

What it means to create a home

This edition of CRUCial Times is an exploration of what it means to create a home. We want to explore how we can assist people with disability to have more than just a bed, a room in someone else's home or basic shelter but a home that others would clearly recognise and maybe even envy. Having a stable home can open doors to community, growth and connection. If we think of home as a safe and secure place to be oneself and from that secure place take up opportunities to work, study or contribute in some way then we need to consider why this is so often out of the reach of people who live with disabilities.

Ten years ago CRU also published edition 40 of CRUCial Times on the topic of 'Creating Home'. In the past ten years nothing has really changed about the fundamental importance of home and how essential it is. What we need to consider to assist someone who lives with disability to create and sustain a home hasn't changed much either. However at a practical level, the introduction of the National Disability Insurance Scheme (NDIS) in Australia means that for the first time having enough funded support to move into a home of their own is a real possibility for many more people with disabilities. We tend to hear about securing a house or accommodation rather than what it takes to have a home. We decided to return to the topic of creating a home to ensure that houses do

become homes and offer the comfort and security most people can take for granted.

We have republished an article by Mike Duggan from that earlier edition as he reflects on home. Through his life Mike moved from his family home to an institution then to a group home and finally his own unit. Sadly Mike died in September last year. It was fitting that he died in his own home, in his own community, supported by workers he had chosen and with friends close by. Mike writes that for people who are often disempowered, disenfranchised and oppressed having control of one's own immediate environment is particularly important.



Illustration: Neighbourhood - Rosie Dog. Artist: Freya Toussaint

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Through their article three members of the Independent Youth Housing Group, Jenifur, Craig and Paul discuss how they have been part of a housing company that functions like a co-operative for nearly 30 years. They describe the roles and responsibilities and the growth and development of their group. While the model may not be common the purpose is the same. They remind us that being able to help out a mate, being able to relax and chill out and having security of tenure is critical to the health and wellbeing of their tenants.

Nigel Webb generously shares his personal reflections on life growing up in an institution a long way from his family home; his escape the day after school finished and now the home he shares with his wife and children. Nigel contrasts his early experiences of not even being able to have friends come back to his place after school with his life after settling into his own neighbourhood. He has made his home a launchpad to education, employment, travel and relationships. Nigel reminds us that having the freedom to make the decisions also brings responsibilities and like every other young adult he had to learn about paying bills, cooking and cleaning. Having the confidence that his tenure was secure meant that getting to know the neighbourhood, meeting the neighbours and lobbying for local accessible transport was worthwhile.

Some people make the move with the assistance of family or friends while others rely on a service or support workers to help them. Organisations and workers can play an important role both in what they do to assist a person and also what they don't do. A particular challenge is creating and maintaining a home when it is also a workplace and this requires close watching and monitoring. Mike and Nigel write of how the sanctity of their home is threatened by workplace health and safety requirements and industrial arrangements.



Just like everyone else who leaves home for the first time, people with disability will make mistakes and they too need the chance and the support to learn.

These articles illustrate that with the right opportunities, planning and support, not only can it be possible for people with disability to have a home of their own, but that it can be a cornerstone of a life in community.

Margaret Rodgers
Chief Executive Officer



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Home for me is sanctuary

Home for me is sanctuary - a place where I feel safe and secure. It is also a place where I can be myself, relax and unwind. It is a space that I can have control over and have the things that provide me comfort. It is a space that I can call my own, have my family, friends and acquaintances visit whether that be for a cuppa, a meal, a party or some entertainment. It is often the place that people get to know me the best as they can observe and witness for themselves the things that matter to me. My home tells a story about me and is much more than bricks and mortar. I have a sign out the front of my home that reads "A house is made of walls and beams; a home is built with love and dreams". People often comment on how I have created a lovely space that is warm and welcoming and a place they would like to revisit.

A home provides stability. When I reflect on some years of my life, I was having to relocate on a regular basis (at times on an annual basis) for a variety of reasons - rent became too expensive, the landlord wished to sell, and the list goes on. There was no real opportunity of putting my roots down in my local community. It also cost money to relocate and set up home again. If something went wrong with the plumbing or something in the home required attention, I was always at the whim of the real estate agent or the owner as to when things were fixed.

My home also offers me stability in terms of having equity and choice on how I want to live out my retirement years. Home ownership is something that is still valued in Australia and rightly or wrongly provides a certain status to the home owner. We need to expect this for people with disability.

My home has become a launchpad into my local community where I have become connected and known by neighbours. I am a regular visitor to local cafes, newsagent, chemist, post office, gifts shops etc. I am known by my name and I am not just another person being served. From time to time one of the shop owners may even ask my opinion around something they could be considering changing. They value my input and therefore I have become a valued customer.

Home as a sanctuary for many people with disability does not exist. For many years I have been a visitor to group homes where people with disability live. Their home environment does not tell a story about the individuals who live there but rather a story about the service provider who has taken control of the space and made it into a workspace for workers rather than a sanctuary for the people who live there. They have no control over the space despite often being the ones paying the rent.

Many people with disability are not awarded the same right or opportunity to having a place that they can call home.

Josey McMahon

Secretary



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What makes home 'home'? Mike Duggan

Mike Duggan was a well-known and respected member of Queensland's disability community and was a member of CRU's committee for 23 years, 16 of those as president. Mike passed away in his own home in 2018, surrounded by trusted workers and his impressively large personal library. Mike's home was close to his church, his friends and the vibrant West End community – all things that meant a lot to him.

We include here his 'From the President' article from CRUcial Times 40 (2008) which was on the topic of home.

What makes home 'home'?

Welcome to this place of reflection about home. I would like to make some personal reflections about home and explain briefly why it has become so pivotal in my life over the years. To set the scene: as a child I was raised by my parents in an old Queenslander house – for me this really was home. Then, through necessity, I put myself into an institution – certainly not my idea of home. After my escape from the institution, I lived for a number of years in several group-share homes. These weren't too bad, but now I'm living in my own inner city unit – a place I really call home.

It appears that most species need and have a shelter, but for we humans it has to be much more than just cover. It's a place where we find rejuvenation, a sense of being, and a sense of our true selves without experiencing the scrutiny, interference, or criticism of others. We are even free to sit around in the nude, if we so desire, without offending anyone (unless it's a shared situation). At home, one has control of one's own immediate environment. The notion of 'King of the castle' exists because it speaks to people's reality.

As someone who has a disability, my home is most important to me, dare I say even more important than it might be for some other people who do not share the vulnerabilities of many people with disabilities. Maybe this is because there are numerous situations where I feel disempowered, disenfranchised and oppressed. But in my own home I feel in control.

Another dimension to living in my own home is the need to keep a watchful eye on the maintenance and general upkeep of my home. This is a far cry from living in the institution or service run facilities. It serves as a good reminder that I am living an ordinary life, even if it's a chore at times.

I mentioned before the joy of having control. Having control over one's home is under threat for many people. The sanctity of one's home can easily be transgressed by service workers, visitors and even by well-meaning strangers.



A simple example occurs when a worker has a key to the person's home, and uses that key to enter, without even knocking. For some people, there may be very good practical reasons for this. Nevertheless, there is an impact on the spirit of home. People experience a change of feeling as suddenly the person's home becomes a 'facility'. It is also too easy these days for one's home to become a place where Work-based health and Safety take prominence.

Although I definitely wouldn't swap my situation for the world, to say things are easy all of the time would be an overstatement. Firstly, it's difficult to 'fly solo'. One of the challenges for people living alone is of course the potential for loneliness. Please do not misunderstand me. I don't mean that all people with disabilities should live together. I am simply observing that periodic loneliness is a by-product of living alone and that one needs to find ways to have people in one's life.

There is also a practical problem. One has to ask for help as there's nobody there to give incidental assistance, and this takes courage. It means putting oneself regularly in the role of dependant and this is not an easy position to be in. So, what can one do for company? I refer to unpaid company, freely given relationships, not paid workers. This is an ongoing challenge for not only the individual, but also for the people who support that individual.

There are broad implications that flow from these brief observations. We must get much smarter and more diligent at providing people with disabilities with the most appropriate supports so that we can live meaningful lives in the community. We must gain a better understanding about what it takes to live in the community. The service and its workers may not appreciate that what they are doing is supporting someone to have their own home. This can deteriorate to a situation of passive 'community minding'; that is, minding someone in their own four walls.

We need to understand that the role of the worker is in the context of helping people to make their home comfortable, meaningful and authentic for that person. Home is part of the person's identity, and the person's identity is expressed through home.

Peace.

After my escape from the institution, I lived for a number of years in several group-share homes. These weren't too bad, but now I'm living in my own inner city unit – a place I really call home.



That's ordinary in my home

Independent Youth Housing Group

The Independent Youth Housing Group (IYHG) is a rental housing collective that provides affordable rentals to, and is run by, its members who are currently all people with disabilities. Established in 1989 around Nundah, a suburb in Brisbane's north it has expanded to twelve homes – four of which it has purchased itself. The co-operative is supported by the Community Living Association (CLA) but runs with its own board, policies and governance.

In this article three IYHG members, Craig, Jenifur and Paul share their experiences of being members of the co-operative and how these tenancies differ from their experiences in the mainstream rental market. They have all held governance roles in the co-operative and reflect on the benefits to having long-term, stable and quality housing and how this sets them up for 'life'.



That's ordinary in my home

Community Living Association (CLA) was established in 1986 as part of the Commonwealth Rehabilitation Service. The aim of the original program was to support young people with an intellectual/learning disability towards independence. Young people and families who were part of CLA incorporated it as an independent organisation in 1989. IYHG is a company that continues to be affiliated with and supported by CLA.

CRAIG Back in 1988 I was about to move out of home with the support of CLA. Jenifur and I were in the same batch of guys and girls going through same program run by CLA. The way it worked was you paid rent in a share house run by CLA and a certain percentage was saved for you to put on a bond for a new place of your own. I was ready to move in to a place but unfortunately for me, the landlord saw dollar signs because of Expo 88, upped the price and CLA could not afford to pay that much and so I lost the unit. This meant I didn't move out at the same time as everyone else.

Once CLA got me started I moved in to share houses with friends of mine. I eventually moved in to my own place which was great, but I couldn't afford to live properly. I was only getting \$280 from the pension at that time and paying \$180 on rent. I only had \$100 to live off. I lived very frugal at that time – cans of tuna and rice. That's it.

JENIFUR That's the point. You were paying more than 50% of your income per fortnight in rent alone and then you had to keep everything else in track with what was left. You could forget about going out, you were lucky to be able to buy food. For me it was quite different. For starters, being a pre-op male-female transsexual I HAD to move out to a place of my own. I needed the space to be me.

CRAIG It was the beginning of 1989 that Morrie (the CEO of CLA) came up to me at a BBQ and shared his idea with me. After a few meetings about it we came up with the idea of the co-op and CLA helped us get the funding for our first property. When we set up the co-op we made sure we had a set area we would buy in; and all the areas we live in are very good areas. They're safe. That's what everyone wants – a secure place to live.

The first place was a 3 bedroom house purchased through a federal government grant. A friend of mine and his wife moved in to that house because they were the only married couple in the group. We thought it would be easiest to let them have that.

JENIFUR We thought that once they were in and stable we could start looking at expanding. We then had to try and keep things going which wasn't easy because we didn't know up from down in running a business. When you've got a number of places it's important to manage things properly.

The first co-op place I moved into was a case of just taking what was available at the time but it didn't feel like home. Things went south and then I got the chance to move in where I am now. I walked in to the place and I knew this is mine – I felt comfortable instantly. It's that feeling of 'this is where I belong'.

CRAIG I think I was about second or third member housed – and after 27 years I'm still living in the same place. When I got my unit first up I had a friend struggling to find a place. It only took him a week, but it was good to be able to help him out. Later on I had someone else living with me for a while and it didn't work out. It was after that experience I decided I won't put myself through that again. It's just me and my place.

We had lots of problems at the beginning, people not paying their rent (often me to be honest) but also with people we employed to help. We had a woman come in to help us with book-keeping and she ran off with our money. We then had the Department of Housing try and shut us down.

JENIFUR That was 1997. At that point in time the company's policies were a mess, we were still trying to deal with the fallout from the funds being stolen so the company's books were not submitted for audit which meant we couldn't accept state government funding for a few years. In some ways the book-keeper did us a favour because all that funding came with strings attached and we were forced to be more self-sufficient.

CRAIG A lot of changes had to happen too – we set up a system where everyone's rent was automatically paid from their welfare payment straight in to the housing co-op's account.

PAUL This was when I joined the co-op. Before I moved in to my flat I was living with my mum and dad. It was hard at first, especially with not having enough income, but now I'm finding it a lot easier. I live pretty close to the train station so public transport isn't an issue for me. I was 20 when I moved out and doing things on my own has made me be more independent. Now I'm finding it a lot easier.

Having my own home gave me a lot of freedom to do the things I wanted to do and try new things, like grocery shopping, washing my clothes and things. I think it allowed me to expand my horizons. I do a lot more things with CLA now than when I first moved out. I was recently a keynote speaker at the ASID conference at the Gold Coast.

CRAIG Paul's expanded big time. He used to just be himself, in his place, but now he presents for ASID and is on the board of CLA.

PAUL Yeah, so I'm on the board of CLA and on the board of the housing co-op. I've been the treasurer on both committees for almost 21 years, and will stay until I get sick of it. My house is pretty much set up now too. I've got the kitchen and lounge room set up with my stereo and TV and my main bedroom and the spare room is where I use my computer. Having a roof over my head means I can come home from work and just relax and chill out.

CRAIG I'm quite proud of being the first president of the housing co-op, and with the help of other people, getting the ball rolling on doing things. Now I just show up to meetings. I can still voice my opinions about things. The way the co-op works is that our members are our tenants. In our meetings our members voice their opinions and policy gets sorted out from that. We used to meet every fortnight but we found that untenable.

JENIFUR It wasn't so much untenable, it was simply that we got it to the point where everything was working properly. When things get so routine you don't need to meet so often, that's how we got through it! Now we only meet every six weeks. We call it a co-op because of how it operates, but in actual fact legally and how it's managed it is actually a company.

Being the company bureaucrat has been my job in the organisation. I started as secretary, then vice-president and now I'm back at company secretary again. I'm in there behind the scenes keeping things ticking over. A good example of where I've been involved is in all the company policies. When we've got to sort out company policies I end up writing a lot of them – so when everything goes wrong everyone looks to me and expects me to instantly know what the policy is – so my big job is being a bureaucrat.

PAUL And making sure we stick to the rules. It's hugely important.

JENIFUR That's what I'm good at. When you've got a number of places it's important we manage things properly. For me, going out and speaking in public like Paul does, that utterly scares the hell out of me. It's not where I am. That's the thing: each of us have things we can do well for the company and that's what we work on. Everyone benefits.

PAUL We've got twelve properties we manage, most of which are held under caveat by the Department of Housing. We do six monthly maintenance inspections too. Jenifur and I then liaise with the company's housing resource worker to prioritise what needs to be done.

JENIFUR The inspections help the company keep on top of the maintenance that needs to be done but it also acts as an incentive for members to keep their properties in proper order. We are not just a co-op, we are an actual business and as landlords we have to keep our properties in order. We also renovate our properties so they are nice to live in. Over the past 10 years, I've had a new kitchen installed, and a few years later, had the flooring done. While the co-op owns the properties, they're very much our homes.

Running the co-op ourselves means we are in charge of doing things that are important to us. The savings scheme is another thing which started small but has turned out to have huge benefits for all the members. When we started everyone was having trouble juggling funds and saving money. The point was that every time someone had a major expense they were scrambling to get the cash together - you couldn't get ahead. We thought about how to simplify it so people could save money. We have now organised that member's rent includes a component of savings that automatically builds up for them.

PAUL It's been a really good system because we've all saved money. If I need to buy something major I know I've got the funds there to do it. The extra funds also mean I can go away on bowling trips and to conferences.

CRAIG Safety is really important to me. I don't go out at night – I'm just at home. If it's a work night I go to bed early to wake up early and when I get home I get to chill out and relax and do what I have to do.

*That's what it came down to for me.
I needed the space to be able to be me.*

When I'm home I feel a lot more calm and happier. A lot of the times Paul and my other two friends come over for tea, or we go out for tea. Our social life is pretty good – we get out and do things.

It's been really good to see how the co-op has helped other members. There's a lady who has a kid. She used to live in a suburb a fair way away, but now she lives walking distance from her daughter's school and her work. She wouldn't have what she has now if it wasn't for the co-op.

JENIFUR Like I said, I wouldn't be able to be here today if it wasn't for the co-op. That's not in any metaphorical sense, it's in quite a literal sense. In the transgender community the suicide rate is so bloody high it isn't funny and being secure in your own home is absolutely critical. It's that simple. That's what it came down to for me. I needed the space to be able to be me.

Unfortunately with my mobility issues, I need to look at moving and I'll definitely be sad to move out, but it's good to know the co-op will help me with another place. The co-op realised in 1999 that some of our houses did not meet the changing needs of our members, so since then, we have steadily been taking steps to replace some of our less-accessible housing. I've been involved in looking for a place that will suit me in to the future, and I will be moving in to my new place next year.

PAUL I guess my proudest moment would be the first night I spent in my unit. I guess also it would be that as a co-op we have bought four of our own units with our own money. It'll be 30 years for the co-op next year.

JENIFUR This is what I mean. We've been going that long. It's quite a history. We started to solve a problem, we had to learn to be a business and keep on going. We succeeded together against the odds.



Anita O'Brien is the Melbourne-based mother of two adult sons. Anita and her husband are committed advocates for her son Warren and Anita has served on the boards of numerous organisations. She has been a strong advocate, supporter, presenter and writer for many years.

This article is a collection of excerpts from her 2016 book 'Because it's better... to live my life within community'. These excerpts chronicle the changes in thinking that led her to move Warren from a group situation with other people with disability in to a home of his own. Anita also shares the ideas, frameworks and strategies that helped Warren embrace a life embedded in community with a job, friends and opportunities to craft a life of his own.

Because it's better

In June 2002, we became aware of an 'accommodation' option for our son Warren with other young people with a disability in a home established by a group of parents in 1982. I was excited about the possibility for Warren as I had been working towards a similar initiative for some time. On contacting them I discovered the parents' motivation for creating this place was due to their concern about the lack of community-based accommodation for their children, a universal worry.

Seven residents lived there – each person with his or her own bedroom complete with ensuite. They shared the living areas plus full cooking facilities; a lead tenant and casual staff supervised the dwelling and supported the residents. All parents were required to be a member of the committee. I was pleased that the house had been set up by parents and was financially independent of government funds and control.

Basically, we decided it was perhaps a first step and maybe the only opportunity for Warren to move to a 'home of his own'. It was certainly worth a try and to be honest, would give Allan and I some time to reconnect without some of the worries of Warren being unhappy and extremely anxious. We thought having day-to-day company would reduce his loneliness.

Warren moved into a bedroom with ensuite in the home at the front of the property, and there was one other resident who had a similar setup next to him. There was a little lounge room outside the 'boys' rooms, but it was not able to be used.

A purpose designed house had been built behind the original weatherboard home that housed another five residents. He was well-liked in the house because of his usually happy and fun nature.

Warren needed more daily support than others in the house, and so helping him to choose his clothes for the day and keep his room tidy were necessary and this support was provided by the lead tenant. Unfortunately, there was a limit to the support, especially in regard to personal care.



Moving out of our comfort zone

Warren was showing us by his behaviour and reactions that he was not happy living where he was. He was becoming more and more anxious to the point of vomiting and would not get out of the car when we arrived back after a day out. Allan and I had a conversation with Warren and asked him if he wanted to stay in his current 'home', return to live in the flat on the lower level of our home, or live in a unit of his own. He wanted to come home – to his community – and on asking him why he said "because it's better".

So I moved out of my comfort zone when I was 59 and Warren was 30 to embark on a journey with Warren towards discovery of who he was created to be.

“The greatest danger for most of us is not that our aim is too high and we miss it, but that it is too low and we reach it.”

Michelangelo

So I moved out of my comfort zone when I was 59 and Warren was 30 to embark on a journey with Warren towards discovery of who he was created to be. I looked at the lives of others who had achieved a good life for their child with a disability and decided it was possible, not that it would be all too hard. I too was inspired by others! Parents have said to me that they could not achieve what we have for Warren. I hope, through the rest of the story, you will gain some insight that will give you courage for whatever in your life seems too hard. Believe in the possibilities instead!

Perhaps, if you are a parent, you think the risk is too great, that your son or daughter would be unable to live in their own home. When we dream we don't think of why not, we think 'wouldn't it be great if this could happen'. If we limit a person's right to dream because of their disability, their life becomes a reflection of what we allow, not their choice.

One of the traps is that we determine how people can be safe, before we look at what they require to be happy. We forget there is no such thing as a risk-free life, that risk is relative and has context. What we need is to begin with an understanding of what is required for the 'pursuit of happiness' and then seek to reduce or avoid risk within that context.

I started with the belief and created a vision for Warren with a goal to get him a good life and one that made sense for him – a very broad goal. I had no idea where that would lead us, or what was needed for the journey. I just believed we had to do our best to help him, just like we did for Matt, his brother. The vision needed to include principles that we would continue to refer to as positive people surrounded him and helped him to articulate his thoughts and dreams.

Warren's vision

Life objective:

To live a good, full and happy life that gives to others by exploring a range of typical and valued ways to contribute to the community.

Vision:

To have the opportunity to be on the natural pathways of life in valued roles that make sense for me. This means that I will have the individual assistance to be myself in 'normal' roles and, be enabled to have access to life conditions which are at least as good as those of the average citizen.

We decided that Warren is unique and his life needs to reflect his own distinctive attributes, skills and abilities, and we would assist him to pursue the areas of life that interested him. Helping to find his 'sweet spot', the place where he could follow his passions and dreams would be our vision.

Though this was new for Warren, I endeavoured to listen more carefully to him, and in the re-thinking remembered what he had indicated through responses in the past about what he did not want to do.

Living Distinctive Lives

Our family connected with Living Distinctive Lives (LDL), a small family-governed arrangement focused on supporting individuals with a disability to create a meaningful lifestyle typical of other members of the community.

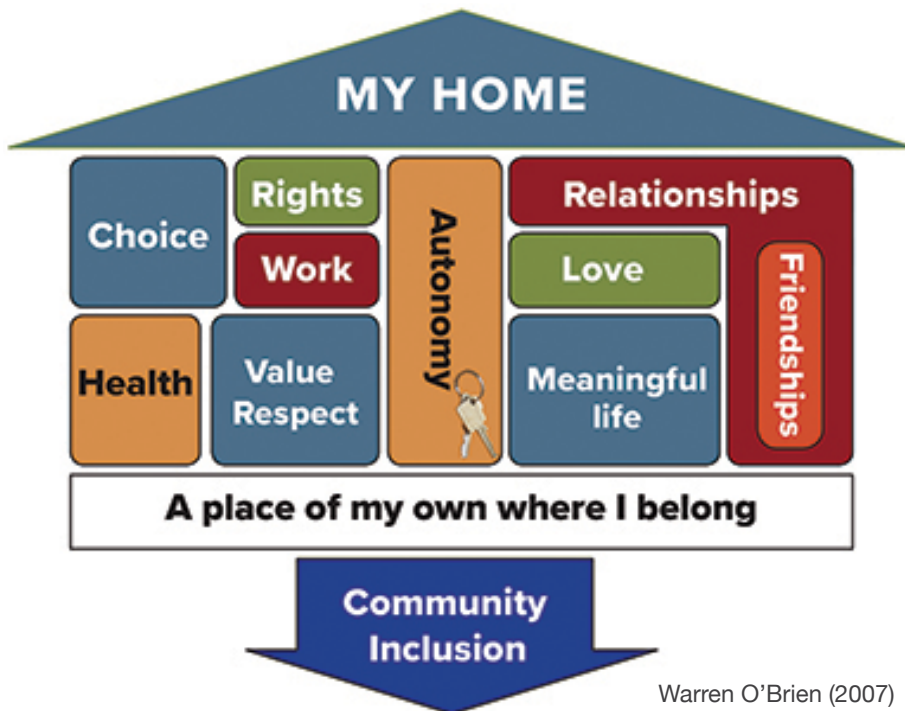
Through LDL I was introduced to the concept of a person with a disability living in their own home with the support of a housemate. Most arrangements were based on the concept that this would be a reciprocal arrangement with benefits to both the home owner and the homesharer.

Warren's first housemates were a former support worker and his partner. This couple lived with Warren for two years – during which time they had their first child. After they moved on Warren met a housemate through a service that links people with disability with potential housemates in a life-sharing arrangement. Warren lived with this housemate for over eight years and they remain friends, still catching up a few times a year.

The housemate model of support has made it possible for many families to see their family member with a disability live in their own home.

Home model

In 2007 I created the 'Home' model shown below that demonstrates a home is not just the house in which you live and the people with whom you choose to live, but is also the community in which you have chosen to live. A sense of belonging can be found when home is in a community where you find connection to people and places and are able to participate and contribute to that community. It also gives the opportunity of developing many different friendships and relationships, and is a place where you are valued, respected and loved.



In developing a range of both formal and informal supports we have found that:

- The inclusion of housemates as part of the support structure for a person with support needs is most beneficial and renders the budgeting of available funding affordable.
- The natural support of housemates can be targeted at the times and in the way that is required.
- The arrangement provides opportunities for the development of natural relationships and friendships.
- Housemates can be a pivotal link to the other supporters (both natural and paid), and they can provide invaluable insight when participating in the Circle of Support that is a crucial element in the support plan.
- Whilst it may not be for everyone, this is one of the most valuable ways to support an individual with a disability in their own home, so they can live a life that is typical of others in the community.

Looking from a very personal perspective, the success in recruiting housemates for Warren has involved prayerful belief in the possibility, and trust, especially through difficult and often painful adjusting to relationship building, and when 'life happens'. The housemate model has not, and will not always be smooth sailing, and there will be changes, as we have all experienced. But this is just mirroring life for everyone.

Living Distinct Lives (LDL) learnings on housemates

Over the years, LDL families have been inviting housemates to become an integral part of making this vision come alive for them.

- By sharing a home, housemates are given an opportunity to come to know someone with a disability in a real way. They learn about their trials and triumphs, their hopes and dreams, what struggles they may have and what successes they achieve each day.
- They get to know someone for who they are, and not for whom they assume them to be.
- This is the same for the person with disability. As they share with a housemate, they come to realise who they are and what it's like to live in their own place, with all the responsibilities this entails.
- They relate with a housemate in everyday, normal ways.
- They are no longer just in relationships with their parents or paid staff.
- They get the opportunity to step out of a preconceived or long-existing role and discover what it is to be 'them', in their own place, sharing with another.
- All the regular housemate things occur: sharing, arguing, discovering about each other, working out rules and who does what chores, etc. Added to that is a unique and rich experience of interdependency, acknowledging the importance of belonging, friendship and genuine care, discovering and acknowledging strengths and weaknesses, and of working together to make a home that works for all.

This has not necessarily been an easy road for many, but it is one that LDL families continue to choose as they value real relationships, of giving and sharing and of regular community life. This outweighs the time, energy and effort it can take to make these arrangements a success.



Nigel Webb is a disability activist with over 30 years' experience in disability organisations in Queensland. He is currently Chair of Queenslanders with Disability Network (QDN) and is the Co-Chair of the National Disability and Carers Advisory Council.

In this article Nigel reflects on the stages of his life as he moved from living in an institution in his youth to being an adult living in a home of his own. Nigel describes his home as a place to entertain and a sanctuary, both of which help him to take his place in community.

The importance of home

I was born in, and spent the first few years of my life, living in regional Queensland west of Toowoomba in the early 1970s. I was born premature to a young mum (the proud wife of a farmer) and was eventually diagnosed with Cerebral Palsy – Spastic Quadriplegia. A decision was taken in 1975 that I would be placed in an institution in Brisbane 'to receive care, therapy and an education.'

Moving to Brisbane might as well have been like going to Mars to a four-year-old boy and this move would have profound impacts on my family, their lives, their known community and importantly, me. Moving away from the family home at a young age meant separation from parents, siblings and friends; and this was not easy for any us.

The long and regular commute between the family home and Brisbane became a ritual each school term for the next 14 years. My family and I were on a collision course with the medical model, the Education Department and countless therapists. I was living in a vortex: every aspect of my life was organised, measured and delivered via a series of programs. This institution became my all-encompassing community.

In the early 1980s it was decided by my parents and a multidisciplinary team that I would remain living in the institution but start attending a mainstream primary school. I recall a Social Worker telling me "it was ok for me to go to a regular school because I could independently toilet myself."

During the decade I had 3 distinctly different revolving lives and quite separate communities. The first was my life in the institution: very segregated, noisy and sterile place; one had to be disabled enough to get in, yet independent enough to be released to another's care regardless of purpose or duration. I recall only 3 external outings each year facilitated by various charities.

Second, my school-life where I was told to 'integrate' into an environment that didn't yet understand much about physical access features, the notion of inclusion or the concept of reasonable adjustment for learning. The few school friends I had could never come to my place of residence in the institution after school.

The third, my life with family 12 intermittent weeks a year where my care regime was disruptive to family life, physically demanding for mum and totally foreign for my siblings and relatives. Later, my parents had retired and the family moved to the Sunshine Coast and travel was very much a goal for them.



In 1989, I graduated year 12 with average results. The day after leaving school I moved out of the adult institution with some funded supports into a shared accommodation house in Brisbane. The life lessons really began full throttle, I was an adult, a student, a tenant, a citizen – I could vote.

Importantly, I was free to decide what was going to happen for me each day. Then, reality checked in: I had to learn to cook something, pay bills, clean, share space, manage support workers and their bureaucracy. I took some time to learn how this was going to make sense for me. One of the best things was that my 'community life' had begun: making friends, solving the world's problems and having fun in the process. I became interested in social advocacy and social justice and sought to 'right the wrongs' I had witnessed.

Having security of tenure and knowing my space in the community has provided me with confidence to pursue my education, employment, health and travel goals.

Having experienced several different 'shared' arrangements I finally was offered a tenancy in a retro-fitted public housing detached house.

Yes, I'd done it! This house was going to be my home. What did this all mean? I recall being given the keys, signing the lease, paying the bond and doing the first roll through each room and thinking 'my bum is the only one going to be seated on the accessible toilet'. Looking back now as a husband and father, how little did I know just how wrong that statement would be.

Being a good country lad, I went about getting to know my neighbours. Over several days I introduced myself to about 3 blocks of my neighbours. Most were polite or welcoming but there was some mixed reactions. One lady said 'People like you belong in institutions.' I replied; 'That's fine, I had just come from one' and showed her a photo of it. Another said 'You living next door devalues my land.' I advised her that she could sell as I wasn't likely to be moving!

I realized that attitudes were in need of change, including mine, and I was going to need to build my resilience if I was to succeed with my plans. For months, I ventured out and about as far as my chair would go each day getting to know my community and all that it contained. My confidence and frustrations each grew as I explored the available options and obstacles.

Transport became key for me as my old chair couldn't cope with the often unreliable terrain and while many train stations had some form of access, this did not include my nearest station. I approached the station master to ask how I could board the service and they were not in the least bit interested in my request.

I decided that they couldn't just ignore me if I turned up daily like anyone else. I did that for months and started writing letters to politicians. Many months later I was contacted by an official advising me a portable ramp was now going to be carried on the train if I would simply tell them I was coming. I could now travel further – yes!

I wanted to work and study like my friends so I signed up with an open employment service for assistance. At first I was advised that I first had to


have spent three months in 'sheltered employment' before I would be eligible for open employment supports. I simply refused to comply stating my education qualified me for assistance like everyone else and with further advocacy (and embarrassment) the service accepted my application and offered me some supports.

I began job-seeking and volunteering. I signed up with a number of community groups, joined their committees and attended countless conferences. As I had become adept at communicating with governments about their policies, opportunities came to get involved in influencing the political process and being part of the change led by people with disability. Having security of tenure and knowing my space in the community has provided me with confidence to pursue my education, employment, health and travel goals. I'm now even looking at becoming a home owner.

We all face many challenges in everyday life and we need refuge from this. This is why my home must be a sanctuary where I feel safe; a place where I can welcome friends, house treasured possessions and enjoy my family. My house is not an industrial workplace where I happen to reside for the receipt of any time-limited supports - it is my home, and it is my launchpad for contributing to the global community.

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Bringing the good life to life

 Have you visited the CRU website designed to resource people bring the good life to life for people with disability?

This website contains a broad selection of articles, videos and ideas drawn from CRU's existing resources and over 25 short films. It also has lots of interesting content from around Australia and the world.

The content is useful for people with disability, their families, friends and the people who support them – both paid and unpaid.

visit thegoodlife.cru.org.au

The website contains 7 pages that cover the following topics:

-  **The Good Life**
-  **Getting Started**
-  **Including Others**
-  **The Role of the NDIS**
-  **Funded Services and Support**
-  **Blocks and Barriers**
-  **Keeping on Going**
-  **The Bigger Picture**