

Invitation on the Journey

Margaret Rodgers has coordinated a project designed to build informal networks or circles of support for people in Brisbane for the past four years. In this project, circles are one strategy for bringing people into the lives of people with a disability. Margaret has assisted nine adults who have a disability and their families with the establishment of circles of support in this time and shares with us some of the lessons from this journey.

'Come back to me when you have a project. I don't have time for the airy-fairy stuff – this 'drawing arrows on butcher's paper'. You make me feel mean when you ask me to do things that I don't have time for.'

This was the response given by a woman who was the friend of a family when she was asked to join a support circle for that family.

What is striking about this story is that this is the only time this has happened in three and a half years of 'asking' people to be on circles on behalf of young adults with disabilities and their families. In that time, about one hundred and fifty people have been invited to be involved in the lives of people, so one rejection makes for extremely good odds. Sometimes we are fearful of asking because we expect that the above response will be typical. Yet, the more typical responses are: 'We have wanted to be involved but haven't known what to do'; 'It's a privilege to be invited'. Or, from time to time: 'I don't have the time to be part of regular meetings but I will keep doing what I am doing'.

To date, we have not gone into the wider community seeking particular types of people with particular skills or of a certain age. The people we have asked have been selected by the person and their family from extended family and friends and have been invited because they know and care about the person and their family. Thus, the circles are made up of brothers and sisters, neighbours, cousins, brothers-in-law, old family friends and the children of old family friends. When people are already known, there is less risk of inviting someone who may take advantage of the person in some way. Most people we have invited don't know much or anything about the disability sector and may not even know another person with a disability. Most of the time, this can be a great asset. What they do know is that life for young adults with disabilities and their families looks very different to their own lives or the lives of their sons and daughters: the usual doors are not opening; the usual separation from parents is not happening; the usual plans and dreams are not being explored.

People often join a support circle feeling quite mystified as to what they can do, they may have known the person with a disability for a long time, yet they may not know them very well or have spent much time with them on their own. They may need some information and support to help them extend and deepen their relationship with the person.

Sometimes, people who work or have worked in the disability sector are invited to join a support circle. Their experience can be useful if they can contribute without overwhelming the voice of others in the support circle, who do not have that experience. Circle membership requires them to be biased. Their loyalties may feel divided as they take part in conversations about one person, when they are acutely aware of the needs of many others. In order to be an effective circle member they will need to suspend these broader concerns and focus on this person. Generally, we would not invite people who are currently employed for or by the person into the support circle. This is an attempt to separate the formal support from the informal support. If staff is invited to become a member of a support circle, then clarity about what their role is and why they are there is even more important than for other members.

Support circles create an opportunity for the person and their family to invite people they know and trust to join them as the planners, instigators and decision-makers in their life. The service provided by service providers can then fit into their overall plan and vision for the person, rather than the more common trend of the service provider making plans for the person and the family and friends having to fit in.

People coming together to talk things through and support each other is as old as civilisation, but when it comes down to working out, in an Australian lounge room, just exactly what this group will be and do, it can feel a bit awkward. Having a facilitator for the support circle, someone who is not one of the immediate family, helps to introduce a semi-formal structure to a group who all know the family but may not know each other or who may have previously only met socially. A level of semi-formal direction helps to keep the focus on the reason for coming together – the needs of the person with a disability. Without someone to assist and focus the conversation, it is likely that the group will remain at a social, informal level, which, though very pleasant, is not usually the best way for a person with a disability to communicate their issues, concerns, hopes or dreams. Parents will probably also hesitate to raise the deeper, more personal issues in that forum.

The group will need to decide when, where and how often they meet and for how long. This is one of the ground rules to establish in the initial stages. With the best of intentions, support circle conversations can easily move into areas that the person or their parents are not ready to discuss. Working out in advance what the person and their parents should do, if the circle gets too personal is also time well spent. Keeping and circulating notes of the meeting will also help to keep people informed and involved and become a record of the changes that are often very subtle.

One of the most important and ongoing issues is deciding on the purpose of the group and who the group is for. If this is done by the person and their family before the invitations are issued, the better the chance of a good match between the circle members and the purpose. It is helpful to clarify if this support circle is for the person with a disability, or the parents, or both together. It also helps to be clear about why you are bringing people together; some circles have a short-term role to achieve a particular task and others have a long-term, safeguarding focus. If there is an expectation that circle members will drop in spontaneously or help to fill a social vacuum, then inviting people who are busy and live some distance away is unlikely to be a satisfying match for either party. Similarly, if the group is established for the person with a disability, but all the members have more in common with the parents, then it may be difficult for them to empathise with the issues of the son or daughter. However, that same group might be ideal if the purpose is helping the parents plan for the future for both themselves and their son or daughter. Revisiting and refining the purpose will need to happen again and again; anniversaries of the support circle are great opportunities for the group to stop and reflect on what has been achieved over the year and to make any changes for the coming year.

Having gathered the members and established the purpose and the ground rules, what then? Jeff Strully from California says that after twenty five years their support circle continues to address the same question: Is life good enough for our daughter? Some groups that I work with ask a similar question: What does this person need now? Starting with such broad questions works very well for some groups, but to be really useful, they will need to find the links between those broad vision questions and the detail and relevance of everyday life.

One woman for example, who is a single parent, has asked the circle that supports her and her son to help her deal with the range of issues that arise day-to-day, without losing sight of the long term. Their circle meetings start by catching up on what has happened for that young man and his mother for the last month.

Over time, themes and patterns emerge in this way, which direct the group to the bigger, longer term issues that need to be discussed and, in turn, leads the group to identify the broader vision questions. Wherever a group starts, they will still need to work out what is right for that group of people at that time. Setting time aside to plan for the person's future can also help the group to identify their role in that process. Initially, it may be unclear, a little confusing and at times frustrating, as people work out their roles and the group finds a pace and style that is comfortable for the person and family at the centre of the group.

In this project I have assumed that the person will be present at meetings. Sometimes it is difficult to discuss delicate issues when the person is present, but by taking the time and being respectful, it is not only possible but it is important that the person is given every opportunity to be there. I have gained confidence that this can be a positive experience for the person with the disability; people develop trust in their circle and the confidence to articulate their hopes and dreams. Support circle members can share their own life experiences, most of which is more helpful to the person than what he or she might learn from watching Home and Away or movies. One circle talked about what it was like when they first moved away from home; another talked about their experience of boyfriends, girlfriends and relationships. This can mean that the person will begin to seek out and ask for advice from their support circle because they know that the group both understands their issues and cares about them.

Circles of support are not a cheap alternative to replace services and support circle members are not unpaid staff members. Support circles are not support groups for people with a disability or support groups for parents of people with a disability. They are neither strategic think-tanks, nor should they be set up by a service provider who thinks a family needs it.

Instead, support circles are a very powerful strategy for inviting ordinary people to walk alongside, focus on and make a commitment to people with a disability and their families, as they dream, plan and achieve the lives that they want.