

family

A D V O C A C Y

Building Networks of Support

“The beginnings.... of all human undertakings are untidy.”

(John Galsworthy)

The Building Informal Networks Project has grown and developed over the past four and a half years. As we have worked with each person and their family, our understanding of what is possible for them, and therefore for others, has grown. As we reflect on what we've learnt, we don't want to give the impression that we had it all worked out when we started. What we have done is listen to what people and their families are asking for (what they are saying and not saying); invited other people to be part of the journey and together, kept focusing on how we can help that person build a rich and meaningful life. Each of the stories is very different. One of these stories will be shared.

What is Building Informal Networks

- We are part of a Brisbane family support organisation. Mamre and we see this work as family support.
- Our role is to walk with people and their families, as they work out the next step.
- The project started four and a half years ago because some adults and/or their families asked.
- Some people had post school funding and some had no funding at all.
- To date, 10 families have been involved. Seven people are now living in their own homes. Some of the families have lots of family and friends; others have very few.
- Each family has more people involved in the planning, thinking and doing.
- Circles of Support have been a key strategy but not the only strategy.
- To date, we have invited people who already have a connection with the family.
- Every group has had the involvement of adult brothers and sisters.

“Real friendship or love is not manufactured or achieved by an act of will or intention. Friendship is always an act of recognition.”

John O'Donohue

Why invite others in ?

- We assume that friendship and relationship is an essential part of a full and meaningful life.
- We assume that ALL people want to love and be loved and be in relationship with others ... that people need each other. (Even if that doesn't appear to be the case when we start.)
- We assume that all people have a lot to give and to receive – and that being labeled with a disability makes no difference to that.
- We recognise that most of us have connections outside our family.
- It is people that keep people safe. Not services or trust funds or bricks and mortar.
- Others often want to help but don't know what to do ... and need information and an invitation to be involved.
- A semi-formal structure, such as a Circle of Support can help to harness a lot of goodwill and commitment.
- Circles of Support can create opportunities for that recognition to occur and to flourish. Sometimes people are committed and supportive to a person with a disability but neither party would necessarily see each other as friends. Sometimes deep and genuine friendships also develop. We refer to these groups as Circles of Support not Circles of Friends.
- Building is intentional and step by step. This is not about just hoping that people will come.

My Life

By Jamie Carrigan

I am Jamie Carrigan. I would like to tell these people about my life and what's important to me.

I am married to Nikela.

I have a Mum and Dad and two brothers. They are both married so I have two sisters in law. I am a Godfather to Bridie. I am part of Nikela's family too. We live in a flat under Jenny and Vern's house. Jenny is Nikela's mother.

On Mondays I go shopping for groceries with Nikela in the morning and then go to work in the afternoon. I am a volunteer at the RSPCA shop. On Tuesday I have a relaxing day at home while Nikela is at work. I wash the clothes.

Margot and John come at night to cook with me while Nikela is at Tae Kwon Do.

On Wednesday my support worker Kelly comes. She helps me with my shopping business. We shop for one client.

On Thursday I go to HAND where I learn life skills, reading and writing, computer skills, internet.

I like to go there to meet my friends. Thursday night is family dinner at mum and dads.

On Friday, my support worker Sam comes. We shop for another one of my clients and I go to my Personal trainer. I go to Michael because I want to be healthy and get my heart healthy.

On weekends, we sometimes go and see a movie; sometimes we sleep over at a friends place; or have a friend over. Not all the time though. Nikela and I need couple time.

We do a lot of things by ourselves but with some things we need some support.

Sally helps anyone in the support network who wants to go out with me and Nikela. I like that.

We have lots of friends who support us.

They help us to cook; we go out to movies; sometimes plays. Sometimes to dinner at their place or to a restaurant.

My hobby is learning about TV stars. I get on the internet and look at their pictures and find their real names. I get magazines and copy words about what happens in Home and Away.

In July, my cousin Sally put on a show at the Judith Wright Centre. It was called "Everything but Alf Stewart". It was about Home and Away. I was one of the actors – one of the cast and crew. I'm a very good actor. I'm so proud and happy.

I have other dreams and goals. I'm getting another paid job soon – to support me and Nikela.

I want to be a business man for TV stars and have my own office.

By our second wedding anniversary next March we want to save our money and go to Hawaii or Jamaica or Hollywood or New York.

I haven't been there and I want to go.

Annette's Story

Jamie's mother, Annette Carrigan talked about how she made a deliberate decision when Jamie was born to put her energy into developing his social skills and social networks.

I believed that I wasn't really up to the job of raising Jamie by myself, and that my family and I needed all the help we could get. In my eyes, but not the eyes of my husband and sons, Jamie

belonged to the world and the world belonged to him. When I rang a friend to give her the news of the diagnosis, her response was, "This could have been any of us. We'll share this with you. He belongs to all of us." I grasped the offer with both hands and firmly held to that in all Jamie's interactions with his community. I expected the members of my community to feel that he belonged to them and that they had a part to play in his life.

They all responded magnificently. I never felt that I could do it better than they could. So, when they offered to have him for the night or for a week-end, I simply handed him over with no suggestions of how he should be treated, what he should be fed or where to get me if they needed me.

I trusted them to love and care for him and I trusted him to be lovable and good company.

Another friend said, after being told the news of diagnosis in the first few days of his life, "Don't ever worry about whether or not he can read and write. But, make sure that he can make his bed, clean up after himself and help me prepare meals when he comes to stay." Those words fitted well with what I believed, and those skills together with exceptionally good manners were part of the key to his acceptability and adaptability in any situation. Whatever your beliefs about good manners and what they consist of, they are very endearing.

Jamie has lived in a wonderfully generous and loving community. He's been part of a number of families. He's been to all the important events in the lives of his neighbours, friends and family – birthdays, weddings, christenings, and considered by them to be an important guest. He makes the 'A' list on every invitation list.

It was, nevertheless, hard to start to think about this group of friends and family as a formal network. Up until now, I had thought of it as a network that I was building with subtlety and discretion. The community were hardly aware of my intentions. When it came time to call them together, I felt bad about asking them to make a commitment to Jamie and his then partner, Nikela. But they responded again with generosity and enthusiasm. Jamie and Nikela have been living together for four years now and as you heard from his presentation, he still has a rich network of family and friends involved in his life.

In some ways, involvement in this project over the past four and a half years, has been getting other people to continue the work that Annette started – to help to keep Jamie's friends, neighbours and extended family involved in his life now that he has moved out of the family home and is married. Initially Jamie and Nikela had a Circle of Support that met monthly with them and their parents and

helped them plan their move into their own home. Over time the mechanisms for keeping people connected have changed. Currently, a facilitator works with Jamie and Nikela and their network of family and friends to keep them in touch and there is a focus on social activities. This is reviewed regularly.

SOME THINGS WE'VE LEARNT IN THE PROJECT

1. It's about safety and commitment

- When asked, most people have said yes.
- Friends, neighbours, cousins have become involved and stayed involved over the years and this has provided a constancy of relationships that is an antidote to the coming and going of workers and support workers.
- Establishing a Support Circle of Support can provide a semi-formal way to bring people together. A little bit of formality can also help families to broach some of the topics that get left unspoken.
- Having a facilitator is a safeguard – someone else is responsible for keeping the Circle of Support or network going. If it starts to fall down it is not up to the parents to get it started again.

2. It's about Creative thinking

If Plan A doesn't work; we go to Plan B..... we can't stop and say "Well that didn't work. See I told you nobody would want to be involved..."

- It's important to have someone who encourages you to keep going and to keep thinking creatively.
- Time and again, when people have been invited in, they have learnt more about the person; seen a need and have done much more than anyone would have ever asked.

3. It's with people with disability not about them

- Usually people with disability are present at the Circle of Support meetings.
- With time, care and thoughtfulness it has been possible to discuss some very delicate issues.
- Generally people have enjoyed having a Circle of Support.

4. It's a way of thinking

- Many families have already done a lot to connect their son or daughter, even if they haven't thought about it intentionally or put a semi-formal structure around it. This is about building on what you have already done.
- Some families are prompted to start inviting people to be involved early, when their child is young. Other parents start because they are getting older and are concerned about what will happen in the future.
- We have learnt that it's never too early and it's never too late.

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