

## Editorial

Over the years there have been countless words, poems, songs, papers and books written about love, friendship and relationships between human beings and this edition of CRUCIAL Times will add to that collection as we too take up the theme of friendship, connection and the importance of freely given relationships in the lives of people who live with disability.

We start the edition with a reminder on just how critical relationship and connection is in the lives of all people; we hear stories of people who have moved from isolation and loneliness to having friends; we hear of people working to prevent loneliness and promote belonging; and importantly we share some clues as to how that has been achieved.

We can't buy friends; we can't make people be friends but we can certainly do some things that increase the chances for friendship to happen.

Our writers, Michelle Mullane, Luke Cowan and Hugh Mackay start the edition reflecting on friendship and freely given relationships and why they are important to human beings and such a critical facet of what we would consider a good life. Luke and Michelle describe friendships that formed when they were involved in local groups – for Michelle it was through church; for Luke the Ukelele Club.

It may seem obvious how fundamental the need for friendship and connection is, and one could ask why we even need to talk about this. The stark reality is that many people with disabilities are lonely. For some, the only people who really know and appreciate them are family members. Others have no one in their life who is not there in a paid capacity. Sometimes families are isolated too. The legacy of our support systems, our segregated schooling and our past policies is that we find ourselves distanced from each other.

Children who have a disability have not been educated side by side with their siblings and neighbours. The only support offered to some families was that their son or daughter; brother or sister was taken away to grow up elsewhere. Some people with disabilities have never been given the extra assistance they needed to communicate, connect and get to know people. All of these experiences have formed our way of thinking so that now, people can be living near us yet invisible to us. They can be seen as more different than the same. We can assume they need something more, or more specialised, than we can give. We have come to believe that only people with disability would enjoy the company of other people with disability so that the whole community misses out on the option of enjoying diverse relationships. Our service system is generally constructed as though relationships and connection with other people is not important or necessary or if considered at all fits more as though it is an optional add-on after all other 'care' is provided rather than a fundamental human need. How do you meet people if you don't go to school, swimming lessons, Scouts, soccer, Uni or work with the other people in your town or suburb? And if you don't have the option of seeing people often and having a broad range of acquaintances then what are the chances of having friends?

It is important that we understand that, in general, this loneliness and isolation is not caused by, chosen by or in some way the fault of the person themselves.

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A person doesn't have to be fixed or improved in some way to have friends but interestingly having friends can help us all to be better people. Being liked and appreciated brings out the best in us all. Having an interesting life gives us more things to talk about and being listened to gives us confidence to speak more.

I imagine that most people reading this will be able to list the benefits they have experienced through their relationships or friendships with people who live with disability, whether that is in a family relationship or someone you met through work or leisure.

While we can articulate the benefits to our lives we can often then baulk at the notion of offering that opportunity to others. We have been put off by the stares and blunt questions and have been so concerned about the rejection or risk of rejection that we have not been brave enough to ask.

We tell ourselves that people don't care; are too busy; will be cruel and yet there is lots of evidence to the contrary – in this edition alone there are examples of citizens who were asked and who said yes and know their life is richer for the experience. When Carol Adams went to volunteer at a special school she didn't expect to find a friend like Les who has stuck with her as a good friend for 23 years. Les is not able to write his side of this story but people who know him feel pretty confident that he enjoys Carol's company as much as she enjoys his.

Ronda and Maggie were introduced through a Citizen Advocacy program and together they have spurred each other on to bring about some very big changes. Ronda writes the story for both of them and illustrates the message that it is 'people who keep people safe'. As a committed friend she has uncovered a side of Maggie's life that our formal system didn't get to. She also shows us how she worked with Maggie to increase the number of people in her life. Friendship with one person became a launching pad to bigger networks.

Supporters have an important role and responsibility to ask and to think very carefully about how to ask, to maximise the chance of citizens and 'potential friends' saying yes. It is important to understand that it is not the role of the supporter to fill the gap and be the friend but to spread the word of how much this person has to offer. We wanted to include some strategies that have been used to bridge the gap and invite people into the lives of people with disability. Neil Barringham shares with us a list of some things that, from his experience, people in the supporting role can do to increase the chance of connection between the people they support and others.

Nobody starts life knowing how to be a friend; getting the hang of relationships takes time but we learn by doing; by our mistakes as much as our successes. People with disabilities don't need some sanitised, romanticised form of friendship and relationship. With practice they will be as loyal, thoughtful, self-centred and annoying as every other person who enters into a relationship. They will let people down and be let down and they will be comforted and cherished too.

Anna and Keith Coventry think a lot about their teenage son Will's future and like most parents they particularly want him to be safe; to be loved and to belong. They share with us some very practical things they have done in the primary school years and are doing now to help that happen for Will. They have recently invited others to join them as a Support Circle and while it hasn't been easy to open up lots of private family business, they are seeing the benefits for them and for Will as they plan for his adult life.

If as friends, family and supporters of people with disabilities we believe that



friendship, relationship and connection are the highest priority then we can adjust how we do things to match that priority. We can take up offers and find ways that people can help. We can concentrate not only on connecting with new people but ensuring that we assist people to maintain the friendships and relationships they have and not unwittingly disconnect. We can resource and reassure 'potential friends' who don't know enough or don't feel confident rather than criticise them for their fledgling efforts at connection. This re-prioritising can be started now; one person at a time; we don't have to wait for changes in funding or policy; we don't have to wait for government to do something or 'til it can change for everyone. If we are waiting until the whole 'community' suddenly decides to welcome people with disability then we will continue to be part of committing people to lives of isolation and loneliness. We could start by deciding to be brave and work out what one person could say 'yes' to. If we consider how many years of experience in friendship and relationship we have and put that experience to good use then we know all we need to know.

**Margaret Rodgers**

Chief Executive Officer



## From the President

Recently at work we were involved in a team building exercise that included a version of personality profiling. The woman who presented the course explained in some elaborate manner why it was going to be critical in the future that we understand how different types of people think in order to understand them and build strong working relationships with them. This explanation that she provided was almost as if we should be very afraid of being left out if we don't follow suit.

As I pondered her teaching, it felt to me that to induce fear in people in order to make them interested in learning about relationships was somewhat misguided. To my way of thinking, we need to try and build relationships with people because there are more than seven billion of us on the planet and life is going to be a lot easier, and a lot more enjoyable, if we can get along with at least a few of them.

Some group chatter evolved and someone pointed out that it is difficult to connect with some people, and another person stated that they have absolutely no interest in getting to know their work colleagues.

All of this is truly baffling to me. I made the point that I connect with people on the basis that we are all human. That is the common denominator for me and a place to start when forging a relationship – whether at work or otherwise.

It is important to me to make relationships, those at work and those outside. My relationships make each day so much better and they make my life fuller. Having friends at work makes it more enjoyable to go to work and on days when life seems hard to get through, having friends, certainly makes everything seem more bearable. So why wouldn't this also be true for my brother, who is labelled as having an intellectual disability?

I have been concentrating here on the importance of creating relationships at work because I had this recent event take place that made me think about it. However, I think it is also important that we put the same energy into our relationships with our family and friends outside of work. Friends quite often come along because of mutual interests so they may be easier to navigate. Family relationships tend to be long-term but at times can need lots of time and attention to keep on track.

When we are supporting people with disability, whether in a familial way or not, we remember that it is also through their relationships, that their days will be fuller and have more meaning. As with all of us, having friends means that the difficult days may not seem quite so onerous and lonely.

Having a disability, we know, can limit the opportunities people have to make new friends, but the need to have relationships is just as, if not more important. With this in mind, one can see that it is important to be intentional in our approach to forming relationships and friendships for people with disability. At the same time, it can be tricky to work out how to assist people in this pursuit without taking over. Therefore we must look at how we can proactively contribute to the building of supportive relationships alongside people with disability.

**Sharon Daley**  
President



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# Friendship is a two-way street

Michelle Mullane

**Michelle Mullane** spends five afternoons a week taking care of children after school. She is a dog lover, an Elvis fanatic, a devout Catholic and a committed volunteer. Michelle shares the parenting of her four year old daughter with her partner and a foster family.

In addition to the love and support she receives from a broad range of family members and friends, Michelle also appreciates the support of a small group of men and women who meet with her regularly. This is the story of what friendship brings to Michelle's life.

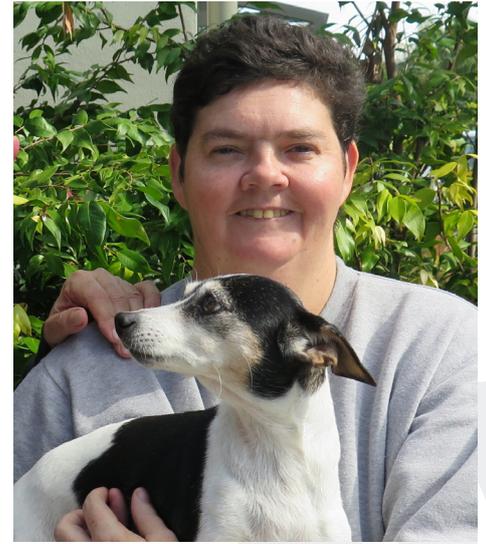
## Friendship is a two-way street

The Newmarket community is very lucky to have a citizen like Michelle. Growing up only a few streets from the unit that she now lives in, Michelle has only ever lived as far as a few suburbs away. Michelle enjoys being known and knowing others in her local community, "A lot of people know me; I see people all the time. I think I'll always stay here because it's so handy."

It is the support that friends offer one another that Michelle regularly returned to as being the most important thing about friendships. "I have always liked giving to other people...I'm always giving." Michelle is well aware that others will be willing to help her out because of everything she has done for them over the years. "I've got plenty of groups so if I need anything they'll pitch in because of all the stuff I do. I'll have plenty of help around."

The parishioners of the Newmarket St Ambrose Church would likely be some of the first to admit how grateful they are to know Michelle and have her as part of the church community. Michelle is due to have surgery later this year and when reflecting on the six to eight weeks recovery time required, she remarked, "Newmarket Church are going to miss me! They're going to find it pretty hard without me because I'm the backbone of that church." Here Michelle recalls her past voluntary and paid work with the church, "I did before school and after school care, I helped in the parish office, cleaning and everything...now I'm constantly up there, five days a week and on weekends I go to church." Michelle currently volunteers as a church sacristan at St Ambrose's, opening and closing the church for ceremonies on weekdays and Sundays, as well as helping with preparations for Mass, baptisms and funerals.

**"I have always liked giving to other people...  
I'm always giving."**



In addition to a whole range of friendships from Michelle's voluntary work, special interest groups and the local neighbourhood, Michelle also has a more formalised circle of support around her. The impetus for starting this circle came about when Michelle needed to find a more permanent home after a long-term house and pet-sitting arrangement was coming to a close. "A good friend, Trish suggested for me to set up my own network group. I thought it was a good idea, planning for myself and planning for my future." With the help of an organisation that assists families to set up circles of support, along with Trish and Michelle's Aunty, Michelle invited about seven members of her Parish to be part of her circle. Thanks to the group's energy, brainstorming and some hard work, Michelle now lives in her own unit in Newmarket. When asked about this home Michelle said without any hesitation "I love it!"

During the initial period of helping Michelle to find a home the group met regularly, at least once a month. Although the group is not currently meeting on a routine basis, the circle



# She said hello to get to know me

Luke Cowan

members remain closely connected; the members speak on the phone, are in regular e-mail contact and catch up informally at church. Some circle members have taken on specific roles to help Michelle with things like finances, tenancy or health-related matters.

Michelle's circle of support has recently been helping her to get on top of some health concerns. In Michelle's words "I've got the group who've helped me get through. They come with me for the appointments... otherwise I wouldn't be able to manage, because they [medical professionals] just push you down because you've got no voice for yourself."

Michelle sees her friends and family as an important aspect of her life "I wouldn't know what to do if I didn't have the support, the friendships, the relationships, my friends and family. I don't think I'd be able to get up and do what I do every day." The thing that Michelle likes most about friends is that "you know you've got someone there in times of need, or if you just need someone to talk to."

**"A good friend, Trish suggested for me to set up my own network group. I thought it was a good idea, planning for myself and planning for my future."**

**Luke Cowan** loves people and loves to talk with people – his family, friends, neighbours, co-workers and people he meets in life.

Luke connects with people through a number of long-term volunteer positions, his neighbourhood, his membership of the Ukelele Club and poetry. Luke is an accomplished Brisbane poet, and writes and performs with the Brotherhood of the Wordless and Poets on the Park. He shares his love of poetry with primary school students in his Co-Teaching role at a local Brisbane school. Luke is a member of Kalpana, a collective that supports him to live in his own home.



***It's very nice to have someone who cares for you from the heart. Having each other in life beats loneliness.***

## She said hello to get to know me

I have a friend called Pushpa.

She has a lovely nature.

She said hello to get to know me.

We chat a lot together now.

How did I meet Pushpa?

I used to see her every month at the uke club.

She was very friendly and said hello to me.

It's very nice to have someone who cares for you from the heart.

We dine together. We visit the club together.

Pushpa is becoming part of my family.

You have to be free with me.

Pushpa does not judge or care about my funny times.

She is there for me because she really wants to be.

I meet her at the club each month. She likes to listen to our music.

I invited her to my home. She invited me to play lawn bowls.

Pushpa is going to be with me for a long time I hope.

We have an understanding even though not verbal.

Friendship is a feeling. Pushpa has those feelings.

I like her and hope that our friendship will grow with love and care.

I hope Pushpa cares for me as much as I care for her.



# The good life is about relationships

Hugh Mackay

**Hugh Mackay** is a social researcher and the author of sixteen books – ten in the field of social psychology and ethics, and six novels. A newspaper columnist for over twenty five years, Hugh is currently an honorary professor of social science at the University of Wollongong, an adjunct professor in the faculty of arts at Charles Sturt University, and a patron of the Asylum Seekers' Centre. In 2015, Hugh was appointed an Officer in the Order of Australia.

This series of excerpts are taken from two of Hugh Mackay's books, *A Good Life* and *The Art of Belonging*. They highlight the universal nature of what it means to live a Good Life.

## The good life is about relationships

Excerpts from *A Good Life* and *The Art of Belonging*

When thinking about what makes a 'Good Life' for people with disability one only needs to think about what would make a good life for all people. Often there is a consensus about what makes a good life: having a home of one's own, having a job, making a contribution, having opportunities for learning and growth and so on. It is because of this consensus that a common framework used for crafting a good life for people with disability is to think about 'ordinary' or 'typical' lives – a life like anyone else's.

As a social researcher and philosopher, Hugh Mackay speaks about universal human yearnings. By examining readings that reflect on the broader human experience, we of course also come to understand the experience of people with disability.

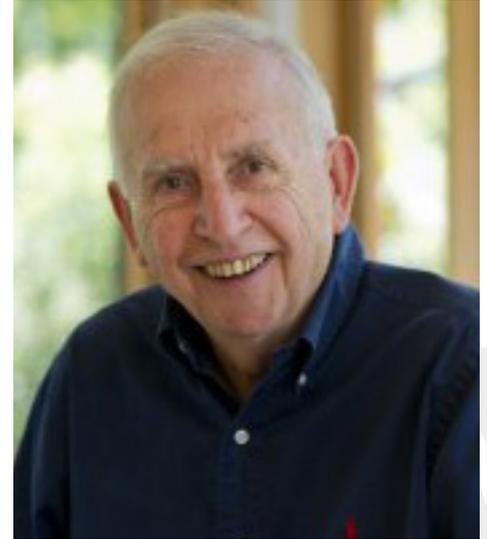
In his books, Mackay regularly returns to the point that it is our relationships with other people that are at the heart of what is considered The Good Life.

*"For most of us, life's richest meanings spring from our personal relationships and connections. That's why the desire to belong is a throbbing urge that won't be stilled until our hearts find safe lodgings."*

Here, Mackay talks about the importance of relationships in the context of 'love.'

*"Ask yourself this: what is the most powerful, creative and fruitful force for good in the world? Answer: Love. (Do you have a better answer?)"*

***"The desire to belong is a throbbing urge that won't be stilled until our hearts find safe lodgings."***



***"The good life is primarily about others. What else could it be about?"***

*Love, in all its many manifestations – kindness, care, compassion, generosity, tolerance, encouragement, support – is the source of everything we admire and appreciate most in human behaviour.*

*Next question: how can we make any sense of love without putting it in the context of a relationship or a community? Love, given or received, is about our engagement with others. The answers to those two questions lead us logically, inescapably, to...If love is the ultimate source of goodness in our lives, it follows that the good life is primarily about others. What else could it be about?"*

You might be thinking, “I know that relationships are important but it’s difficult to find people who make an effort to really get to know people with disability.” Mackay reminds us that all relationships are difficult and naturally have ups and downs. Despite the deep feelings of hurt that can be felt in our attempts to build or sustain our relationships, we rarely give up on the idea of relationships altogether.

*“From our chance encounters with total strangers to our long-term associations with family, friends, neighbours and colleagues, our connections with other people form the test bed of our sensitivity, our moral courage and our capacity for love. After all, our relationships, whether fleeting or enduring, are the source of life’s richest meanings, but, as we struggle to establish them, nurture them and sometimes forsake them, they teach us that happiness and sadness are mere accidents of our fluctuating emotional state, incidental to the great realisation that it is in loving we are made whole. And yet love’s work is the hardest work of all, which is why this...is about the good life, not the easy life.”*

So, love’s work is the hardest work of all and yet we pursue it anyway because relationships are so important. Because of the challenges inherent in building and maintaining relationships, it is necessary that we be intentional in our efforts. Without deliberately seeking out friendships and placing ourselves in situations where friendships are likely to form then it is unlikely that we will be successful.

If you need any further convincing about the power of relationships then keep in mind that it’s not only that social interactions and loving relationships sustain us, but isolation and loneliness will have a profound negative impact on our wellbeing.

*“We are not only defined but actually sustained by our social networks. We thrive on being part of a community – whether that’s familial, social, residential, intellectual, cultural, political, religious, professional or vocational...We’re tribal. We’re social. We’re communal. We need to belong...If the deepest truth about us is that we are social creatures by nature, then it follows that social isolation is unhealthy for us. Even a less-than-optimal daily dose of social contact can have a deleterious effect on our wellbeing, our mental acuity and our outlook on life: nothing keeps us on our toes like random, unplanned conversations. Reduced Social Interaction (let’s call it the other kind of RSI) carries a hefty penalty...”*

Indeed, isolation is not abated simply by being surrounded by people. It is connectedness and a sense of belonging that are the antidotes to isolation. A sense of belonging might come from feeling as though you truly ‘fit’ within a group or from sense that ‘these are my people.’ Friends are usually people who

share similar interests, people that we have something in common with and people that we choose to spend our time with. Unsurprisingly, it is not enough for people with disability to be grouped with others with disability for us to conclude that the experience of loneliness and isolation would be resolved.

*“Feeling lonely in a crowd is not an uncommon experience. Even being in the midst of a friendly, noisy group can be an isolating experience if this does not feel like a place where you belong; if there is no sense of connection or acceptance at a level deeper than superficial sociability.”*

In the midst of busy lives, connection doesn’t just happen. As well as being deliberate in our efforts towards our own search for belonging, we also need to be conscious of being open to inviting other people in.

*“The art of belonging is not just about finding your own place in the networks and neighbourhoods that sustain you; it’s also about creating space for others to join (or rejoin) the circle. Social exclusion is a crime against humanity. While it’s true that people sometimes exclude themselves, our duty as humans is to ensure that they receive every encouragement to reconnect, knowing that the longer they remain excluded, the harder it will be for them to emerge from the shadows.”*

***“We need to belong...If the deepest truth about us is that we are social creatures by nature, then it follows that social isolation is unhealthy for us.”***

*The Good Life (2013) and The Art of Belonging (2014) by Hugh Mackay (Macmillan Publishers) are available at all good book stores.*



# A 23 year friendship (so far)

Carol Adams

**Carol Adams'** first contact with people with disabilities was made when she decided to volunteer at a Brisbane special school in the early 1990s. Prior to this her work history had been in accounting. Carol continues to be involved in a parents and friends group where her good friend lives and currently serves on the management committee of a small disability service started by that group. In retirement, Carol enjoys spending time with her grandchildren and scuba diving when she gets the chance.

## A 23 year friendship (so far)

When I volunteered at the Red Hill Special School in 1991 I didn't expect it to be the start of a special friendship which has lasted for over twenty years. Leslie and I first met about eighteen months before he had to leave school. His wonderful teacher had probably been the most consistent person in his life until then, as she had taught him for about ten years, and she was worried about his life after school. At that time there was no provision for activities for people with Les' needs, although it is better now. I agreed to keep in touch with him, which wasn't difficult as he was so courageous and cheerful. I can't believe that was more than twenty years ago.

Back then we were able to go out in my car. I also took him for long walks and generally became a presence in his life. We got to know each other better: I learnt what amused him and he learnt an awful lot about me and my family which I hope he will never repeat. Les loves gossip! Over the years the number of visits and kind of activities we have shared have fluctuated because of Leslie's health, management changes where he lives and my commitments. Even so we have probably met an average of once a week over that time.

Les really likes to be in situations where no-one else has a disability, where he can sit and listen to conversations or music and feel that he is not at a disadvantage. He has various disabilities but he has the keenest hearing and readiest smile of anyone I know, so that when I visit him that welcoming grin often greets me before I have a chance to speak.

There are wonderful carers where Leslie lives and he is very close to some of them, but I think a friend is something different. For most of us a friend doesn't dress us but admires the result when we're dressed. I think this difference means something to Les.

I have made some mistakes, though. I believed that when Les visited me that was his time and shouldn't conflict with visits from my three small granddaughters. One day they were all unavoidably there at the same time and Leslie's delight and amusement as he tried to follow all the different conversations going on at once showed me just how wrong I'd been. Now I try to get them together whenever possible. He takes a particular interest in the youngest, I think because she was so small when they met.



Because I have known Les for so long I think I know him pretty well which is useful for him in a variety of ways. For example, there are times when I am able to speak up for him such as when he has to go to hospital and is among strangers. I also have fun thinking up extra activities which he might enjoy; because he lives with a number of other people with disabilities, the staff tend to have limited time and resources for individual attention. I am always on the lookout for outings he would enjoy such as the comedy and musical shows which he went to last year. At my place Les shows a distinct preference for anything where he can get wet and dirty.

Les is someone who I know will always greet me with a smile and listen to my problems. He generally laughs at them which puts things into perspective. For him, just the fact that I have been around for so long probably means a lot. Originally, Les didn't like it when I spent time talking to the others where he lives but now he accepts it cheerfully because he knows that it is always really him who I am visiting. As well as great carers and family, I also believe that he appreciates the dimension added to his life by having a friend.



# Relationships and community: The essence of life

Anna and Keith Coventry

**Anna and Keith Coventry** are parents of two boys; Henry aged 19 and Will aged 16. Will lives with a disability and as he enters the later years of schooling they are determined to ensure that he continues to have a good life in which he contributes and is valued for his contribution. In this article Anna and Keith speak about the ways in which they have sought to build relationships and make connections for Will.

## Relationships and community: The essence of life

Last year our son Will participated in his school swimming carnival. At school pick up that afternoon the Principal came to me as he wanted to let me know how well Will had participated – he swam the 25 metres freestyle, breast stroke and backstroke – unbelievable! Then a big, burly year twelve boy from Will’s house said to me, “Hey Miss, Will did really well today”. The following week I was at the school gate, when a new Mum at the school told me she had attended the swimming carnival. She recalled that when Will swam the whole school became involved and chanted his name, supporting him – she cried.

Our son Will attends an inner city co-educational catholic school. Will shares a passion for sport, as does his older brother Henry. He has a wicked sense of humour and is a gentle and loving young man. Swimming, horse riding, spending time at the beach and at his Grandparents’ property in the country are some of Will’s other interests. His favourite subjects at school are Outdoor Education and Catering. Will is blessed to be a member of a large supportive extended family network.

In his infant years Will was quite ill and his severe myoclonic epilepsy was not well controlled resulting in numerous hospital admissions. During this time, our focus was on surviving from day to day. It seemed like life stood still for some time, as we sought to unravel what was happening with our Will.

Around the age of five or six years Will’s seizures were better controlled and he was more medically stable. He began to attend the nearest local special school, nineteen kilometres from our home. After a while, we started to question Will’s school placement and ask ourselves why he was not attending our local school, where Henry had attended and where we were known. Our friends had children at the local school and we increasingly realised these children were engaging with Will and inclusive of him in social situations. We believed he needed to be present in our local community so that he could make friendships and connections.

*We believed he needed to be present in our local community so that he could make friendships and connections.*



Will commenced part time at our local school in year three. This was to be a split placement between the local school and the special school and continued as such for the rest of Will’s primary school years. During Will’s time at our local school we would take every opportunity to inform his class and the school about his rich and full life – a family trip to Uluru in the camper trailer, and attending rugby matches and cricket tests at the ‘Gabba. When they asked for family photos for the power point at assembly we always made sure we sent a photo in.

Someone once said I was constantly ‘putting Will out there.’ Not really, we hoped this was informing the community that Will’s life was like all other school children. He had the same interests and dreams as everyone else, just difficulty in expressing them.

*In addition to friendships and support at school, as a family we have always sought to make connections in our community - the local shops, newsagent, butcher etc.*

Will had a group of four mates with whom he would play and socialise. When we were out and about, children were always coming up to say “hello” to Will. It was here in our local school that we first experienced the power of belonging and the support of other families. We also experienced our greatest challenges regarding inclusive education at this time. However, it was the support from other families that made us realise this was all possible and inspired us to continue to pursue our dreams for Will, especially with his secondary education.

For Will’s secondary education we looked at local schools but our final choice was an inner city location. We sought a school that embraced diversity and a community where Will and we could belong, contribute and continue to make connections. This school was close to Henry’s and under the auspice of the same education organisation. Will commenced here five days a week in year eight. Like all students beginning at a new high school, Will had to begin building new friendships and finding his place in the school community.

When Will showed an interest in a sport or activity we would look for ways in which he could be involved. The school has a great reputation for basketball and Will developed an interest in this. In year eight or nine he would train with the junior team and he and Keith would go along to support the senior team at their matches. As a result of being present at these matches Will was given the role of water boy. He also developed a close bond with one of the coaches who is now a significant person in Will’s life.

Will has recently begun rock climbing at Rocksports as part of his outdoor education subject. As a result of this, he has become a member of the school climbing group which he attends every Thursday after school. By participating in these activities Will is building relationships and connections with people who share a common interest. Will participates in all aspects of school life – swimming carnival, cross country, cultural night and he is currently the roll monitor for his home room. Last year Will was ill and had an extended stay in hospital. During this time the school had a visitation roster whereby twice a week a staff member and three or four students would visit Will, play UNO and spend time with him. This was amazing support.

In addition to friendships and support at school, as a family we have always sought to make connections in our community - the local shops, newsagent, butcher etc. We have been very conscious of making these connections for Will and of sharing his story through our interactions, as he has difficulty telling it himself. We focus on Will’s interests, achievements, hopes and dreams. As people have grown to know Will, they understand how he communicates and they look out for him. It was at our local IGA that Will first shopped independently. We have a local coffee shop that we frequently visit where Will enjoys a coffee, especially a flat white. Over the past few years they have come to know Will and are aware that he’s presently undertaking a hospitality course. Henry and I were having brunch there the other day when the staff asked about Will and his hospitality course. In addition to being a connection for Will, it’s great for Henry to see Will being valued. This is an informal connection but significant; it’s through these sorts of interactions that we create natural supports in our community. It may lead to a part time job one day – who knows!

*We wanted to create a more formal support network around Will to assist us in planning for his future, especially his final two years of school.*

Now as Will reaches the final years of school, we are preparing for life after school. This is quite daunting and at times we have been overwhelmed by the enormity of preparing and planning for this next step. It was whilst attending forums and conferences we first heard about 'Circles of Support', a formalised group of people who come together regularly to support a person with a disability.

Keith, Henry and I talked about this as a possibility for Will. We would have discussions about the purpose of the Circle, who we would invite to be a member, who was significant in Will's life and who we felt would be willing to contribute. We wanted to create a more formal support network around Will to assist us in planning for his future, especially his final two years of school. We believed the Circle would assist us with this and also help to ensure we had ongoing support for the future as there will come a time when we are no longer able to provide this.

We had our first Circle meeting eighteen months ago. We were nervous about creating Will's Circle. It took courage to formally invite people into our family life and share with them the challenges we face. Everyone invited wanted to be part of it and were delighted to be asked. The circle consists of his immediate family and his Godmother, two uncles, a cousin and two friends. All of these people were actively involved in Will's life previously but the circle has deepened that involvement and their commitment to Will. Each member brings their own skills and gifts to offer the circle.

One of the very first meetings involved us sharing very personal family information about Will – this was difficult at first. However, if they were to assist with planning for Will's future they needed to know more information about Will's abilities, his passions and interests but also where he needed support. They needed to know a typical day in the life of Will. The focus of our meetings has been organising work experience and making connections within the workforce. As mentioned Will has an interest in horse-riding and the outdoors. One of the circle members has a business contact in the racing industry. He was able to organise work experience for Will at the stables at Eagle Farm racecourse. We have a vision and we creatively brainstorm about pursuing our hopes and dreams for Will. Having the group's assistance with thinking, planning and particularly sharing their local contacts is such a practical support for Will and for us.

*We have worked at creating and maintaining these friendships and connections for Will. It has not always been easy.*

After our first meeting we felt a sense of relief and also empowerment, by having these people committed to sharing the journey with us. They challenge us, push the boundaries and keep us on track. The circle meets about every three or four months – some meetings we have more to discuss than others but it's a formal way of staying connected and communicating about Will's life. Will loves the meetings and we are trying very hard to have him actively participating. Being a member of the circle has enriched everyone's lives in a way they didn't expect. They want to be a part of Will's life and to make it happen. We find they go out to their own networks and look for opportunities for Will. The members are actively seeking ways to be engaged with Will well beyond what they did previously.

In addition to family and now the circle, Will has numerous friendships and connections in his life that vary in closeness. We have worked at creating and maintaining these friendships and connections for Will. It has not always been easy.

What spurs us on is that we can see that these relationships give meaning to his life; it is through these relationships that Will feels valued, has meaningful things to do and contributes to his community. We believe that a network of people around him will be essential in ensuring that Will lives a safe and fulfilling life.



# Forming friendships and finding family

Ronda Quinn

**Ronda Quinn** is a retired Inclusion Teacher who lives on the Sunshine Coast. Her business card lists her job as 'Possibilitarian.' She believes people at risk of being devalued by their community need opportunities to develop real friendships with members of their local community. She has been an advocate with Sunshine Coast Citizen Advocacy for six years.

## Forming friendships and finding family

While driving home after a long working week my tired mind began tuning in to snippets of a dialogue on the car radio. The phrases I heard intrigued me: "being a loyal and accountable advocate and promoting, protecting, defending the rights and interests of people who have intellectual disability." My ears pricked up with curiosity. The speaker was Bob Lee, Coordinator of Sunshine Coast Citizen Advocacy. What I heard about in that radio discussion was the respectful nature of a mutual relationship that could develop over time, empowering both parties.

I contacted Bob Lee and we had a lively discussion on the principles of advocacy. He explained the goals of Citizen Advocacy: to take actions which result in a better life for the person with a disability, to give them a fair go and to be treated with respect as valued members of our community. I signed up.

During advocacy orientation I learnt that having an advocate could position a person with disability in a place of equal status with the other parties involved in their lives, such as their service provider or the Department of Disability Services. It is the task of the advocate to vigorously represent the interests of the person with disability to those third parties. People with intellectual disability and limited informal networks may need an advocate to act on their behalf due to their weakened ability to represent themselves to other parties, who may have no understanding of the person's needs or wishes.

Citizen advocacy could involve representing a person's best interest in making formal appeals, for example, to a medical specialist, a housing department or a service provider. When a person's life decisions are in the control of third parties, he or she is susceptible to things going very wrong. An independent, unpaid advocate who has no divided loyalty or conflict of interest can act on their behalf during a crisis when uninformed decisions are being made that may have a detrimental effect on the person's life.

By having a deep awareness of the nature of the person's vulnerability, an advocate can also act in advance to prevent crises from arising. An advocate commits to a long term relationship with their charge which enhances trust.

I was matched with Maggie in November 2009 and from our first meeting we just seemed to click. Although Maggie is unable to speak she can make herself understood through gestures and facial expressions indicating a yes or no response. I was immediately aware of her strong sense of self and her desire to be in charge of her own life. We started getting to know each other through weekly visits to her house for a cuppa.



There was little information about Maggie other than that she had been in an institution overseas as a child and was informally adopted by a person who brought her to Australia. On that person's death, Maggie was vulnerable, alone with no support and had no voice to represent herself. We talked over what we came to call "me being her person in her corner" and we began building a connection and a loyal friendship.

During visits I began to gain some insight into what Maggie was up against. I realised I had never had to deal with the kinds of things she had to deal with on a day to day basis. It wasn't just a matter of poor treatment and lack of choice. I saw that she was never going to get to experience the things I got to experience. I decided I would need to stay involved over a long time, taking action to ensure things did not go wrong for her.

*We talked over what we came to call "me being her person in her corner" and we began building a connection and a loyal friendship.*

Maggie had some urgent and practical needs which I talked over with her. I had observed that she had difficulty swallowing and drinking liquids and was at risk of choking. I bought her a container of thickener for liquids and asked workers to cut up her food into smaller portions. Eating and drinking was then safe and more pleasurable. Even seemingly small changes can result in a much safer and better life; I made a simple book of photos showing options of food and activities and she demonstrated her ability to make choices to her support workers. She began to vocalise loudly when workers did not use her book and allow her to choose. Maggie had found her voice and decisions would no longer be made without her regard.

Our relationship grew into a mutual friendship. We often went out together for coffee and lunch. Maggie made it clear that she enjoyed my company and welcomed my friendship and support. She also made it clear that what I enjoyed doing was a bit tame for her and it wasn't long before she began requesting we do more interesting things together. While on a riverside picnic she saw a jet ski and requested a turn and then another and another. I have come to know her as a person who loves the feel of speed and enjoys risk-taking sports. Instead of the craft-based activities she had been doing for years Maggie now goes swimming, surfing, wheelchair-dancing and sailing instead.

With my support Maggie lodged a complaint against a service provider and was able to select a provider more suited to her needs. As time went on we dealt with her protracted tenancy matters and had funds released for her to go on holidays.

Over the period of six years that I have known Maggie, I have become more able to predict the unique and special features of her needs and Maggie has built her trust in me. Our long term advocacy relationship and friendship became a bridge from the devalued world into the valued world. As our relationship developed, it was natural that Maggie's circle would grow as my family and friends got to know her. Maggie began to flourish. She started using an iPad to communicate and has her own Facebook page. Together we worked out a plan to start addressing her desire for a relationship. She bravely invited a male friend out on a date to the movies and they are now enjoying each other's company on romantic dates as partners.

Being wanted, needed and loved was something Maggie yearned for. As an adopted person who was unable to tell her story she longed to belong somewhere and to someone, as she once had in her childhood. Her cultural heritage had been lost to her long ago when she came to Australia and yet she remained emotionally connected to New Zealand through music.

On April 19th 2014 I was granted legal guardianship of Maggie and we celebrated with friends over a glass of champagne. Guardianship allowed us to explore further dimensions of Maggie's life without requiring the consent of a third party. I sent out certified copies of the guardianship order to a variety of government agencies requesting any documentation of Maggie's background and arrival in Australia.

Maggie had told me she could remember her family of origin and yet there

*As our relationship developed, it was natural that Maggie's circle would grow as my family and friends got to know her.*

*Maggie always knew who she was and who she belonged to. She had waited patiently for me to find out.*

was no paper trail of her heritage. A chance comment led me to a copy of an extract of entry for her birth. It showed that her family surname was not registered at her birth; however, it did contain the name of both of her parents. An internet search led to a descendant's page and contact with Maggie's ten siblings was made. Unfortunately both of her parents had passed away but her siblings were overjoyed to be reconnected with their sister who had been taken from them 38 years before. Maggie always knew who she was and who she belonged to. She had waited patiently for me to find out.

Recently Maggie and I flew home to her family reunion which was full of tears and joy. Maggie is now making arrangements to live near her family permanently. She is taking legal action to have her family of origin surname recognised as her legal surname. At last she has family photos to put on her wall, sisters and brothers to Skype with and family plans to make. I look forward to relinquishing my guardianship to one of her sisters.

When Maggie no longer needs me to be her advocate I will have an enduring role in Maggie's life as her friend. I see her as a gifted and unique person of extraordinary strength. I have gained much from our friendship and our relationship will continue to be reciprocal. I have grown as much as she has or perhaps even more by knowing her. She and Citizen Advocacy have taught me what's important in life. Who else gets the opportunity to do what she allowed me to do? I was not just a trusted friend; I got to act as a moral activist on her behalf.



# How does a worker assist people to build relationships with others in community? Neil Barringham

**Neil Barringham** is the manager of A Place to Belong, a small agency which focuses on assisting people with mental health challenges to participate more fully in community life. Neil continues to be involved as an Inclusion Worker and has a particular interest in facilitating spaces of safety, welcome and openness between people. Neil has postgraduate qualifications in community development, management and social work and in his spare time enjoys his rainforest backyard and neighbourhood chook cooperative.

## How does a worker assist people to build relationships with others in community?

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Sometimes as workers we can get in the road and inhibit people's connectedness – simply by our presence – as well as by our practice.

How can we turn this around? How can we do things differently in our efforts to assist people to become better connected?

Before we consider what workers can do we need to remind ourselves of the responsibilities of those in the governance structures who employ and support the workers. In this era of corporatisation and regulation we know that for workers to assist inclusion, agencies need to support flexibility and responsiveness, agencies need to work with and mitigate risk rather than flee from risk, and agencies need to encourage workers to spend time in community with the people they assist. Further, we know that workers need to be employed, inducted, supervised and trained to be aware of these community dynamics. Thus, a not insignificant part of the responsibility rests with those who employ and supervise the workers.

### A few things come to mind regarding what workers can do:

First, we workers need to consider our purpose. Even as we enter our work role with a person we can consider why am I in this job? Am I here to simply further my own needs to feel wanted and to be seen as a wonderful person or am I here to genuinely assist this person to be part of their community? If I want to do the latter then I need to be willing to facilitate, to be in the background at the right moments and to be aiming to make this person look good and not just make me look good. Thus we need to examine our motives and sense of purpose around our roles. Our purpose will shape whether we, for example, are attune to a facilitation vision rather than a 'mothering' or a 'messiah' vision.



Second, from the beginning of our work with a person we can negotiate with them and with others around them to ensure there is conscious attention given to how our presence inhibits or assists their empowerment and connections with others. This will include regular and ongoing negotiation around our role at particular events and times. From the time we begin assisting someone we can ascertain with them how they want to be connected with others, how we can use our time with them to achieve this and how they want us to support this process.

Third, we can watch, listen, ask and discern how the person is grounded or connected already. We can craft our role around supporting and assisting the connections that might already exist.

*Am I here to simply further my own needs to feel wanted and to be seen as a wonderful person or am I here to genuinely assist this person to be part of their community?*

Fourth, we can watch our body language. As we move around with someone we assist let's keep in the background at the right moments and ensure that the person we assist has as much centrality in presentation and verbalisation as possible. If a shop attendant addresses us, let's stay quiet, move backwards or gesture to the person we assist to respond, for example.

Fifth, let's talk about the person's strengths and human yearnings rather than narrowing our communications with others to that which is disability specific. The way we speak about people will educate and prepare others to respond openly and humanly rather than withdraw with the mentality that this person needs specialised care and I am not in that role.

Sixth, let's also talk with others about the person's desires or aims to be connected. Thus we want to minimise the chance of others thinking that because we are there in the person's life they do not have a role. Thus, rather than just communicating I am here to support this person I can go further by articulating that my role is to support this person to have an enriched life by meeting others and by having lots of contact with others in their community.

Seventh, we can approach our work with micro-focus based on the broad purpose of our role. That is, when we are with a person we can aim every time we are with them to be a catalyst for connection. Even if it is just the simple, microscopic encounters with neighbours, shop attendants and acquaintances we can work towards this with purpose and consciousness. Most of us appreciate having acquaintances who know our face and name as well as more intimate friendships. In addition to the micro-connections we can also obviously assist in enabling a person to participate in their community and we can bring others into their life which may lead to closer and more enduring connections.

Eighth, we can evaluate. We can look back over our times with a person and consider – how did I spend time with others when I was with the person this week? What opportunities did we experience to meet or interact with others and how did I assist this process? When I withdraw from my professional role with this person will they be more connected, more engaged, and more enabled....or not? As part of our regular reviews with the people we assist we can ask them how they feel we are going in supporting their connectedness with others.

Ninth, we can keep in mind that the community space is not a managed space. Community is a space where there is room for the spontaneous, the unexpected and the creative; it is the space where joy and pain can be expressed, a place for laughter and sadness; and we can enter this space with the person we assist with curiosity and openness to whatever the universe might bring across our path. It is amazing what connections can happen in the unexpected, unplanned, unmanaged moment! It is amazing what connections can be missed by our busyness, our 'managedness' and our lack of curiosity.<sup>1</sup>

It must be noted that these few points take us far deeper than technique. They speak to our purpose in the work, our approach to the work, our framework of engagement, our values, our heart and even our soul – as well as our skill and technique.

*...when we are with a person we can aim every time we are with them to be a catalyst for connection.*

This work is beyond technique. This work is about our engagement with self as well our engagement with the person we assist and our engagement with others. This work is about our spirit as well as about our skills. This work is about passion, purpose and soul. This work is about watching and listening as well as acting and intervening. This work is about dreaming and doing, faith as well as action. This work is about professional curiosity rather than about professional arrogance – professional 'unknowing' rather than professional 'knowing'.

As Westoby and Darling say "we are required to resist the shallow-ing temptations of technically oriented work and instead to orient our work towards dialoguing by embracing depth, re-imagining community as hospitality and infusing our practice with soulful orientation."<sup>2</sup>

Let me share an inspiring story which reminds us of what is possible when a worker approaches their role with purpose, passion and skill:

In a regional town in Queensland a support worker has been working with a man with disabilities. Each day this man walks a small circuit around the area where he lives. Walking this beat with the man the support worker noticed a pub that this man would occasionally visit. The support worker was hoping and talking with

1. For an excellent discussion about curiosity and professionalism see Wissmann, D. 2004 *The Art of the Professional: Learning to become a person. New Paradigm*. VicServe. June. Pp.15-25.

2 Westoby, P. & Dowling, G. 2009. *Dialogical Community Development: with depth, hospitality and solidarity*. Tafina Press.

this man about a better life. They decided to look around at the pub to consider any possible roles in which this man could participate. The support worker soon thought of an idea as she observed some of the tasks around the bistro. She noticed that the cutlery from the bistro was wrapped in paper serviettes. She talked with the man about this and together they agreed that he would see if he could develop the skills to wrap cutlery in paper serviettes.

The support worker then bought some serviettes and at home with the man began showing him how he could wrap cutlery in the serviettes. His fingers were not very pliable and he had to practice for a while before they were agile enough for the task. Soon he was proficient enough for them to visit the hotel and offer to the bistro staff that he could voluntarily wrap the cutlery in serviettes. The staff were very open to the idea and immediately they set up times where he would come to the hotel and carry out that task.

This went very well and eventually the bistro staff approached the man and told him that since he was actually saving them some work they wanted to pay him for the task. He agreed to this and went on the payroll at the hotel. By spending time at the hotel others were meeting him and the staff were witnessing his attitude to the work. They began to ask him if he could carry out other tasks as well such as hosing down and cleaning the beer garden. This man agreed to work on those additional tasks and now, sometime later, he is still being employed at the hotel. Sometimes in the evenings he goes to the pub for a drink and socialises with people as well.

Full marks to this man and his support worker for working with imagination, with skill, and with focus. At one stage the man's old push bike was stolen. People at the pub heard about this and decided to pass the hat around. Sufficient money was raised from the people at the pub for him to buy a new bike. This man has presence and participation in his local community – his contribution is recognised and people are willing to contribute to his life.

Finally, let's be reminded that this community thing is not that easy for any of us!

We know that we live in communities that are fragmented. We know that our competitive capitalist societies are founded on individualism. We know that our 'affluenza' (*The bloated, sluggish and unfulfilled feeling that results from efforts to keep up with the Joneses*) undermines our energy levels and ability to welcome others who are different from us. The real estate advertisement that trumpeted you will never know your neighbours are there, tells us something of our suburban penchant for privacy. We also know that fidelity, loyalty and generosity of spirit are values that we struggle with in our busy, stressed lives. This writer for one, is an inclusion worker who struggles to facilitate his own inclusion! In this context, those of us who are seeking to facilitate inclusion with people with disabilities can easily feel we have it all against us!

***This man has presence and participation in his local community – his contribution is recognised and people are willing to contribute to his life.***

Yet we also know that around our country are beautiful and sweet places and spaces where people with disabilities are contributing and are being valued. There are many stories being shared telling of love and kindness of support and friendship. How this happens is sometimes a mystery. There is an art and a science to this work.

What we need are people who will join the countercultural drift.

Will you come with us?



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