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Guest Editorial

Karin Swift

Creating Home: An Exploration Of The Efforts And Commitment To Create Individual Lives, Not Just Bricks And Mortar

'The green, green grass of home'
'Home is where the heart is'
'Wherever I lay my hat, that's my home'
'Homeward bound'
'Home Sweet Home'
'There's no place like home'

Much has been said, sung and romanticised about home. Our home is meant to be our sanctuary, a place that both defines us and separates us, as well as protecting us from the outside world. We are meant to be free to be who we really are in our own home. It is also a place that shelters us, sustains us, and gives us a sense of belonging and pride of place.

Sadly, for many people with disabilities, home is merely a place for having their basic needs of food, shelter, clothing and support met. For some people, home is merely a vacant bed needing to be filled, or a place to receive a service. Many people live with few or no supports at all. These are people who live with families that are struggling with providing support – a support unmet by any government or community agencies. There are also people living in boarding houses and hostels whose tenancies and lives are very vulnerable. Even worse, some people fall through the service system cracks completely and are homeless.

Layers of bureaucracy, government and human service policy, procedure and practice get in the way of creating homes for many people with disabilities. Many options get put before people with disabilities that at first may seem attractive, but end up with people languishing for years in facilities that are tied instead of to the hopes and dreams of an individual. These options reflect

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CRU's MISSION STATEMENT

- To challenge ideas and practices which limit the lives of people with disabilities.
- To inspire and encourage individuals and organisations to pursue better lives for people with disabilities.

failings in the system.

The current, dominant funding arrangement is via block grants to services where funding is attached to ‘places’ rather than individuals. One of the recent funding processes was euphemistically called ‘capacity funding’. It is clear that this program would build the capacity of services, not necessarily the capacity of individuals.

The rise of vacancy management has meant that when a ‘vacancy’ arises, services are under pressure to fill it so they don’t lose vital funding dollars. This leaves little room for considerations like the compatibility of people who might be forced to live together, and no room for individual choice or options in types or styles of housing. In services operating several group homes, people can be moved around from house to house to ‘fill a vacancy’, meaning that any opportunities for people to develop relationships and connections with the people with whom they live are always tenuous and seen as secondary to service viability issues.

Two patterns of service delivery demonstrate an intrusion by service matters into the personal and private domain of an individual or family. People’s homes are turned into workplaces where matters of occupational health and safety, industrial relations and risk assessment take precedence over people’s homes as a sanctuary for the occupants. Secondly, while it might be appropriate for a service to be involved in issues concerning their own staffing such as rostering and staff training, sometimes this crosses over into what is clearly family business such as family dynamics and relationship issues.

On the whole, current government policies do not encourage services to focus on individuals. This is evident in the dominance of block grant arrangements and a focus on centre-based models with congregation and segregation as core features of the model.

Another popular pattern is where the service provides both the support arrangements and the housing. This may, at first, seem an attractive option, as it would appear that this would meet people’s needs. However, problems arise if there is a dispute with a landlord that leads to eviction, especially when that landlord is also acting as the service provider. Conversely, people living in this situation, and their family members, may think twice about raising a complaint with the service provider when their tenancy could also be at risk.

This is also true of the housing sector, with some recently proposed models from the United States responding to homelessness by building large blocks of units that congregate homeless people and people on low incomes together. These units have support services ‘onsite’, and a ‘concierge’ who monitors who comes in and who goes out. The environment soon becomes institutional in situations where support and housing services are combined and people’s coming and going is monitored.

At a policy and funding level, there is currently a blurring of responsibilities. Community disability support agencies are being funded to build group homes. Housing departments and agencies which would typically be responsible for building and managing properties are intruding into support issues. It would be much more helpful if human services and their funders got on with the business of supporting people to have real lives.

In recent times, there has been an increased emphasis on certification processes that strive for ‘quality’, ‘best practice’, and ‘continuous improvement’. These processes are largely paperwork-driven and, as certification is linked to funding, they serve as a distraction from the core business of human services.

An alarming recurrence in social policy is the move to legalize restrictive practices such as chemical restraint, containment or seclusion, and mechanical constraint. This has a huge impact on ‘home’ for vulnerable people. It is difficult to view the legalization of such practices as anything but a retrograde step in disability service delivery. The formalisation of restrictive practices is a violation of the human rights of people with a disability and is a disappointing response to a complex issue. It is acknowledged that all individuals need to live and work in safe environments and be protected from harm; however, other alternatives to restrictive practices must be investigated.

The core business of human services is to do with ensuring that people are supported well, and live lives of purpose, and have connection in their community. For many, it is reasonable to presume that this support begins in their homes. One can argue that if a person is well supported in their home, then they are able to pursue other areas of their lives, such as meaningful activity, family, and relationships.

In our efforts to create homes for ourselves, our brothers and sisters, our sons and daughters and the people we serve, there are certain efforts and commitments that need to be put in place. These can then ensure that our vision for an individual life becomes a reality. This edition of CRUcial Times explores many of these alternatives.

Karin Swift is a disability activist
and Coordinator of
Queensland Disability Housing Coalition.

From The President

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!! Mike Duggan

My Life, My Home, My Solution

Madonna Nicoll

***Madonna Nicoll** draws on her experiences of living in four different arrangements in her pursuit of a lifestyle that is authentic for her. Her experiences have given her insight into how different circumstances can either impede or facilitate a person's lifestyle, based on their needs, likes and desires. In this contribution, Madonna shares some of these insights about how she has created a life by influencing support arrangements according to her own expectations.*

I was born with a physical disability and was raised by my paternal grandparents. They were the most amazing people and I loved them dearly. However, many times over the twenty-two years I lived with them, their dreams and my own differed greatly, significantly influencing some of my opportunities and happiness.

I lived with my grandparents and attended a special school during my primary years. When it became obvious that attending to my needs was becoming more difficult for my grandparents, I chose to become a weekday boarder at the residential facility where I had attended primary school. Around this time, I also decided to pursue regular education. I attended the local State High School, participating in regular classes with the option of seeking assistance through the Special Education Unit when required.

> **We had a ball but mostly we just lived.**

The residential facility was not a home. It was a building that provided shelter in a restrictive, inflexible and often frightening environment. Meal and bed times were fixed. I was wheeled through main hallways from bathroom to bedroom in a shower chair with little more than a shred of a towel to maintain modesty. This was degrading. What was even more degrading was being in this situation when visitors were escorted into the private sections while this was happening. My friend and I dreamed of a day when life wasn't focussed on physical assistance, schooling, physio, mealtimes and homework as designated by others. Our basic needs were met but the support was at times less than desirable – the fear of retaliation maintained our silence about bad practice. I always complied with workers whom I feared the most – not saying anything even if they hurt me.

Some in-home support became available after three years living in the institution, so I returned home to live with my grandparents while finishing my schooling. It was a huge relief to move 'home' and know that I was loved. However, my grandparents had more control over my life than I did. As a young adult, I wasn't permitted to have my own key and return home late at night like a lot of my friends. I didn't get to go nightclubbing or do many other youthful pursuits at age 18 because my grandparents were frightened of what could happen to me.

This is when I started to develop the idea of my dream life. I dreamt of a day when I would live in a home of my own choosing, fill that home with my own personal touches, do what I wanted to do when I wanted to, live with people I chose, have parties and take part in life! A part of this was the opportunity to make my own decisions, make mistakes and learn from them and be successful. My best friend and I made an application for public housing. We had shared the educational journey and institutional life and at this time, the choice to live with another person with a disability was our decision, not anyone else's. We were first and foremost best friends. The fact that we shared the commonality of disability did not mean that we should or should not live together. It was our choice.

Of course there were a number of issues that impinged on the realisation of my dream to begin with. My grandmother was highly concerned about my safety when my friend and I finally moved into emergency accommodation. Much to my discontent, she used to tell me all of the things that could go wrong. However, as I pointed out, these were the same for anyone moving out of the family home and I had a right to make a home of my own so that they too could live their lives.

When I had been living on my own for a number of years my grandmother admitted to me that her concerns were unwarranted. She had watched me learn and grow from making my own mistakes and experiencing life. My friend and I learnt quickly about the freedom of having our own home. 'Stanley' was often a companion of ours and when asked who 'Stanley' was we would look at each other and laugh and tell that person to look in the fridge. They quickly found out 'Stanley' was a cask of wine, which we enjoyed together with many laughs. I believe if my grandmother had been there at times I would have received a stern, "Madonna, you really shouldn't be drinking that." We had a ball but mostly we just lived.

Another impediment was sharing support arrangements with my friend. Sharing the amount of support and all of the arrangements about staff compromised one person's lifestyle such that the other person could not do what they wanted or needed to do. As time progressed we realised that although we loved each other we wanted our own space. However, we were still restricted by the number of support hours.

After many years of applications we both received individualised funding. With the separation of our support arrangements, we now moved into our own homes while maintaining a strong, unfailing and long-term friendship.

I am now living the dream in my own unit with my cat and cockatiel. I make all of my own decisions, including the nature of support. Physical support is extremely personal, requiring a trusting relationship, so I interview the applicants. Having control of my own lifestyle requires organising my own support rosters to have a flexible, free lifestyle that makes me happy. Most often this support relationship develops into friendship that exceeds the working relationship long after it has ended.

These experiences have made me a well-rounded, competent person. More importantly, over the years I have had experiences. I have laughed, cried, and been happy, sad and angry. I have worked, studied, partied, made friends, lost friends, started a relationship and ended a relationship. I have watched both of my grandparents and my best friend pass away and have grieved for them. I now continue the journey with my father and many great friends and continue to look forward to the next great adventure – you just never know what waits around the corner.

My original dream was about bricks and mortar but it became so much more.

Thoughts about Home

Peter Millier

***Peter Millier** is an independent consultant and Senior Trainer in Social Role Valorisation, who is based in Adelaide. In this article, Peter reflects on the places which people with a disability call home, especially group living arrangements that are often imposed, without paying attention to those aspects of 'home' which we all recognise and value.*

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In 1989/90, I had the privilege of sharing a home for six months in upstate New York with four people with an intellectual disability. The home was part of an intentional community, where people with and without disabilities lived together, and shared in each other's lives.

As well as sharing in the ups and downs of their daily lives, I learned much about the dilemmas and dramas for the people with a disability, the people who shared in their lives (called assistants) and their families. It challenged many of the assumptions that I had formerly held in my work as a disability professional and bureaucrat who had been involved in the development of community-based living arrangements and supports for people with disabilities and their families. The people with whom I lived were my teachers and the lessons they taught have stayed with me for the past 18 years.

I learned that the agency that funded the home did not allow the people to have a guest come to stay. They had to conceal the fact that I was living there. It struck me immediately that the people who lived there did not have much control over many things which the rest of us take for granted, like having someone to stay and offering hospitality.

It also became obvious that living in a home within a loving community could not undo or address a lot of the rejection and abuse from the past. David, one of my housemates, had lived in an institution for over 20 years. There he had acquired tuberculosis and hepatitis, which eventually killed him. He had also had to fight for his food each day in the institution. So, even though there was plenty of food available in the house in which he had lived for 11 years in a loving and caring environment, he still snatched at food on the table and stuffed it down his throat. The community could not resolve this. They simply walked along beside David to ensure he had a loving home for the remainder of his life.

The longer the time I spent with my four housemates, and learned about their previous lives, the more things I found to reflect upon and be sad about. Yet there was lots of fun and joy too. In particular, I enjoyed the evening meal, which was a real celebration and communion. Friends and family dropped by without having to make an appointment. We went out together to wrestling, basketball and also just to visit other friends. There were the rhythms of the day around work and recreation as well as doing household chores. There were holidays.

Another of my housemates, Mary, aged 50, got married. The community had a few conniptions about this; Mary said it was like having many parents telling her what she should and should not do. Eventually they found a way to support Mary and her husband when they moved into an apartment after their marriage. The community had to learn and adapt too. Mary was telling them that, although the community met many of her needs, it could not address her need for an intimate relationship.

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After Mary left the house, Eric moved in. I asked what the process was for someone new moving in, and was told there was no formal process. The assistants and housemates would simply spend time getting to know Eric, learn about his life, his gifts and his needs, in order to find the best way to support him – so simple, so uncomplicated, so sensible.

Yes, my housemates taught me lots, not just about joy and sadness, but also about tolerance and forgiveness, as well as not a little humility. The home in which they lived was not perfect but it had many elements of home with which I could identify. Henri Nouwen, who lived in a L'Arche community in Toronto wrote that the people with disabilities form the heart of the community:

> *They are there to stay; they are there to build fellowship; they are there to offer stability. Ironically, it is they who are the strong ones, they who welcome their assistants and offer them a home.*

Nouwen was making a profound point. He suggested that the assistants, as much as the people they served, were in search of family, friendship, intimacy, affection, faithful relationships … a place to call home. He was also asking how can it be possible to create a home for others if we do not have a deep understanding of 'home' in the physical, emotional and spiritual sense.

I carry these, and many other thoughts with me when I go to visit and/or evaluate the various community living arrangements called home by people with an intellectual disability. So often I find people with good hearts and good intentions manage these homes, but the essence, the essential ingredient of a home, is missing. Rather, people are living a programmed life; sometimes even the meal is a programme, as are so many other aspects of home life that we take for granted.

A parent on a team which I was leading to evaluate a group home, where every activity seemed to be a programme, asked when were the residents going to get to the 'get a life' programme. He too was making a very important point. Many people living in all sorts of community living arrangements are spending their time preparing for the life they are never going to get.

So what do I look for when I go to visit the home of a person (or persons) with an intellectual disability? I pay particular attention to the quality of the relationships and the amount of real control that the person with a disability has. I endeavour to have a meal with the person(s) wherever possible. I listen to the conversation. Is it real or phoney? Is the tone of voice respectful or demeaning? Who decides what happens? Often, even such an apparently simple matter as choosing a video/DVD to watch is controlled more by staff than by residents. "Oh, you have seen that video a hundred times already. Why don't we watch …?"

Do people have a key to the door? Do they have their own space(s) to protect their favourite possessions? What is the 'feeling tone' of the house? Are visitors welcomed? Can they drop by without having to make an appointment? Who owns the living spaces? How much is staff territory that is off limits to residents? How is an individual's privacy and dignity protected? Are personal matters really discussed in private or are they everyone's business? Is there a sense of fun and joy? How are major life events celebrated?

Despite the fact that I visit many houses which look like home and which remind me of the four people with whom I shared a home 18 years ago, so often I find a place that isn't a home – a place without a welcome, without a common table, without friendship and intimacy, without any sense of joy and celebration. To quote Nouwen again:

> *There is much homelessness in our society: the homelessness of the elderly person, the homelessness of the single man or woman, the homelessness of separated couples, and the enormous homelessness of the many who are alone together*.

References available on request.

My Own Home

Melissa Noble and Sue Austin

***Melissa Noble** supports **Sue Austin** to live in her own home. In this article they discuss the enrichment, wellness and joy that Sue gets from living in her own home.*

Mel explains: When I first began to work with Sue in 2006, she had been in her house for three years. Before that, she had spent time in various hostels, mental health wards, hospitals and then in private accommodation. It seemed that Sue saw her home as a safe haven in a potentially hostile world and she was often very reluctant to leave that home. Sue went out shopping once a week and mostly attended church on Sundays, went to bingo on Friday nights and attended hydrotherapy. Sometimes Sue was reluctant to go to these places and would change her mind at the last moment.

Mel: When I began to work with you Sue, I remember that you liked to have a lot of things done for you. Now you do more and more for yourself. You also seemed to have fond memories of being in places where you were looked after – hospitals and mental health hospitals. I'm wondering what you think has changed about how you feel in your house now?

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Sue: Now I have my own space. I don't have to share my bedroom with other people. I don't have people harassing me. I have my freedom and I can come and go as I please. I can choose my own food and mostly cook for myself. I can have a dog staying in my home for company. I like having all my things safe and my house looks very nice. I can go out and water my own garden, check my own mail, answer my own phone and invite people to my house … whoever and whenever I please.

Mel: So now you feel safe. Is that a big difference?

Sue: Yes, I feel safe because I can concentrate. I don't have people fighting and swearing and using bad language and fighting over money and smokes and stuff. I don't have to listen to other people's music playing.

Mel: Who are the people who've supported you in making your house a home?

Sue: My sister Deb made sure I got this house and she has wanted me to have the same things that other people have. Now, I phone Deb without having people yelling in the background. I can have her come and stay in my house and also have my family visit. My support workers have also helped me feel that my home is a good place to be.

Mel: These days you do a lot more activities. For example you do scrap-booking and beading. You also cook for yourself and do chores. You go out to Access Arts and have people over to visit and you enjoy your garden. Did you ever imagine that you might have your own home when you were living in boarding houses and staying in hospital?

Sue: I imagined it, but my social workers and doctors thought I couldn't cope or manage; they just wanted to medicate me all the time. We used to have meetings about it, but people thought I just wouldn't be able to cope if I had my own house.

Mel: Do you think that feeling safe in your house has meant that you are confident about trying new things?

Sue: Yes … I always have my house to come home to. I feel independent and want to try new things. Now I want to use my walker rather than the wheelchair, before I didn't. Before, I used to get people to do things because it made me feel I was in control. I was scared that if people didn't have to do things for me they would resign. Now I do more and more things and people are still there when I need them. I still worry that something might happen to my house … but it's just worrying.

Mel: You've also impressed us all with your self-control in losing weight and managing your eating. Do you think that would have been possible when you were living in the boarding house?

Sue: No, because we used to eat fatty foods. I used to like fatty foods and junk foods. In my house, I've learned that healthy foods can taste good if you cook them properly. I have herbs growing in my garden. I still like fatty foods and sweet foods sometimes … I dream about them. I can have them sometimes but just as a treat.

Mel: What are the important things for you about your home?

Sue: Privacy – my bathroom is nice and I don't have to share it. I have my own toilet. I have pictures painted by my mother on the walls. I can make it nice and do different things in my house such as scrap-booking and having people over for morning tea.

Final thoughts from Mel: So what are the elements that contribute to an environment where Sue can grow and develop? These include the support and guidance of Sue's sister Deb, workers who are willing to support Sue in exploring possibilities and achieving goals, advocates whom Sue trusts. Most importantly, Sue has a willingness to explore new possibilities, overcome obstacles to independence and take ownership. Sue embraces change with enthusiasm these days.

This is all to do with her house. Without the security of her house and all that this has meant, Sue would not now be in a situation that has enabled her to make real changes in her life. Her home has provided a secure base for change and growth. In Sue's words, "I know that I can leave my home safely and always have it to come back to.

A Life With No Comparison

Jude Lang

Jude Lang lives on the Sunshine Coast with her husband, and has been key in helping their son Indigo to get a home of his own and a life that is rich with possibilities.

"Bye-bye Mum," – the sweetest sound I could ever hear. People overhearing this statement coming from Indigo, my son, would cringe for me, realising that this was code for "Buzz off". They would feel apologetic about it, no doubt wondering, initially, if he was anxious to get rid of me because I had been treating him badly. They would gradually loosen up and enjoy my smiling response, particularly as, if I didn't get going right then, the next step would be, "Bye-bye, Mum; I love you." ("Now, I really mean it: please GO! What more do I have to say to get you moving?")

Sweet, because it means that Indigo is actively happy now, in his own place with his own staff, people he would rather spend his time with than with me. He is telling me clearly that he does not need me – bliss ... and that he is slowly gaining greater awareness of having control of his own life. Mind you, if I am completely out of his life for too long, he doesn't handle it so well. Last year when my dear husband, Kirk, and I went off camping in the bush with our two dogs for a couple of months, things went pretty pear-shaped for him for a while. His staff, with commitment & determination soldiered on to a point where they felt he got through his grieving, was reinventing his life without me, and discovering that it wasn't all that bad.

Indigo has been in his own unit near us for over two and a half years now, having previously lived in a shared house in Brisbane with three other people with disabilities for many years. He was not happy. He hated going back after his regular visits home to us in the Sunshine Coast hinterland. He seemed to be developing more complex and challenging behaviours as the years rolled on, some of his own invention and some absorbed from his housemates. Their house, and its 'fifth bed', was often used as a temporary residence for people who were 'difficult to place' and the needs of these people had often supplanted the needs of our family members. Sometimes, the lives of our family members went on hold for months, or even years, at a time.

This is not to say that staff were awful, though some were, and we were often frustrated by our lack of power in keeping good ones and getting rid of bad ones. So often, someone who worked really well with our family members would suddenly be moved somewhere else, sometimes because their skills were seriously needed elsewhere to put out fires. Sometimes it was just to remind all of us that we shouldn't get too comfortable and make emotional attachments. My heart broke many times over the years when someone Indigo had grown to love – and heaven knows this was a hard thing for him to do or to understand – would suddenly disappear completely from his life. No wonder he gets jumpy if I go away for more than a couple of weeks.

One of the joys of an independent life in our community for Indigo is that he now has some control over keeping relationships going with staff who have moved on for one reason or another. One beautiful young woman stopped working with Indigo, to have a baby, but she is still part of our family. To ask to see someone who has been a personal assistant and to be able to invite them over for a barbecue or even to visit them in their own homes is, well, normal, and nice. Yes, this really crosses the barrier between 'worker', not taking your 'work' home, and friend, but I value this deeply.

> *My heart broke many times over the years when someone Indigo had grown to love – and heaven knows this was a hard thing for him to do or to understand – would suddenly disappear completely from his life.*

For many years, Indigo was on a housing waiting list for a transfer to the region where we live. Nothing was happening and nothing was likely to happen. “Heck,” we were told, “he had accommodation; what more could you want for him? Consider the needs of all the others out there.” However, an incident of abuse brought things to a head and it was decided that he would be safer near his advocates, his family.

So began the long search for someone to share with and somewhere to live. This would be the only way we could make his funding stretch, we were told. But we realised that to share with another person with a disability would put us straight back into being powerless in another mini-institution, albeit nearer to home. However, we did meet some very good people through this process, who are now part of our broader community.

When Indigo was allocated a unit through public housing, it was time for the disability support funder to match its own claims. It said it believed in individual responses, but this required them to ‘unbundle’ funds from a block-funded arrangement. This proved to be sticky, but eventually my husband's reasoned arguments and my pig-headed determination led to the right thing being done for this young man.

Indigo now has the best possible chance for the best possible life he can lead, and I am well satisfied with that. In his own home, he is not told “don’t.” Staff think carefully about the words they choose. He is shown what he needs to do, so that he learns more control.

Every time he, his staff and I walk into his lovely, calm, open and welcoming home, we all feel good. This life bears no comparison to the one he had before.

Segregation and Congregation and the Gaining of a Real Home

Bob Jackson

***Dr Bob Jackson** is a well-respected consultant from Perth (WA) who draws on 30 years experience in human services and education in writing this article, which critiques the limits of group homes.*

The pull of a group home has always been very strong for many families who have been counselled for decades by professionals that this was the optimum placement for their son or daughter. The appealing promise of a group home was that they would be included in the community but looked after by staff, and so be safe from exploitation and harm.

Group homes attempted to address the many shortfalls of institutional life. Research over several decades that compared quality in institutions versus group homes has shown that large institutions reach only 10% of the maximum score when objectively evaluated. On balance, they do much more harm than good. In comparison, similar research on community housing (that is, group homes and similar arrangements) shows that they often reach 'acceptable' levels where the balance of harm and benefit to individuals is approximately equal. In fact, when the number of people in a group home is three or fewer, the probability of a positive score goes up considerably, but still falls far short of the 'ordinary life' achieved by others in the community.

In considering the problems with group homes, it is worth thinking about the implicit assumptions that they embody. Their presence implies that people with a disability should be congregated 'with their own kind', that general members of the community would not choose to share their lives with people with a disability, that the support provided needs to be paid rather than freely given, and the needs of people with a disability are less than other members of the community.

On this last point, general community members' lives are rich with valued roles, have considerable power in decisions such as who they live with and where they live, enjoy a positive reputation in the community, are filled with challenge and growth, and the home is the launching pad to a rich and valued life. It is unlikely that anyone would claim that a group home achieves anything like this ordinary life and research on the outcomes of group homes supports this.

To be included or belong in the community one needs to be there, to be socially participating, to have valued roles and the skills to be in those roles, to have learning opportunities, to have a positive reputation, to have a positive view about oneself, and to be surrounded by positive expectations by others. A group home allows one to be 'in' the community, but not necessarily 'of' the community.

To be congregated with three or more other people with a disability has several consequences. It is telling the community that the most important aspect that they should notice about you is your disability – why else would you have been put together on that basis? As disability is a devalued characteristic, the grouping of people on the basis of impairments heightens the likelihood of rejection and avoidance by others, whereas one person with a disability living with one or more valued community members would be much more likely to be engaged and included.

We need to start with the will to try for an ordinary life.

Being grouped with other people with a disability almost certainly means that the available role models are also deficient in skills. We know that when we are surrounded by others of equal or lesser skill level our skills do not develop as well as when we are surrounded by more competent models to copy and be inspired by. Also, the expectations of staff working with the group tend to be 'disability related' rather than reaching for community level expectations.

Even worse, disability groupings can cause major loss of skills because the service is geared to the lowest common denominator. For example, all are locked in because one person wanders, or all are kept home because of the antisocial behaviour of one individual.

It is very difficult not to cause a community reaction of fear and avoidance when four or more people with disabilities are supported in a group in the community, even when there is no difficult behaviour in the group. Neighbours are not likely to invite four or more people with a disability as well as staff to a BBQ or neighbourly events. In fact, the reaction to a group home opening is often one of hostility, whereas one person with a disability moving in next door is likely to be accepted and even welcomed.

Overall then, the group home continues the processes of the institution in many ways. The congregation of people by disability is highly likely to cause rejection as it causes focus on this devalued characteristic and so feeds the stereotypes that exist. It continues the problems of loss of control over major life decisions, vulnerability to unreasonable demands of staff, stereotyping around negative roles such as incompetent or childlike, low expectations, and lack of community belonging. If we think of the goal of an ordinary life – and surely that is not an unreasonable goal – then it is clear that the group home model will have great difficulty making this a reality.

We now have many examples of people who, in their own homes, in work places and in other places in ordinary life, have made substantial gains in their development. They are surrounded by more competent role models and normative expectations that do not seem to occur in disability groupings.

All around the world we see people achieving an ordinary life in the community with natural support from ordinary members of the community. I cannot believe that we are incapable of achieving what others have managed. We need to start with the will to try for an ordinary life. Then with creativity and focus on what is ordinary and valued, we can start to build ordinary lives for people who will otherwise continue to exist in lonely and unstimulating environment.

AT LEAST THE BARBED WIRE HAS GONE NOW

Bob Lee

***Bob Lee** lives and works on the Sunshine Coast. In this article, he draws on his extensive experience in the lives of people with disabilities as a service worker originally and as the Coordinator for the local Citizen Advocacy Program in more recent times.*

Many years ago I was visiting a friend in the small room (more of a cubicle really) he occupied in a nursing home. It was quite a momentous day. It was the last day he was to spend in the institution he had endured for much of his life. We were quietly talking about all the things he would soon be able to do which were not now possible. Not very radical really, not even irresponsible! Just some of the things you can do in your own home. Things like … sleeping in on the weekend, staying up late at night, eating between meals, having a friend over for coffee or a meal, having a garden, and maybe even having a pet cat.

Just as we were getting a little more ambitious with the expectations, some new faces appeared at the door. It was a group of concerned looking people arriving to say farewell … well not really. We all knew that it was a last ditch effort to talk him out of moving. The leader of the group shuffled in as I shuffled out to make room. She loudly exclaimed about the ‘lovely’ room and said the fatal words … “I don’t know why you want to leave here. I’d be happy to live in a room like this!”

I will never forget the next few moments. He was always so quick to spell out his words on his communication board. This time however he took his time, taking great care to ensure that his response was clearly understood. “GOOD … YOU CAN HAVE IT … I’M MOVING OUT TOMORROW!”

During the rather strained silence which followed this exchange, I reflected yet again on the tension which always seems to exist between two genuine concerns involving people with a disability. On one hand there are those whose primary concern is for the safety and security of vulnerable people, and on the other there are those who are struggling to assert their legitimate rights to have a regular life as part of their community. This tension is perhaps most obvious in the continuing passionate discussions about where and how people with a disability should live.

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> then we could
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> of our good intentions.

Like many others who were living in institutions because there were simply no other options, my friend moved out and made a home for himself with the support of family, friends, and newly employed paid workers. He, like those who had gone before, found that far from being hostile and dangerous, the ‘community’ was in fact welcoming, accepting and determined that people with disability should have a fair go in life. He found that his neighbours, local shopkeepers and others he met in his new neighbourhood were quite willing to offer advice and assistance without having to be paid, and to his great delight he found someone who shared his love of gardening.

Like others he found that relationships with those who were paid to support him were very different from his time with workers in the institution. He found that without a staff room to go to, his support workers would have their coffee break with him. He found that loyalty, accountability and respect were re-oriented to him rather than to the employing agency. He shared the experiences of so many others and found that genuine reciprocal friendships developed which more often than not, went far beyond the work role, and endured long after the working relationship had ceased. Some people with a disability who employed students as support workers now have lifelong friends who are doctors, lawyers, journalists, movers and shakers. In other words … friends in high places.

Perhaps most welcome of all was the unexpected sense of safety and security he came to enjoy. He had anticipated, because he had been relentlessly warned, that the cost of gaining some independence, autonomy and privacy was that he would no longer be protected by the walls and rules of institutional life. To his surprise however, he felt safer than he had since he had left the family home years ago, and certainly safer than he had ever felt while living in the institution.

Those who are planning for the future are often convinced that a choice between group home or living in a real home means choosing either the safety, security and supervision of an institutional model, or the risk taking and unknown dangers of ordinary community living. Many of those who live or have once lived in institutional places will remember their own experiences and react with laughter, sorrow, or abiding anger at this deeply flawed thinking. Such thinking ignores the existence of the routine humiliations, and regular incidents of abuse and neglect which continue to occur behind the closed doors and high fences of institutions.

Nothing has moved me so much as seeing the unrestrained, inconsolable grief of a man who asked me what it was that he did wrong, to be moved to an institution six hundred miles away from his family home where he had lived as part of a loving family for forty years. This man needs more than an explanation. He needs to go home. He needs to have the opportunity to live close to his family and friends, and to be once again part of the community he belonged to for most of his life.

However challenging it is to say so, the truth is that satisfaction, safety and security for vulnerable people are not provided by buildings of any kind, particularly buildings which serve to isolate people from the community in which they live.

It is all about people. What is most effective at keeping us safe is exactly what makes life interesting and fulfilling for us. It’s the connections we make, the relationships we have with others which make our lives safe and secure. If we live where we are detached from the unconditional support of our families, and are prevented from making other independent relationships, then we are truly isolated, and buildings will not protect us from the predations of those who seek to do us harm.

People have found that really effective safety and security comes from knowing the neighbours, having friends and family who visit, and being part of a community whose eyes are watching what happens. A community which has a belief that people with disability should be treated with respect and given a fair go, will simply not tolerate the abuse, neglect and exploitation of those who are vulnerable.

I have never met anyone who was placed in an institution because those who did the placing wanted them harmed. The motivation is most often about safety, security, professional care, and ‘peace of mind’. Unfortunately, when isolation, rejection, abuse and neglect comes along as part of the bargain, peace of mind gets considerably diminished.

We all need to resist the temptation to associate the strong walls of institutions with protection from harm. We need to resist the temptation of seeing the congregation of people with disability as anything like family life.

Perhaps if we listened a little more carefully to those with personal experience of institution or group home living, then we could do more to avoid the unintended consequences of our good intentions. Recently, I found myself at another institution visiting a man who had lived there for many years. He was a quiet, gentle person who liked to sit in the sun. He was placed in the institution by family members who were reassured by the talk about the place being ‘just like a big family’. As we sat together one fine morning I asked him how he liked living there. He glanced up at the two metre high chain wire fence with the three metre high posts surrounding the building and said … “at least the barbed wire has gone now.”

How Genuinely Supportive Persons, Agencies And Systems Can Enable People To Have Real Homes Of Their Own

Michael Kendrick

__Michael Kendrick__ is an international consultant, specializing in values-based leadership and social change in the disability and aged areas. The following analysis provides critique and insights that are relevant to those who seek to improve the service and system responses to the needs of people with disabilities.

Introduction

It is not always the case that what ordinary people may think of as a ‘real’ home agrees with what agencies and systems may think of as a ‘real’ home. This is because everyday people exist in the world of normative culture in which a home can mean much more than simply a place to live. A ‘real’ home is not solely one’s dwelling place, but rather a key crucible in life that helps sustain and uphold much that is deeply personal, private and intimate about us. It reflects our deep identity, values and preferences for a good life.

Agencies and systems are not impervious to such concerns about home, but they may often come under the sway of other intentions and preoccupations that can distort how ‘home’ becomes interpreted in practice. What follows are some initial guidelines as to how supportive persons, agencies and systems can define their role in such a way that they can become a help rather than a hindrance to achievement in the lives of those who may require support in order to obtain a home of their own.

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

Supportive persons, agencies and systems should recognise that people should have sovereignty in regards to their homes and lives.

It is quite normal for people to want to be ‘captains of their own ship’ and to have the dignity of being master in their own lives. Often, when such persons require assistance in their lives, this dependence upon others can often act to undermine this autonomy, especially if the supporters act in ways that assert their dominance over the person’s life and home. On the other hand, should such support persons, agencies or systems be deeply appreciative of the person’s need to preserve and assert their personal sovereignty, then it would help create the ‘right relationship’ between such persons and those who seek to support them. In most instances, the ideal result is that one’s home is one’s castle.

Supportive persons, agencies and systems should ‘idealise’ what is a ‘real’ home and be guided by this.

It is unlikely that supportive persons, agencies and systems can properly uphold the fullest potential of what might be a ‘real’ home of one’s own, without first taking the step of defining what ideals should guide the growth of people in their own homes and lives. Such ideals, if properly understood and appreciated, can then help guide their conduct, roles and perspectives relative to people and their lives. In this way, they may move from possibly undermining ‘real’ homes to becoming champions of this cause. Nonetheless, they will fail in this task if they do not first thoroughly clarify and sincerely embrace the ideals that best represent ‘real’ homes. Should this occur, then it becomes possible to help people to optimally obtain and sustain ‘authentic homes of their own’.

Supportive persons, agencies and systems should recognise that one’s home should be principally a private and personal setting rather than a public one.

There is much to be lost when one’s home has become a public rather than a private space. For this reason, it is necessary that supportive persons, agencies and systems intentionally start from the premise that people's homes ought to be kept private and personal rather than be converted to places that are no longer private. 'Public spaces' are settings that are not controlled by the person but rather are dominated by impersonal entities operating in the public domain such as agencies and systems. This tendency may be further strengthened by laws, regulations and practices that assert more authority over what happens in one's home than the person whose home it is. This intention to keep the home principally that of the person does not mean that it cannot be supported by public funds. Rather, it simply means that having a home of one's own can also be the goal of public funding authorities.

Supportive persons, agencies and systems should recognise that designing, establishing and sustaining a home of one's own should be principally done by the person whose home it is.

Though many individuals may require assistance to fully design, establish and sustain a home of one's own, this is no reason not to have them unambiguously central to this process. When a home becomes dominated by persons and entities other than the person whose home it is, it raises the quite legitimate question of whose home it actually is. The only way to know for sure is to eliminate any other possible rivals for dominance of the home and to entrench the person as the undisputed sovereign of their home and their lives. Further, such individuals should have the opportunity to explore and pursue all of the rich and diverse options for what home life can be, so that their eventual 'home' is as fully developed as it could be.

> ***Supportive persons, agencies and systems should recognise that designing, establishing and sustaining a home of one's own should be principally done by the person whose home it is.***

Supportive persons, agencies and systems should recognise that whenever a vulnerable person requires safeguarding or supervision, that this should be accomplished without subordinating or weakening the person's sovereignty in their home and life.

The tendency to 'take over' a person's life can readily be justified by many if the person's conduct is wanting or if the person is facing harm or damage. Though in moments of panic or anxiety on the part of supporters, it may not always appear this way, supporters can readily undermine people's sovereignty by refusing to approach personal supervision and safeguarding from the view point that this supervision and safeguarding need not come at the expense of their sovereignty over their homes and lives.

Supportive persons, agencies and systems should assist the person to individualise their home and lifestyle.

A person's home is an expression of who they are, and it is expected that this home should reflect the personality of that person. It should not be assumed that this personalising of home is always immediately possible, as with some individuals it may be harder to do. Such individuals may simply require more support in order to do as well as they can. Further, since each person is unique in their needs and requirements to succeed with making a home of their own, the type and extent of support should be adjusted to best address the person-by-person nature of 'home' and lifestyle.

Supportive persons, agencies and systems should not own and control people's homes.

The argument for a separation of housing from support has been made on many occasions and has much merit. However, simply separating these functions alone may not entirely resolve this issue. Even in exclusive support roles, many persons and agencies could still exert control and dominance of the person and their lifestyle. The advantage of agencies not 'owning' the person's actual home is to emphasize the person as holding unambiguous home ownership or tenancy. It also narrows the question of whether the supportive person or agency undertakes its support duties within the proper framework of respect for the person, their home and lifestyle.

Supportive persons, agencies and systems should adopt approaches to management that shield people from unhelpful or invasive bureaucracy.

While not all bureaucracy is noxious and invasive, there are variants of bureaucracy that are. Increasingly, many conventional residential services are awash in bureaucracy of all kinds due to the requirements of the agencies that either support or fund such settings. This invasive bureaucracy can radically turn one's private home into a regulated site such that it begins to become the agency's home due to the agency's ability to impose its requirements on the home. Though many people may not realize it, much of this bureaucracy can be diverted from people's homes or otherwise minimized in terms of the amount, noxiousness and level of control that has an effect on the person and their home. To do so will require that the agency take intentional measures to bring this about since it is the principal vehicle for both the imposition of such bureaucracy as well as its withdrawal.

Supportive persons, agencies and systems should not compel nor coerce people to live together.

Though coercion of this kind is not a practice that agencies like to acknowledge, it is nonetheless quite widespread. This is in contrast to the occupants of homes largely deciding with whom they wish to live, including opting to live alone. These practices can be overcome by simply relinquishing sovereignty to people to decide with whom they wish to live. Put another way, it means that all relationships of home sharing must be entirely voluntary and the specific terms of these negotiated between the parties rather than household composition being imposed by other parties outside the home. This also applies to supporters that may either reside in the home or visit. These relationships should also be voluntary in nature and respect the shared and individual sovereignty of the persons who reside in a given home.

Supportive persons, agencies and systems should welcome, respect and cooperate with the person's relationships and personal networks.

Part of making a home of one's own is to integrate one's home life with one's web of relationships and one's lifestyle. This task will be thwarted if the supportive people or agencies in one's life lack suitable regard for the people in one's life. Relationships are an integral part of home life and personal lifestyle and it is important to uphold the relationships and networks that are important to a person. Relationships can also be very private and personal and therefore will need to be respected by supportive persons and agencies. It may also be true that some individuals would like to strengthen and expand their relationships and networks and may benefit from competent and thoughtful assistance.

Supportive persons, agencies and systems should utilize arms-length governance to enable people to have directive authority over shaping the supports they receive.

Many agencies are unaware that they can fashion ways to partner with people to ensure that such persons are placed in a directing role relative to the supports they use. Such empowered options can include various mechanisms such as hosting of service- user governed projects, providing administrative, financial and other back up to self-directed or self-managed individual supports arrangements, and even cultivating new mini-agencies or projects. To do this would require agencies change their preference from authority resting only with those in elite agency positions to delegating decision-making about the design of services downward and outward to the service user and their allies. This would make agencies champions of the empowerment of people and extensively reduce their role as an obstacle to people directing their own supports, including those that come from unpaid sources.

Supportive persons, agencies and systems should avoid support arrangements that unduly commercialize relationships with supporters in home sharing arrangements.

The sharing of home with 'ordinary' people with whom one is compatible is clearly an option for many people. The voluntary nature of these relationships can become obscured whenever people are paid to live with a given person, such that the money becomes the rationale for home sharing. In many instances, where the amounts of money are sizable enough, the paid home sharing essentially becomes a job and the home a place of work. In extreme instances, the paid person quits their former employment because they can make comparable money 'home sharing'. While such homes may preserve much of what makes a home a home, it is nonetheless a return to homes being a part of agencies and systems.

Conclusion

Genuinely supportive persons, agencies, and systems can become welcome allies for people who want to have genuine homes and lives of their own. At the same time, they can also be an obstacle if they do not appreciate the many ways that they can get in the way of this goal. Becoming a useful ally of people does not happen by accident, and it is important that people, agencies and systems that want to be genuinely supportive, carefully study the differences between what helps and what hinders. In this way, they can make and uphold the decisions and principles that matter most.

Helping Create Home: Working In The Midst Of Relationships

Craig Brown

***Craig Brown** works for a small foundation in WA that provides individual accommodation options to people with disabilities. Craig assists John, a 37-year-old man with an intellectual disability who lives in his own home. His parents have been instrumental in supporting him to gain funding for this to occur. The article acknowledges and works through the tensions that can exist between the interests of the family, the individual and the service.*

John works at a sheltered workshop, enjoys tinkering with machinery, helping out his neighbours, having his friends over from work and playing computer games. He knows what he wants out of life but is influenced by his family, especially his parents, who want to keep him safe and protected from the world. John's happy go lucky nature makes him a popular person, but his height (6' 3"), weight (145kg) and forthright opinions can sometimes be off-putting and intimidating.

John's family love him very much. They have worked hard over the years to secure ongoing funding to support him and find him his own home specifically built to suit his needs. They have very set views on how John needs to be supported and the way he should live his life. John has often asked for more independence, but they have been very reluctant to respond to this. They do not want John to fail in ways he has in the past and believe that the world is a hostile place full of opportunists ready to take advantage of his vulnerabilities.

John's support structure was designed to keep him safe, secure and supervised at all times when he was not at the sheltered workshop. A team of four support workers were engaged to live-in with him over a rotating fortnightly period. John and his parents understood 'support' to be 'staff' that were there to look after him as well as protect him. This role did not sit well with some of the support staff, while other staff had decided it was all too hard and they would do whatever they wanted, whenever they felt like it just to get through their shift.

> *…the complexity of support work… requires good thinking, clear direction and planning, and the need to listen to and respect the wishes of the individual.*

Coming into John's life as a new coordinator, I was astounded at the lack of direction, consensus and commitment in place to assist John toward having a regular life where he had opportunities to grow emotionally, develop more skills and take more responsibility for his own life. His parents were mostly happy with the support structure but said that John needed to be more controlled by his supports for his own good. They wanted him contained and controlled so he was not in any danger and did not pose any problems to others.

This raised a great conundrum. John was reliant on his support staff to do things for him, to help him prevent overstepping boundaries or to rescue him if he did. He liked having others be responsible for him but at the same time resented having the supports around him all the time. John's support staff seemed to be completely confused by what their role was. His parents were telling them how to support John, as 'they knew their son best!' and they had certainly known him the longest and been through much with him. John was telling them what he wanted, which was usually based around having someone wait on him when he wanted and then leave him alone as he resented their continuous presence around him. Then there was the role they had been engaged to perform with a duty statement that talked about promoting independence.

My challenge in assisting John to move forward was to find a way to have him heard while at the same time protecting the relationship with his parents, the relationship between John and his supporting agency, and the relationship between the agency and his parents. His supports also needed clear direction and guidance to understand their role in supporting John into the future.

An external advocacy agency agreed to assist John through the process of being heard. This was an important step as it enabled John to be supported by someone independent of his support agency, gave legitimacy to his wishes in the eyes of his parents, and meant that his parents could not be upset with John's supporting agency. It also enabled John to take responsibility for the decisions he was making.

The advocacy agency worked closely with John to identify his issues and supported him in taking responsibility for what he wanted to happen. They outlined a clear process for him to follow and supported him through this. John countersigned correspondence to his parents. His parents and other key people in his life were invited to attend a planning meeting to discuss John's wishes for his future. His parents declined the offer to attend and the planning meeting proceeded, with John outlining his goals for the future. All of John's goals were reasonable and appropriate and all were recorded. This plan gave the supporting agency a clear direction to follow.

As a result of the planning process, the support model was restructured to one that allowed John to take more responsibility for his life while still safeguarding him. John now has a support person living across the road from his home, providing him with regular and incidental support. He has blossomed over the past four months since the restructure, and is making significant gains toward achieving many of his goals. He now uses public transport independently, has more control over his personal finances, has friends visit him and goes out with them without support. He is happier and more productive at work; he has joined a local gym and his relationship with his support staff has improved.

John's parents continue to be involved in his life. They appear to be warming to the new arrangement slowly. They still have regular, mostly positive contact with John's supporting agency. John's supports staff are happier in their role. Their interactions with him are more positive and they are pleased to see him progressing toward his goals, knowing that their interactions are assisting him to grow and develop.

John's story highlights the complexity of support work in helping people get their own home. It requires good thinking, clear direction and planning, and the need to listen to and respect the wishes of the individual. Finding a way to protect relationships through a process of change can be tricky, but the rewards at seeing someone happily achieving new things and taking on responsibility for their own actions and lives is definitely worth the journey.

Providing Housing that becomes Home

Susan Austin

***Susan Austin** has worked in the community sector for over 20 years and is currently working for a Community Housing organisation on the Sunshine Coast. She has worked in a range of areas including working with survivors of Domestic Violence, people experiencing Mental Health issues/Severe Emotional Disturbance and Community Housing. Susan has had many experiences to support the belief that a person-centred approach, where the individual is primarily involved with planning for their future, has the most successful outcomes.*

I would like to introduce someone with whom I have worked. 'Heath' is a single guy, about 26 years old, who loves the Broncos. He enjoys having his friends around to watch the games. He has just left his job in a furniture factory as he thought it was boring. This is a brief story of Heath's journey over the last few years; it demonstrates how he was able to think about how and where he wanted to live.

Provision of a unit from a housing organisation enabled Heath to leave his mother's home and share with a guy with whom he worked. This is how we met. It was early on in the share arrangement when Heath told us he didn't like sharing with his flat mate. He told his disability support worker and me as his housing worker. We worked together to consider what options he had. Eventually, Heath was able to live in the unit on his own. He had two hours support a week to help with shopping and paying the bills. Health also had the assistance of the Public Trustee to help manage his money.

As Heath was living in a large complex, he had many other tenants to get along with. Initially he had some difficulty 'fitting in'. One of the important aspects of community housing is that the tenants are encouraged and assisted to live in a harmonious environment. Tenant participation is crucial so that tenants can live in a safe and secure 'community'. Holding working bees is one good way this can happen. People also share lunch together after the working bee, and this creates a spirit of community. As it had been difficult for Heath to become involved in the general activities at the complex, the housing managers encouraged him to help out with the working bees. They encouraged the organisers to include all interested tenants. Initially, Heath helped grudgingly, but through good humour and camaraderie, he soon became part of the working bee culture. He nominated the jobs he would do and even enjoyed the barbeque at the end of the work.

Heath experienced some problems with his neighbours. Some of his visitors were making too much noise and this caused complaints. Some of the tenants were able to tell Heath directly that they did not find these visits acceptable. Because of a good working relationship with Heath and his support worker, the housing manager was able to assist Heath in putting some boundaries in place for his visitors. Some of these visitors were even unwanted by Heath; they intimidated him and he felt he could not ask them to leave.

> *A positive relationship, where they feel they are listened to and have supports in place, helps them to achieve the best possible outcome.*

With the help of his support worker, Heath learnt some ways to tell visitors that their visits were getting him in trouble. He kept his front door locked and told them he did not want them to visit. Heath was able to live more comfortably and not be frightened of unwanted visitors.

Heath was originally housed in this unit complex due to a vacancy coming up. It is difficult for people when they are housed in this way, as it does not give them a choice about where they live or with whom they live. They can feel they do not have any control over their lives, as they are not able to live in a way that is comfortable for them.

Over time, Heath let us know he no longer wanted to live in the town he was in. He wanted to be closer to his sister and mother. After many years, when an appropriate transfer became available, we were able to offer him a unit closer to his mother and sister. As excited as Heath was, when the time came to move, he became very emotional about missing all the other tenants and was torn between moving, and leaving his well-developed network at the complex. However, the lure of a new start won out and he was strongly encouraged to come back and visit with the other people at the unit complex anytime.

One of the challenges faced in the current housing environment is the issue of the shortage of low cost, secure housing. Often a person isput in the position of having to take a property that is offered to them; however this property may not be their first choice. This clearly overlooks the needs of the individual. He/she may be encouraged to share a unit because a room in a unit becomes available, but they may not have a relationship with the prospective tenant or want to share a unit at all. Often, because time frames are short, there may not be transition time available. Although Heath identified early that he did not want to share the unit, it took time for him to get used to living on his own and subsequently to moving on to an area where he was close to family. This is a focus in community housing, even though it is not always possible.

Heath has been in his new place for about a year now. I called him recently and asked him a few things about where he lives now. I asked him what he liked about living by himself. Heath replied, “It’s good; no one tells me what to do. I can’t live with anyone else.” I asked if he liked living closer to his sister and mother. His reply, “Yes it’s good.” He shops with them, spends time with them. They also help him with transport when he needs it. I also asked what he liked about his new place. “It’s cool. Better location. I miss the people at the complex.” I reminded Heath he was welcome to visit the units and suggested he come back for a tenant gathering in the future. Heath is now settled in his new place and looks forward to living a settled life, in close proximity to his family.

This example illustrates how one person was able to describe how he wanted to live and has been able to achieve this goal. This is not an isolated example. Community housing organisations encourage tenants not only to have a say in their housing but also to work flexibly with them when their needs change.

There are many people living in community housing whose needs can be met by open communication. A positive relationship, where they feel they are listened to and have supports in place, helps them to achieve the best possible outcome. Having a person-centred approach along with formal and informal supports, can achieve positive outcomes for people.

Investing In Community, So That Home Is Possible For All

Richard Warner

Richard Warner works at Community Living Association, assisting young people with intellectual disability who are at risk. Richard has recently returned there after living in the Brisbane l'Arche community. He draws on his experiences in the lives of people with disabilities and with ordinary and intentional communities.

The word 'community' embodies ideals central to us all – belonging, companionship and co-operation. Communities however, are also humble realities, consisting of people and situations of different gifts and limitations, resources and needs. In working with communities to include vulnerable people, it is necessary to pay attention to the ideal as well as the reality. In this reflection, I would like to put forward the concept of 'investing' in community relationships as a way of successfully involving community members in the lives of people with a disability. This word 'investment', more often linked to the hard and fast world of finance, may shake us up a little, and encourage us to look more purposefully at ways of building inclusive communities.

There are four aspects to this type of investment in communities, which have a particular focus on the participation of community members without a disability. These are organising, relating, resourcing and protecting. To illustrate, I shall draw on an example of a successful innovative project where people with disabilities were able to get their own homes and a sense of everyday community. The Project used ways and means directly relating to these four aspects, to bring people with disabilities together with people without disabilities in an intentional building of community.

Investing in community to include people with a disability is an enjoyable and necessary task.

(i) Organising

'Organising is what you do before you do something, so that when you do it, it is not all mixed up'. (A. A. Milne)

Becoming organised was the first aspect of the Project. This involved an investment of time and energy in working with people to help them establish their roles. It also involved helping them as a group to work out ways to share power, sometimes having a single decision maker, majority rule, or consensus. It further involved clearly defining the organisational structure within which they operated, such as choosing whether to be autonomous or linked to an agency, and whether to be an association or cooperative.

The community members without a disability knew what they were committing to when they joined the Project. This gave a sense of security. They knew, for example, that they would be living in close proximity to a member with disability (usually walking distance) with whom they would engage in a weekly social activity such as a meal or gardening. As part of their role, they knew they were also choosing to commit to a reasonable level of informal social contact. Members were assured that their private time would be respected and that they would be supported to manage boundaries. Contact needed to be reasonable and sustainable for them. Individual commitments extended to being part of a group that managed its own housing. Community members were aware before joining that all members were required to participate in monthly management meetings. Here, they would decide on a range of issues. Finally, members knew that the group made its decisions by majority vote and had certain areas of delegated authority from the larger host organisation.

Community members generally appreciated the structure of the Project. Inflexible structure is an anathema to community relationships, but they can also flounder with too little. An enabling balance was required. Community members in the Project liked knowing exactly what their commitment was and that of others around them. They also liked to know what personal and practical supports they were entitled to. This kind of structure helps communities become more organised, so that individual commitments become sustainable.

(ii) Relating

'Without friends, no one would choose to live, though he had all other goods.'(Aristotle)

Relationship is at the heart of a community investment. In the Project, if people didn't enjoy each other's company and there were not visible qualities of connection, companionship and celebration, the heart of our work would clearly be missing. Whilst these qualities can and do arise spontaneously in community, there are also things we can do to assist them to develop and grow. The Project included careful selection and connection of people; ongoing discussion about quality of relationships and group participation; encouragement of healthy conflict; development of a culture of warmth and respect; building of a sense of responsibility and ownership; and importantly, marking milestones with celebration.

These principles were evident in the spirit of the monthly meetings. Celebrations were at the heart of their identity, with birthdays and other achievements commonly marked, as well as a meal shared. At the meetings, a sense of ownership developed as members took on roles and exercised delegated authority to make decisions about aspects of their own housing. A culture of warmth and respect was apparent between people. Members drafted guidelines to reflect this and knew they had a responsibility to gently remind each other, or raise it formally, if there was a breach. The individual connection between members was a key relational support and occurred between members with and without disability. It focussed on a social activity and impromptu neighbourly connection so it was important that the neighbours enjoyed each other's company and had a common connection.

(iii) Resourcing

'Capital as such is not evil; it is its wrong use that is evil. Capital in some form or other will always be needed.' (Mohandas Gandhi)

Providing people and groups with the necessary resources to live out their roles is an essential aspect of creating a community supportive of people with disabilities. This requires a reasonable investment on behalf of an organisation. Clear examples of these occurred in the Project where community members and the group regularly connected with, and were assisted by, workers of the host organisation. Assistance involved helping community members to understand the lived experience of members with intellectual disability and assisting with facilitation of the group.

Affordable housing, located in proximity to other members, was a major asset extended to the Project's members. They either lived in affordable housing owned by the organisation or co-invested with the host organisation, allowing them to part-purchase a dwelling. Affordable housing within a supportive community is a shared agenda of all members and provides a strong tie to the group over time.

(iv) Protecting

Within the Project there were three things to safeguard against: individual vulnerabilities; the vulnerabilities of the project itself; and the tendency for there to be a 'drift' from its central aims.

The people for whom the Project existed were vulnerable within the communities in which they currently lived. They were certainly over-represented in terms of social inequity. We were obliged to pay attention to the community links created, going beyond the standard practice of criminal history checks and references. In a spirit of welcome, there was sometimes a lengthy process of getting to know new members. There was also a three-month trial period of participation in group meetings before someone was offered housing. Finally, the group itself had the authority to welcome or decline applications for new membership.

The group also faced vulnerabilities, safeguarded by regular monitoring and planning. Such work, which sometimes required the help of an outside eye, helped ideas to remain alive, fresh and realistic and to resist the sink into formalism, rigid fundamentalism, or a drift toward unstated aims. Processes were established to ensure this kind of work happened.

The Return on the Investment

Rather than following the traditional model where people with a disability live with others with a disability and are assisted by paid workers, the Project was clearly different. This difference does not mean that there was less of an investment of time, energy and resources. It has the potential, however, to provide a greater return, particularly in terms of community inclusion, for the people involved.

Investing in community to include people with a disability is an enjoyable and necessary task. Organising, relating, resourcing and protecting are four aspects of any worthwhile investment. If you were to picture this symbolically, a humble brick might suffice. It has four points and provides a sturdy foundation even to the most inspiring structure. Adequately attending to this foundation can make our ideal of inclusion a reality and attract a return which is visible, measurable and yet, because it deals with human beings, intangible.

If only our service system had these qualities: seven strategies likely to help people who have a disability to have ‘a home’.

This paper describes those features that are considered by a coalition of leading agencies and individuals across Australia, to be essential if people with disabilities are to get real homes of their own. It is adapted from ‘Joint Submission on the Proposed Disability Supported Accommodation Program’ to Department Families and Community Services, Aboriginal and Islander Affairs, 2007.

The following features, if present in our service system, are likely to lead to people with disabilities having real homes of their own.

Having a positive vision that is based on what ‘home’ means for us all

Most people grow up imagining that one day they might have their own place, maybe they'll rent, maybe they'll share for a while, and maybe one day they might even achieve the great Australian dream of owning their own home. Having a home is important to us all because it gives one a sense of belonging, security, identity and control. These are important yet unrecognised needs of people with disabilities. What people get in response to these needs is often a service-mediated version of home: home-like, but not a real home. It follows then that those who support people with disabilities to have a home of their own must be highly conscious of what ‘home’ means in more than a physical dimension and are skilled at supporting the fullness of having a home.

> ***A key safeguard against an over-reliance on paid service and the intrusion of service into the private domains of individuals is the development of freely given relationships and groundedness in the sanctity of home.***

Recognising and according the fundamental rights of people with a disability

The Australian Government was among the first of 81 countries to sign the Convention for the Rights of People with Disabilities (CRPD). Article 19, Living independently and being included in the community, is an important extension of the right to liberty, which applies specifically to the living arrangements of people with disabilities. The article is directed to the elimination of segregated, congregated and socially isolated environments in which people with disabilities have historically been forced or obliged to live. It requires governments to ensure that people with disabilities are able to live in the community with accommodation options equal to others, and that these options support the inclusion and participation of people with disabilities in community life.

The article also provides that people with disabilities must be able to choose with whom they live. In order to realise these freedoms, governments are obliged to ensure that people with disability have access to the support services they require in order to live freely in the community, and avoid isolation and segregation from the community.

Person-centred ethics and approaches

We all want to be treated as individuals. In service practices, this is reflected in person centred approaches that are underpinned by an intentional commitment to appreciating the world through the eyes of the people who receive a service. This is also revealed in the nature of the relationship between server and served, and the capacity and willingness to share information, resources and decisions. This is also indicated by the value that is placed on the person’s potential and authority over their own lives, on the possibilities that are presented to the individual, and on the nature of the communities that we create together.

Planning is a helpful mechanism to enable person centred approaches. It is a process tool to facilitate the explicit creation of positive visions for a rich and meaningful home and neighbourhood life and to identify how to create and safeguard this. It helps people create a sense of the ideal, rather than be limited by what a system might or might not be able to fund. It allows people with disabilities and family members to have greater authority over their own lifestyles.

Appropriate model and purview

A key safeguard against an over-reliance on paid service and the intrusion of service into the private domains of individuals is the development of freely given relationships and groundedness in the sanctity of home.

Support to live in a home of one's own can come from a range of sources: from those who are in the person's life in a freely given capacity, from generic agencies, and from a disability support agency that has correctly delineated its purview and which does not also own the dwelling. The types of outcomes that are required from any support include the following: authentic community living, valued roles related to home, acquaintance and friend relationships with neighbours and those in ordinary community facilities, autonomy and control, the development of skills, and being regarded positively by others. The rationales for this follow.

Effectiveness is more than economics

An economic argument is often used to support the imposition of congregated living on people with disabilities. High quality outcomes for people with a disability must be valued as highly as cost considerations when decisions are made to fund services. Research literature and anecdotal evidence strongly indicate a consistent pattern of better outcomes and lower costs where housing is integrated into ordinary neighbourhoods rather than larger grouped facilities, where staff purposefully work to achieve the outcomes mentioned previously, where the size and composition of the group is more akin to ordinary home living, where there is not imposed congregation, and where someone with a disability has a say over with whom they live.

> *Instead of investing in group homes, funds need to be invested in a range of ordinary housing options, of alternative supports and the strengthening of the skills of support people.*

Many models that congregate and segregate people with disabilities are unsafe for people with disability

Literature from research and various Senate Inquiries clearly demonstrates that models based on imposed congregation do NOT keep people safe. These models have many of the precursors to abusive social and physical environments, including mass management of those who are served, a lack of personal connection between server and served, high staff turnover, low levels of supervision of staff, and a lack of scrutiny by ordinary community members.

Further, once group home buildings are created, there appears to be an imperative to fill them with subsequent generations of people with disabilities, thereby limiting the choices of those to come. As many families attest, a group home does not solve issues of loneliness and isolation but can actually accentuate people's difficulties and sense of isolation. Vacancy management, poor matches, inadequate supports and poor need-assessment can create and exacerbate a range of emotional, communicative and behavioural difficulties.

The alternative to group homes is not necessarily living alone, or living a lonely life. Instead of investing in group homes, funds need to be invested in a range of ordinary housing options, of alternative supports and the strengthening of the skills of support people.

The separation of housing and support services

It is not culturally appropriate for the owner of a house to also provide support to those in the house. For example, the paid person who fixes the plumbing does not typically also own the dwelling. It is unacceptable for such a culturally atypical practice to be used in the lives of people with disabilities.

Both history and legislation recognise the danger of one service having control over people's lives. There must be a separation between the supply of housing and the provision of support. In traditional services, it is common for the support provider to be the property owner or proprietor. This creates a conflict of interest. If the person with a disability challenges the service for any reason, the support they receive may be withdrawn, thereby leaving the person without housing. Similarly, if the person wishes to change their housing, they can also lose their support. People with disabilities often tolerate a mediocre, even negligent, service because they do not want to risk losing their home. No single service agency should have such a level of control and influence over a person's life. Consequently, investment in buildings by disability funders and service agencies must be the last, rather than the first, resort.

Investment in community-based non-profit service providers

People in the community sector have demonstrated creative and innovative ways to meet the needs of people with disabilities. This sector has demonstrated a willingness to take responsibility for what is a community issue. There are characteristics of agencies that are more likely to be highly responsive, including: very positive beliefs about the value of people with disabilities and family members, the potential in people's lives, an idealised sense of 'home', few layers in the bureaucracy or where people have been delegated authority over their own support arrangements, consciousness about the vulnerabilities of the people who are served and the primary purpose of the service. Further to this, good stewardship of funds has been demonstrated in evaluations of programs where people with disabilities and families have had authority over funds.

> *People should be involved from the start of any decision-making, and to the degree that they can and wish to be.*

There are also social and economic reasons for government investment in the community sector. A healthy and vibrant community sector leads to social capital; capital that is not created by investment in bricks and mortar. Communities that include a range of enduring community agencies reveal greater optimism, increased trust between community members, better health and education and lower levels of crime. There is greater active democracy and more positive perceptions of government institutions.

Caution needs to be shown towards those for-profit agencies that have financial profit and the interest of shareholders at their core. In these cases, the interest of people with disabilities will not take priority.

Individualised funding

For the person with a disability, individualised funding supports portability, being able to change services or move geographically. It also supports choice and flexibility; when the resources 'belong' to individuals, their bargaining position in negotiating their support is enhanced.

For the service, individualised funding creates incentives for individuals to retain their involvement in the service. It is acknowledged that it can require more complex financial and outcome acquittal processes and staff management; however the benefits to the named individuals warrant this.

In order to support individualised funding, community services also need appropriate funding of infrastructure costs. This has been little recognised. Funds are required not only to coordinate support arrangements, but also to manage the agency. This means that funds are necessary in order to meet the accountability requirements of government and the wider community expectations, legal requirements, and the human resource and industrial demands on a human service.

Quality Assurance (QA) that focuses on outcomes rather than systems

Monitoring and measurement must be of the change in people's lives. Key indicators of quality should consider how people came to live in their home, their degree of involvement in decision making, how compatible the person is with others sharing the home, how support workers are recruited, supervised, inducted and trained, and the degree of involvement by the person being supported. Also needing consideration is the potency, usefulness, flexibility and the degree of individualisation of the support.

The key to active involvement in any QA system of people with disability and family members begins with strong belief that involvement is important and valuable. People should be involved from the start of any decision-making, and to the degree that they can and wish to be. Some people with disability and their families will wish to have authority over the management of the service and most will expect authority over the design and management of their own support arrangements. People with disability and their families will only support quality assurance processes when their involvement is authentic and valued, and not merely token.

'Choice' must not be the only driver

A large body of critique exists around the models of support and policies currently in place. Whilst the notion of 'no one size fits all' is to be commended, and having a range of options is vital, the exaggerated emphasis currently given to choice-making is almost wholly driven by ideology rather than considered examination of its likely results.

Choice happens within the limitations of available information. It assumes well-informed decision-making. Most people with disability and their families have little experience of options other than large residential centres, cluster housing and group homes. There are insufficient local examples of people living in their own home. Many families ‘choose’ a very restricted option for their family member with disability because they are unaware of the way in which other options can meet the needs of the family and the needs of the person with disability.

Much choice works against the interests of people with high support needs. The system has developed services in which people with high support needs tend to be congregated at the restricted end where they are forced to trade restrictiveness with intensity of services. The continuum of care model confuses segregation with intensity of service. Whilst some people certainly need intensive supports, this does not have to relate to a particular type of facility.

Choice also typically happens within the initiative and approval of the authorities who control their life circumstances. People who use services are allowed to choose between options that are currently available. For a person living in a group home, choice might be available over which foods they prefer or which TV channel they would like to watch. The choice of leaving the group home and moving into their own home is not on offer.

Final Comments

Throughout history, it has not been an easy task to get enabling mechanisms at a systems level. We can learn from history and from the many positive examples that have been created and sustained since the mid 1980s, where people with a range of impairments and behaviours have been supported to live in their own homes, have authentic and meaningful home lifestyles, live with housemates without disabilities, develop freely given relationships, and are respected members of their neighbourhoods. We can be inspired by the possibilities that are before us.

References available on request.

Contributors:

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