

WHO WILL STAND WITH YOU? HARNESSING THE SUPPORT OF FAMILY AND FRIENDS THROUGH CIRCLES OF SUPPORT

by Margaret Rodgers and Pam Rallings

Margaret Rodgers' commitment to people with disabilities began in a Larche community in 1981. She now works at Community Resource Unit in Brisbane. **Pam Rallings** is the mother of three adults and proud grandmother of three boys. Her youngest son David has a disability and is now in his late 30s. Pam and her husband Paul assisted David to move into his own place 12 years ago and also to find work. David does not receive any funding. The Rallings family have had a support circle for over five years. Pam will share her experience of this. This is an extract from an article that was presented at the 2008 "One Person at a Time Conference" in Melbourne.



About six years ago, in an era when most families in Queensland were waiting for funding in order for their lives to begin, five young people (and?) their families began to talk with the Mamre Association, all quite independently, about the future and they asked for assistance to get on with their lives. They either had post-school funding or no funding at all. Nobody had adult lifestyle funding or support from an adult lifestyle service.

The vision of the Building Informal Networks project is that young adults with a disability will be able to live in their own home with the support of family and informal networks, including friends, extended family, neighbours and others. There are now ten people living in their own home.

Circles of Support have been a key strategy to help people and their families achieve this. Within the Building Informal Networks project, when the same little group meets regularly, we call that a circle; when there are lots of people involved (eg. socially) but not meeting together as a group, we refer to that as a network. Not everyone has a circle, but everyone has more people involved in the

thinking, planning and doing.

What we want to offer today are reflections from our experience in this project. There are some things that have worked well and some things we would be cautious about repeating. People coming together is a very old and very ordinary tradition, so there are no right or wrong answers.

The Rallings family was part of the group that instigated the project. David was already living in his own home, but his parents were concerned that he was isolated. David wondered who would help him when they were too old. With assistance from the project, their Circle began in July 2003. After 12 months, one of the members took over the facilitation of the group. She is supported by the co-ordinator of the project. This is part of their story.

DAVID'S CIRCLE OF SUPPORT: PAM RALLINGS

Our third child, David, was born in 1971 and was not well. He was quite badly battered from the birth and took weeks to regain his birth weight. By the time he was twelve months old, he had been in hospital several times and was

extremely physically slow compared with other babies. We went to lots of special programs at the Children's Hospital and the Schonell Centre at the University of Queensland and began the search for kindergarten and schools. Of course nobody wanted us. David spent all his school years at a special school.



When David left school I just over 20 years ago, I was shocked when I looked at the options. David was sixteen in the January of his first year out of school, and Centrelink's only answer was to put him on a disability pension. I was furious with a system that could not even give time for someone who had taken a long time to learn everything to decide on the next stage of his life.

Somewhere along the way, I decided he would move out at 25 years of age at the latest. We did not even think of funding; there was no individualised funding at that time. David wanted to live in the suburb

where he grew up. The irony of him being on that pension for so long was that he had money saved for a deposit. We helped him buy a house that, over the years, he shared with people. First with a friend that he had known from special school, then he shared with students. These experiences taught David about living with people. While I didn't always like what was happening, at no time did I feel he was in any danger – I kept a fairly close watch. It was a lesson to me about letting go.

We know that David gets so much self-esteem from having a job and being a valued member of a team of workers that the last time he lost his job, we decided to create a resume for him and send it to several nursing homes and golf clubs suggesting he could be a gardener's assistant. He was offered a job at our local golf club, and six years later he is still working there.

The job starts at 5.30 am, 4 days a week. We could not work out any way by public transport or bicycle tracks that he could stay in his house and start so early. So reluctantly, after six years of living in his own home, David came back home to live with us. After five months at the new job we (reluctantly on my part) helped David move to a unit where he could ride his bike to work easily. David rented the unit but I had to guarantee his lease as his income was so low. At the end of the lease the rent was to be raised, so my husband Paul and I decided to buy a unit in the same area so David could rent from us and would never be asked to move as long as he had that job at the golf club.

David's life is busy and he loves routine. Four afternoons a week he goes to the gym after

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work. On his day off, he goes to TAFE for adult literacy and numeracy – he has been going for years, and uses it like a club. On Saturdays, he bowls with old school friends, visits his grandmother, occasionally goes out with a recreation group and comes to visit us if nothing better is happening.

In addition to the support that Paul and I provide, Michael comes for a couple of hours on Wednesday evenings and helps David shop, cook a meal, and make the lunches for the next

week. We have a really good arrangement. Our challenge now is to keep this going for David when we can no longer do it. This is one of

ask people as I have always found it difficult to ask for help.

David and I both suggested people for the

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Circle. They

said they were flattered to be asked. Not everyone could commit to regular

meetings even though they were interested

in David and what the Circle could do for him.

Some people have asked us to call them when we need them. We make sure the Circle knows who they are so they can be invited to social gatherings through the year.

the reasons we started a Circle. I realised that if something happened to me, David would need people around him to do the things that I do in the background that help keep his life on track. I can often anticipate what might go wrong, such as how changes in bus timetables or fares or TAFE timetables will affect David. He needs help with planning ahead and I know he always will. This once led to me thinking that I'm the only one who can do this, which isn't so. However, it needs people who know him

David enjoys the Circle and seems to appreciate the focus being on him. Sometimes I feel they're getting a bit intrusive and give him too much advice but he seems okay with

it. I know he

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would stop the conversation if he

wanted to. I see the Facilitator as

and care about him and who can anticipate what is likely to come up.

Over the years, I have found that my being away occasionally creates the opportunity for Circle members to understand what it takes to assist. Often, people not so close to the situation come up with great suggestions.

Also, the younger members of the Circle see things differently. Some problems need new

an essential role – someone who is on David's side. They can say “What do you think about this David?” I used to worry that David would feel bad about people discussing personal aspects of his life, but the opposite has happened. He likes them to know all his news and grew two feet taller when telling the Circle about his award at work.

The Circle has changed over time. We always

include food

and fun at the

meetings, but

while it is more

relaxed, we

always have

eyes to solve them. I think we as parents can put up barriers by pretending we can do it all and thinking nobody can do it as well, which isn't necessarily so. I needed someone else to

definite things to discuss. As more people know what is happening in David's life, I have been surprised at how people offer to assist with things that I would never have asked for.

At the present time, we are compiling a “Book of David”. We realised that a lot of David's history e.g. courses he has attended, work experience

and some health issues were only in my head.

Members of

the Circle have

chosen different topics e.g. achievements, health, goals.

We have differing numbers at meetings. We have larger meetings sometimes with partners and visitors coming along. At present, we are rotating the Facilitator for a change so each person gets a chance at facilitating if they want to and the Facilitator gets a chance to be an ordinary member.

It's also about being open to opportunities and following them. Recently, the partner of one of the Circle members Richard saw David's truck collection so invited David to come to his workplace and see the big machinery and roadwork vehicles. Richard then asked David if he could come to his workplace. The Circle helped David to organise lunch at the Golf Club so David could show everyone his workplace and what he does there. The day was a great success and we are thinking of making it an annual event. David used to be very shy at Circle meetings and always looked to Paul or myself to answer if he was asked a question. Now he often asks a question himself and even initiates phone calls to members himself – but it has taken years. I still get pre-Circle tension (five years later)! I get anxious before meetings, even when everything is going well, but David looks forward to every meeting, saying “I've got to get my unit cleaned for the meeting, what food will I get, etc.”

When Paul and I go away, the Circle share the

support that we usually provide. They organise themselves to take turns to be available for him. Everyone in the Circle has our itinerary.

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and Paul gave instructions only to contact us if it was life-threatening as I'm a bit of a worrier. I'm very proud to say that so far I have not phoned home at all. These times away make me realise that if anything happened to us, David's life could keep rolling on.

BUILDING INFORMAL NETWORKS PROJECT: MARGARET RODGERS

Other Circles in the Building Informal Networks project have found that:

- Two heads are better than one.
- When it doesn't happen naturally, having a semi-formal structure like a Circle can help people to be involved. Friends and family need information and an invitation,
- Being clear about who and what the circle is for from the start helps you know who to invite,
- Circles can be for the person, or for the person and the parents, and
- They can be short-term to achieve a particular goal, or long-term for safeguarding, social or whatever else is needed.

WHO TO INVITE AND HOW

- People who love and care.
- In this project, the focus has been on people already known – rather than seeking out people with particular skills from the broader community.

- People who are prepared to focus on the person – workers in the field bring disability knowledge but their loyalties are often divided,

gatherings, people with disabilities can fade into the background and the deeper topics don't get aired. Circles find their own balance of work and play.

WHAT HAPPENS – WORKING TOGETHER

- Brothers and sisters, extended family, and
- The person themselves – this is with them not about them.

- Regular meetings help the group to form and work together. Initially, most meet monthly for about an hour and a half. This may change over time.

HOW TO ASK

- Different for each family – some want help with this, others just need help behind the scenes to work out who and how, but they do it,

- Finding a place to start – some circles catch up on the day to day issues, and that leads into discussion about the bigger picture. Others start with more formal planning and follow goals and strategies that come from that, and

- Some send a letter, others a phone call. Some do both,

- It takes time – establishing a circle can mean more work for parents initially. Members take time to learn and

- Depending on the purpose, sometimes it comes from the parents, sometimes the person and sometimes both, and

- understand the complexities of supporting the person. However, over time this can and does happen.

- Some families have invited people to a one-off planning session and then the circle has emerged from that.

GETTING STARTED

- The first Meeting is an opportunity to talk about how the group will work together and when, where, how often and for how long to meet,

- Having a nominated (sometimes paid) Facilitator who shares the responsibility with the family for setting dates, asking people, keeping on track and following people up is a safe guard, and Anniversaries and Celebrations are a good opportunity to reflect on what's been achieved. This can help people recognise the sometimes subtle change that has occurred and inspires them to keep going.

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and Anniversaries and Celebrations

- Having someone to facilitate or chair the meeting keeps it on track and on time, and means family members don't have to do that,
- Keeping notes is helpful. A good record of subtle change over time,

- Food is good, but be cautious of that taking the focus off the discussion, and

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CONCLUSION

Circles are far from perfect. They are not a magic fix-all solution. They are made up of human beings and are therefore messy. However, despite our fears, people with disability seem to have enjoyed having a

Circle and have enjoyed having people focus on them and their future. Brothers and sisters have also reported some relief at having others to share the responsibility in the future. The majority of Circle members keep coming and don't appear to be counting the months or years. They are usually surprised to find how long the Circle has been going. They are much more informed about the person and able to play a role and they are proud to share some of the person's life and achievements. There is a lot of talk today about selfishness, greed and busyness in our society, but across Brisbane alone, I see evidence to the contrary as a couple of hundred people from this project alone come regularly to talk and listen, support and encourage other members of their community. This is being led and instigated by people with disability sharing the gifts they have to offer.

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