

Home: A Place Of My Own Where I Belong

Anita O'Brien

Anita O'Brien has worked as a volunteer in the disability field since the birth of her second son Warren, who was born with cerebral palsy. She recently joined a group of families to create a family governed arrangement called *Living Distinctive Lives* that aims to support individuals to live typical lifestyles in their own home, in the community, utilising a range of support.

When one is with like minded people it is not unusual to say: "You have made me feel at home". Home is a place where you feel comfortable, valued and respected. Home is a place to be you, to share one's life – its joys and pain – with the people you choose to live with and who understand and care about you.

There is a song with the lyrics that say:

*I feel home, when I see the faces that remember my own,
I feel home, when I'm chilling outside with the people I know.*

So home is also about the relationships and friendships that you have the opportunity to develop. Home is not just found in the house in which I live though, and the people with whom I live, but also in the community in which I have chosen to live. A sense of belonging can be found when home is in a community where you find connection to people and places and are able to participate and contribute to that community.

A quote from the L'Arche Community is worth repeating:

Whatever their gifts or limitations, people are all bound together in a common humanity. Everyone is of unique and sacred value and everyone has the same dignity and the same rights. The fundamental rights of each person include the rights to life, to care, to a home, to education and to work. Since the deepest need of a human being is to love and to be loved, each person has a right to friendship, to communion and to a spiritual life.

When I have these things I am at home in the world.

When our sons were born, we had dreams for them like everyone else. And as they grew they had their own dreams. Are they just as entitled as each other to have some, if not all their dreams come true? Our elder son enjoys such things as a home of his own, a wife with whom to share his life, valued roles in his work, leisure and in his community. He has meaningful days and many different friendships and relationships. Warren, our younger son, indicates he wants and needs the same things, not a life lived in segregated settings and controlled by systems and people paid to be in his life.

Warren is 32 years old, has a good sense of humour, is caring and sensitive to the needs of others, loves to socialise and has a strong sense of justice. To thrive, Warren needs to be in environments where he wants to be and with people who value him, who talk to him and with whom he relates! He needs lots of different relationships. His disability is cerebral palsy, with an intellectual and some physical disability, which limits his capacity to plan, work and travel without support. It also means that knowing his surroundings and being able to negotiate within them independently is very important to him. He struggles with an anxiety disorder which is particularly debilitating when he is experiencing high levels of stress or emotional pain.

In 2002, after Warren participated in a 20 week live-in independence program, we decided we would help him to be as independent as possible, living in the flat below our home. But Warren's anxiety increased, and he was sometimes physically ill in the mornings. He was lonely! Where to now?

I found a family governed group home set up by a parent I already knew, and there was a place for Warren. It wasn't in our area unfortunately, but I believed that we would at least have some say in the way the home was managed. I also thought there would be an advantage in that Warren would have people to share his day with. It wasn't perfect, and I felt a little uncertain, yet what other options were there? We decided to work with it.

You might ask why we would take our son out of this group home three years later, a supported home that was family governed and not governed by the system, a place, you might think, in which he was safe and had friends to go out with. Why would we take him out of an Adult Training day program (ATSS) and place him, and ourselves, in a situation where we knew we would have to be very creative, without any funding to start with, to provide him with a meaningful day?

Simply put, our son was not happy. Although Warren always tries to make the best of each situation in life, he was telling us that this is not what he wanted by his demeanour, anxiety, and actions. He was not presenting at his best: his personal hygiene was not good enough, he was very anxious and his choices were limited!

Eventually, through the influence of many people, such as Deb Rouget, the Deohaeko families from Canada, and finally the presenters at the Mamre Conference in Brisbane in 2005, I saw the possibility of Warren living in his own home, and having a high degree of influence over the kind of life he wanted – in community, where it all happens. I linked with a family governed project *Living Distinctive Lives* which grew from the initiative of parents who believed their adult sons and daughters have the right to have a meaningful lifestyle, typical of other members of society, which includes accommodation arrangements of their choice, rather than living in disability service settings.

A whole of life approach is taken by the families. Individuals seeking to set up their own home are simultaneously aiming to form relationships, develop long term networks, and have meaningful roles within and beyond local communities. We believe this holistic approach is the key to living safely, successfully and happily in their own homes.

We had a vision for Warren to have the life of a typical 30 year old, one that saw him on the natural pathways of life, in valued roles that make sense for him. In July 2005 we had a conversation with Warren about where he wanted to live, giving him the options, and he chose to come home to the flat below the family home and to the community in which he had lived. Why? He gave the simple reply: "Because it's better". He returned home late 2005, which meant removing him from his ATSS as well, a step in faith.

Everyday happiness for him was restored when he returned to the community he grew up in and started the journey to an ordinary, yet unique life. Our challenge was to do it better; for him to have his own home, to seek housemates and to develop a life in the community assisted by a Circle of Support. This meant a time where he had no funding, and whilst we needed to be creative, he did have freedom to choose! Whilst agencies can assist and often do well, we are not relying on them for our son's future happiness. We wanted to have people who care about Warren in his life, and assist him to develop many different kinds of relationships, because we believe it is people that will keep him safe and help to maintain his 'ordinary' life.

Warren is now living in a two bedroom/two bathroom flat on the lower level of our family home. Almost two years ago a young married couple came to share his home as housemates, and provide the individual support he needs for daily living.

Warren, Ashley and John (and now Molly born on 29th December, 2006) are all enjoying each other's company. Warren is developing friendships with their family and friends and it has enriched his life. Ashley and John work very hard to ensure the relationship is as natural as possible, encouraging Warren to participate in tasks around the house, and providing the prompts and assistance he needs. They are very sensitive to him and listen to him with the heart and the head. They sometimes go out for coffee, Warren has lunch out with John, and he has had drum lessons with John's brother - just ordinary, everyday things.

There are still struggles and challenges, particularly around helping him to communicate his feelings, but he is most definitely doing that now.

Having his flat below our home has its own challenges of course, and we need to keep open the lines of communication to ensure the intentions of Warren having his own place and being supported in his new life are a reality; and to ensure the well being and happiness of everyone.

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

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

In this journey, we felt that a Circle of Support for Warren, and us, his family, was essential to help him accomplish his goals. The members of the circle include family, friends and others who have been involved in his life, and who have agreed to meet together on a regular basis. They are not paid to be there and are involved because they care enough about Warren to give their time and energy to help him overcome obstacles and increase the options which are open to him.

In our 'get togethers' we have celebrated with him, identified Warren's passions, interests, skills and abilities and what gives him energy, explored some work and leisure possibilities, and talked about his fundamental needs, such as freedom to make choices, self worth and recognition and maintaining a sense of belonging.

Warren has a vision and often dreams. Warren and his family and friends must keep their eyes on that vision, and keep returning to it, because we can so easily find ourselves compromising the dream. I believe the safeguards to that vision should be kept by the family; we can be supported by an agency and their staff, but we must not rely on them to protect Warren from change. For Warren, and his family, to have this high degree of 'say so' returned is indeed empowering.

When changes come, and they have – some more drastic than others - the good days cannot be taken away: the days where Warren is living a more meaningful life, in his own home and a welcoming community, are days that we can treasure. It has been well said: “You don’t stop planting a garden, just because winter comes. Each time a flower blooms you bring joy and encouragement to others.”

It is a journey that requires imagination, hard work and courage, but it is better and it is worth it.