by the person with disability and supported by people who work for a service, not the person. Mena did not live with someone in an intimate way, but she lived in a place of her own over which she had control. With the network of friends, dinner guests and other visitors, she was never actually alone and never lonely. As Margaret once put it in an article about our experience, by supporting Mena to live in her own home, we were giving her wings to fly.

Margaret and I often reflected that creating and sustaining a home for Mena – a home of her own – was the most important thing we could have done for her. She glowed with the love of her own home, where she felt in control, in her own space, safe and secure.



**Bronia Holyoak** is the founder and CEO of Valued Lives Foundation, a peer-led organisation in WA. Bronia has a career spanning 30 years in human services, almost half of which was spent in the Local Area Co-ordination (LAC) Program. Through her work, Bronia has gained extensive knowledge and experience in person-centred planning, exploration, and service design for Individual Living Options (ILO).

Having been on a lifelong journey with her sister who lived with a disability, Bronia has a passion for individual family leadership, a personal understanding of the value of peer support and is committed to increasing society's support for the valued participation of all people.

## Individual Living Options - The Western Australian experience

I have been fortunate to live in Perth, Western Australia (WA) for over two decades. WA was the last state to sign up to the federally delivered National Disability Insurance Scheme (NDIS), and this later start has afforded us the opportunity to learn from the experiences of other states and vice versa.

Western Australia has a strong history of innovative living arrangements that promote people's choice, control, and ability to determine and direct their own lives. At the time of transition to the NDIS, many people with disability in WA were already able to live in homes with flexible arrangements that were tailored to their lives and preferences. These living arrangements did not have to rely on living with other people with a disability or fitting into a vacancy in a residential service to secure funding. People did not have to continue living indefinitely in the family home if those more traditional arrangements were not for them.

The State Government in Western Australia has had a long track record of investing in building the capacity and leadership of people with a disability and family members, and had built a strong Local Area Coordination (LAC) program in for over 25 years. LAC was recognised as highly effective and a respected program that benefitted the lives of many West Australians.

A fundamental element of LAC was building productive and meaningful relationships with not only people with disability and their families, but also with the local community. LACs typically started conversations by questioning 'what does a good life look like for the person?' as opposed to 'what services do people need?' From this starting point it was an organic process that when a person considered planning to move out of the family home, that this would lead to the exploration and planning for an individualised living arrangement, tailored to the unique needs of the person.

It is likely that at some stage in a person's life there will be a trigger point that will lead towards setting a goal to plan to move out of the family home or out of group accommodation or out of homelessness. For over 25 years of my professional life, I have had the privilege of working alongside people with disability and their families, and sharing conversations as they create their vision



and a plan for what a meaningful home looks like for them. Although these discussions are unique to the person's individual circumstances, there are some key themes that typically emerge. People usually say they want a home that is safe with ongoing security of tenure. They want to choose who they live with, stamp their sense of identity in their home and have access to flexible and responsive supports when they are needed. They want to live in local communities, with good neighbours and have family and friends in their lives.

My own concept of home mirrors these sentiments. My home is a safe place to go at the end of the day, a relatively quiet place, except when family visits! It is often a bit messy, with photos of my family scattered around, vibrant cushions and comfy snuggly rugs making it my home and giving me that sense of identity and ownership. I also enjoy the sense of neighbourhood in my community. People know me and often give a wave when they see me, they are curious and ask questions when I am not around. I can walk safely around the lakes surrounding my home and

the local Dome cafe knows how I like my coffee. The local gym calls me when I have not attended as regularly as I should do. My home is a place where I feel a sense of belonging, can relax, and is a key anchor point of my life in the community.

Western Australia trialled a WA-delivered version of the NDIS before joining the national scheme in 2018. When the time came for over 450 people with disabilities with longstanding individualised living options to transfer over to the federal scheme it was evident that these arrangements did not fit neatly into standardised or traditional funding arrangements.

This led to the National Disability Insurance Agency's ILO team working alongside people with disabilities and service providers to ensure that these existing arrangements in WA were retained and, over time, expanded nationally.

There is international and Australian evidence that indicates Individualised Living Options (ILO) are not more expensive when compared with more conventional models of accommodation and support and are more beneficial in achieving participation in community. These outcomes relate to the goals of the NDIS, including the financial sustainability of the scheme.

An ILO is specifically designed around the person, their living environment and has a strong focus on the needs and preferences of the individual.

**An Individual Living Option is specifically designed around the person, their living environment and has a strong focus on the needs and preferences of the individual.**

Typically, there will be a range of enabling supports built around the person, which includes a primary support and supplementary supports such as family, friends, and the community.

The four most common ILO models currently operating in WA are:

1. Living Alone – where a person chooses to live in their own home, typically through a funded package that has highly flexible, drop-in type support arrangements that are supplemented by informal assistance from say, a good neighbour, family, friends and community.
2. Co-resident (Home share arrangements) – where the person lives in his or her own home with one or more people who provide an agreed level of support and/or companionship and who receive either a payment, or reduced or subsidised rent, depending on the type and intensity of support required.
3. Host Arrangement – where a person lives in the home of a non-related person or family (host). The Host provides in-home assistance, emotional support and a family environment for an agreed level of reimbursement set out in a person's plan. The person with a disability pays a Board and Lodging payment to the host family or person, to cover their own day-to-day living costs.
4. Living Together - where a person lives in their own home with maybe one or two people (with or without disabilities), who they have chosen to live with through existing relationships, such as friends, partners or relatives.

ILOs are not typically a one-model-fits-all approach and we often see a mix of these models utilised to deliver a support option that works best for the person and their family and supporters.

It is heartening to see that the NDIA is committed to expanding individualised models nationally. The 2020 NDIS Price Guide introduced some new ILO guidelines and line items to assist participants to explore and create their vision for their future home. This will help all involved to understand the full range of options for how the person can be supported in the community.

This is a great starting point for people to engage a trusted person or organisation that can assist them, their family and supporters to create their vision of home and undertake an individualised housing exploration and design process to guide them.

Creativity is the key to more people having an opportunity to create a place that they can call home; however, it will require much more than simply securing NDIS funding for support as individual living options need more than 'just the money'.

*"We are more in need of a vision or destination and a compass (a set of principles or directions) and less in need of a road map. We often don't know what the terrain ahead will be like or what we will need to go through it; much will depend on our judgment at the time. But an inner compass will always give us direction."*

Stephen R. Covey.

My experience has been that intentional planning with a clear vision, strong ideas and articulated goals about what home means for the person, along with security of tenure, leadership and persistence are the key elements that underpin a successful individualised living arrangement. Add some 'outside of the box' thinking and doing, and the future is looking bright for more people with disability to be able to create homes of their own.