

CRUCIAL TIMES

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Guest Editorial

*This issue of CRUCIAL Times is devoted to the topic of circles of support. We invited **Sandra Kalms** to contribute this guest editorial; Sandra is involved in a circle of support for a young woman in her local neighbourhood.*

It can be difficult to describe exactly what a circle of support is or what it does. Each circle of support or supportive network is unique, so there are as many different circle arrangements as there are circles. A widely-accepted understanding is that a circle of support is a group of people who meet together on a regular basis to help somebody accomplish their personal goals in life. The circle acts as a community around that person who, for one reason or another, is unable to achieve what they want in life on their own and decides to ask others for help. The focus person is at the centre of the circle, guiding decisions about who to invite to be in the circle and the direction in which the circle's energy is employed, although a facilitator is often chosen to take care of the work required to keep the circle running.

However this description does not fully capture the spirit and personal experience of each person involved. Being part of a circle of support is to enter an intimate space where you learn about the very private aspects of a person and their family's life. In this space, vulnerabilities are exposed, fears and dreams shared and common visions developed. It is humbling, exciting and ultimately enriching to be welcomed into the circle space.

We are not talking about a new idea. Circles of support or supportive networks have been a strategy used by people in many parts of the world for many years. There is a great deal of wisdom around about creating, supporting and assisting circles to remain focused over the long term if required. The contributors in this issue provide us with honest reflections on both the strengths and the potential dangers in considering circles for ourselves or those we care about.

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CRU's MISSION STATEMENT

- To challenge ideas and practices which limit the lives of people with disabilities.
- To inspire and encourage individuals and organisations to pursue better lives for people with disabilities.

Human beings often look for simple, quick and all encompassing solutions; what we could call the 'silver bullet' solution. Circles of support do not provide the solution to all of life's issues and they are not the solution for everyone. We all know people do better when we are loved, admired and assisted, yet assuming that circles will achieve this for everyone is a fallacy. Indeed, for some people, who have natural relationships already, forcing these into an artificial structure may actually do harm. For others, having one supportive ally may be the most important safeguard for them personally. If our good intentions to build relationship are not accompanied by thoughtful consideration, we may place people in a position where they could be further rejected, or even abandoned.

One of the issues facing the current movement around building circles of support is the question of who drives the strategy. History is littered with examples of good ideas which turn into bad institutions or practices. At present, most circles of support lie in the control of individuals and families, however there is a danger that the good idea will be taken up by services and systems and modified to suit the needs of structure. Even more troubling could be the notion that 'circles don't work' because they do not fit neatly into systems. In the current risk-management context, one can only imagine the hoops individuals wishing to join circles would have to go through to be 'approved'.

Therefore, it is vitally important that the investment in circles of support remain with people and families. It is the role of services and systems to acknowledge, to respect and to honour the place of ordinary people in the lives of people with disabilities, not to hinder or impede their initiative.

Circles of support or supportive networks can be thought of as a form of glue. Without people who care about us, helping us to solve life's problems, anyone of us could easily become unstuck. Being deliberate in inviting people into our intimate space is about investing in the glue that keeps our personal visions pasted where we can see and touch them.

This issue of CRUcial Times reminds us that it is ultimately worthwhile to support and to put our energy into investing in the glue of support networks and people, as an element of safeguarding a 'good life' for people with a disability and their families.

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From the President

Having a circle of people around you, who love you and will support you through thick and thin and who will dream about the future, is one way that we humans show that we need and care for each other. In my own experience, the support of a group of friends and family was vital in my own move to living in my own unit after twelve years living in an institution and six years living in a group home.

Initially, I may have been reluctant to take notice of a 'gut feeling' that I needed a 'Circle' – that this was something I just couldn't go solo with. I was cautious, I wanted to be in control of planning for my future and I was concerned that others might take over or allow their own agendas to dominate. I wanted to choose the people who would share my journey. I wanted to have a relationship with every one of them and know that they also got on well. I wanted this to still be fun and social but to recognise when things needed to get done and, most of all, I wanted to have the final say about decisions. I set some fairly demanding rules, as you can see.

I was very fortunate indeed to have some very wonderful and beautiful people around me who I could call my friends. These were people with whom I felt completely at ease to share my deepest longings. I knew I could trust them completely. I knew they would follow me anywhere I wanted to go. When I drew my friends and family together to share my vision of moving out of the institution I knew that they believed as much as I did that this was possible. There were many ways that this group worked to assist me to move out and each person brought particular skills, talents and passions to the table. Together, we devised strategies, prioritised our planning, negotiated with bureaucrats, worked out modifications and accessibility issues, monitored progress and found creative solutions to any obstacles. Central to all of this activity was our commitment to our belief in the possibility of my initial vision.

Throughout this long process, I found their support and their willingness to walk beside me, quite invaluable. I had the support of a 'Circle of Friends'. These friends did things with me, not for me. This really emphasised for me how much we all need support at all times during our lives, in particular people with disabilities. I still have the friendships and relationships with many of the people who were part of my circle, though I no longer have the 'Circle'. While circles have a shelf life or might change in nature over time, I know that I can draw on this group of people, should there be the need for others to support me through some future phase in my life.

From my own experience I learnt that the most effective and helpful circles of support share some common and very precious characteristics:

- Circles are not rooted in bureaucracy, but in *common connectedness*;
- Circles give 'ordinary' people an opportunity to use their innate gifts and skills to assist another human being; being in a circle will generate positive momentum and spirit to keep on going on;
- No two circles or phases of a circle are the same; they all have different characteristics at different times to suit a particular set of circumstances;
- Circles work best when people can share their ideas, but do not try to force their ideas. By remaining open to the ideas of others, the circle can work towards assisting the person at the centre of the circle to reach their own decision or, when the person is unable to make their own decisions, to find a decision which is in the best interests of the person;
- Circles should never be classified as a tool; they can be seen as a catalyst for change in the personal realm and in the broader social movement. Using the techniques and tools of social movements, they can generate power to the cause and act as grass-roots social change agents;
- Change is more easily achievable in environments of positive attitudes and shared vision.

Circles can be seen as part of the broader social change movement. Their impact is both at the individual level and at a broader social level and they are an important element of the community living movement.

PEACE!

Mike Duggan

CIRCLES: HOLDING AND INVITING RELATIONSHIP

Janet Klees has been involved with the Deohaeko Support Network in Ontario Canada for the last fifteen years. In this short piece, Janet shares what she has learnt from people with disabilities, their families and friends about the role of the circle in assisting a person and their families to build relationships and to discover a sense of belonging and mutuality. Some of these stories of relationship have been captured in Our Presence Has Roots and We Come Bearing Gifts.

I tell many stories about courageous, hard-working people I know – people who have a disability and their families, friends and allies who try to support their dreams. However, I write and speak about circles of support with some hesitation.

Often – almost always, as it turns out – my stories do include a 'circle' of encouraging people, often family and friends, who work together towards a common vision of possibility as a part of the story of struggle and success. But, there are other consistent parts in the stories that I tell, too. One, they almost always focus on an individual who is known as unique and worthy by at least one other person. Two, other people recognise one or more significant, valued roles that match the individual's desires and interests. Three, there are achievable and typical ways that the individual can take part in opportunities within those roles. Four, events and activities linked to these opportunities take place on a frequent and intense enough basis to form a meaningful part of the individual's life. Five, there are other welcoming, supportive people present, often including a genuine, skilled and reliable support person. My stories have a pattern and a shape that are repeated time after time. And I find that stories of other successes and achievements are not so very different.

However, despite other consistent elements in these stories of living well and personal success, anxious people looking for answers all too often decide that the idea of a circle is the key to ensured success.

So let me state from the start that *circles are not the answer*. They are not the answer to *any* question that you might ask. They are not the answer to how to find a good place to live for your son or daughter. They are not the answer to how to make sure that your family member is an active and welcome participant in her community. They are not the answer to making sure that your loved one is not isolated and lonely. They are not the answer to your fears of who will replace you when you are gone.

People have indeed used the ideas of circles as a way of safeguarding individuals' lives, offering alternatives, fulfilling dreams and moving on with one's life. What becomes worrisome is when a person, an organisation, a policy or a funding body acts as if the circle, in and of itself, is a service or a

technology or a tool which will automatically provide workable solutions to the individual and his or her situation. So, when a person has lost a job, or wants a home, or feels lonely and isolated, they are given a circle. Or, rather are given a visit from a staff person who does not have the resources to find them a job, or a home, or a friend, but pledges to find family members and volunteers and other staff who will form a circle and meet every month with that individual. After many months, the person may not yet have the job, the home, or the friends, and may not even have a circle with any genuine relationships. The real needs of the individual are held at bay. This is a circle used as a tool, a technology, the latest 'fix' which promises to, but will not, make sure that the individual lives a good life.

Such examples are doomed to failure. *Circles cannot and will not take the place of members of society who work hard to listen, understand and come to personally care about a person and their circumstances.*

So what is a circle? A circle is simply one way of holding and shaping the work, the thought, the caring, and the people that are the only ingredients that matter in whatever set of 'solutions' are decided upon. In such a circle, when a person loses their job, they are likely to call a friend, who is a part of the circle of important relationships that keep the person well, arrange to meet them for lunch and work out a way to apply for another job, rather than to wait for or call a circle meeting and figure it out with the whole group. It's not the circle who answers the phone or suggests lunch. It's not the circle who hears about another opportunity and figures it out with the person. It is another person – a person who has come to know and listen to the one who has lost a job. The circle is the place that these two people are linked with a number of like-minded others to move in a common direction. The circle is one way to hold and invite relationship.

A circle is not the sum total of all relationships in a person's life, either. There will be many relationships outside of the circle which are important to the individual. Some families refer to all relationships as a 'support network' or a 'web of support'. Other families include all of these relationships as part of the 'circle' but acknowledge that only a few core members come together on a regular basis. I refer to the circle as the group of

people who want to come together and who find it meaningful to do so, in order to explore and deepen the experience of the individual's life.

My experience with circles comes from my work with families in Ontario, Canada over the past fourteen years. I have been part of long-standing circles, helped to start circles, have facilitated circles and helped others become comfortable in doing so for themselves. I have learned together with many different families and most intensely with the families of Deohaeko Support Network, a family group in southern Ontario which came together about 16 years ago to think about how their then young adult sons and daughters would live good and full lives into the future. They ended up designing and having built, with government assistance, a 105-unit, co-operative housing apartment block in the city where the families lived. The sons and daughters of six founding families call Rougemount Co-operative 'Home', alongside two hundred neighbours who represent the typical profile of people in this area. The community is proud of their intentional community spirit that involves people being good neighbours to one another and joining in the social life of the co-operative. The members with disabilities are individually supported to be full members of their co-operative and the greater community and to lead fulfilling lives.

Over the years, I have spent time with many families thinking about, exploring and living through many different experiences of circle. From John's circle of four to Naomi's circle of thirty; from Brenda's three attempts at getting a circle going to Tiffany's long-term circle which pre-dates my arrival to Deohaeko; from Rob's struggle to find peers for his circle to Caroline's which at times has been held by peers – I have learned from them all. The following are some of my thoughts on many facets of circles and the role of families and allies in their development.

Circles have been a good way to learn good lessons about building relationship. When they work well, circles are the place in which people can begin to experience the belonging, the mutuality and the magic of relationship first hand. People can learn some valuable lessons about relationship with their circle and about faith and trust and dreaming. In a world where relationship is the number one safeguard to vulnerable people's lives, circles may offer a beginning place for relationship to take place.

Initially, people may come out of a sense of duty, or pity or charity or simply because they are unable to say 'no' to a direct request. Over the years, I have come to believe that this is okay. These are *their* reasons for coming to the first

circle gatherings, not ours for inviting them. I've learned to focus on the reasons that we have invited them – the individual's request, similar interests with the person, similar age and community, or even long time history with the person.

Over the long term, I have come to understand that it is more important to work on reasons for the person to keep coming back. Circle members keep coming back when it is an enjoyable experience, when they feel welcome and that they belong, when they feel it is important that they come and contribute, they feel needed in some way, they feel hope, they feel this a place of community, they realise they have something to gain.

However, if we left people at the reasons of pity, charity and duty for their attendance, then we would end up with a circle with very low expectations for both the group and the life of the individual. Indeed, the circle member would probably stop coming because it just would not matter – the difference the circle actually made in the person's life would be so very small. Or, if the circle member did come, then it is likely that suggestions made by others would be readily accepted as good or 'good enough'. And worryingly, suggestions made by the circle member would often be odd, non-typical and devalued because the individual would be seen through their lens of pity and charity.

Therefore, it is necessary to move the circle and its members along to positive, valued and high expectations for both the individual and the whole circle. The quickest way to do this is to have people see and experience the individual as a unique person with his own gifts and talents that they are *privileged* to get to know. The more that circle members see the individual as already holding familiar, valued, age and gender appropriate roles, the quicker they will begin to push themselves to imagine new and different situations where the individual might shine.

Now *that* is an exciting event of which to be a part – worth hanging around for, worth contributing to, worth putting some energy into and inevitably, any honest person would have to admit, receiving as much as they are giving.

Copies of the books *Our Presence Has Roots* and *We Come Bearing Gifts* and the full, unedited version of this article are available from CRU on request

WHAT HAVE SUPPORT CIRCLES GOT TO DO WITH SUCCESSION PLANNING?

Jeremy Ward is the parent of three young adults, one of whom has disabilities and requires assistance to live independently. He works at a family support agency in Brisbane where he leads a team working throughout Queensland to assist families with succession planning.

Disability Services Queensland defines succession planning in its Disability Planning Initiative as 'developing a vision for the person with a disability and planning formal and informal networks to support the family as their needs and circumstances change over time'.

For many families, however, succession planning may have the grindingly dull ring of legalities, with visions of dark timber bookshelves and mountains of papers tied with red tape. Families, fearful of the future for their relative with a disability, may recoil with horror at the prospect of having to deal with this issue by making a trip to a lawyer in an office reminiscent of a set from *The Young and the Restless*.

But talk to families from the country, with properties they want to pass to the next generation, and this is very familiar territory. Planning to them is part of survival and their vision of maintaining their family dream through to the next generation often informs their every day decisions. It's about planning their succession. Who will succeed them? Who will come after them to keep the family vision alive?

Families with a relative with a disability who reflect deeply on the question, 'What will happen when I'm gone?', often come to ask, 'What is it that we really want when we are no longer able to provide the love and support we now provide?'. On reflection, many conclude that what they want is people. People who will continue to provide the love and support they provide, who will look out for their family member and help them to plan, who will do the advocacy, who will ensure that trustees follow the family's vision and who will be there to keep their family member safe.

Planning to ensure an individual is supported to live in their own home, to maximise financial security, to craft a will to the best effect and to set up trusts are all of obvious importance. But without the people to ensure that good supports continue, that services keep focussed, that trustees follow the vision and that the fundamental needs and wishes of the relative with a disability are addressed, the best legal structures and the most generously endowed trust funds will mean little.

Many families who embark on succession planning come to see that planning strategies to keep their relative safe and secure and following their dream, their vision, is of crucial importance. Not all families reach this conclusion at the same stage in their journey but with time, support and encouragement, most get to it. It is not an easy conclusion to reach. And seeing this as the critical issue is not the end of the journey, it's just the beginning.

The key to keeping people safe is to build networks of support around them. One strategy is to develop a support circle; a group of people committed to the individual in the long term. Support circles are not necessarily made up of all a person's friends or even all their family. Ideally, a support circle will include a mix of family, close friends and allies who come together out of a strong commitment to the individual and family.

Support circles have been used to support people with a disability for over thirty years. They have been used by families and individuals to address a number of issues – to help an individual move into their own home, to help a family with advocacy or to assist people to develop friendships and social involvement.

As a succession planning strategy the purpose of the support circle is more long term, indeed life long. If a well-established and resourced support circle is set up, it is more likely that there will be a group of people to carry on the family vision, to help the individual to plan and to ensure they are loved, safe and supported when family alone are no longer able to do so. Over time, members of such a circle may even step into informal and formal decision-making roles, for example, as a trustee, alongside or as alternatives to family members.

The building and consolidating of a support circle takes time and needs to be nurtured. Families, who have found success with support circles as part of their succession planning, report that clarity of purpose, namely long term safeguarding, is critical to success.

If, for example, a family is driven by an urgent need to develop informal day-to-day supports, care will need to be taken to ensure that the support circle is not seen as the answer to that need. The role of a long term support circle will be to assist the family to find a solution to that sort of issue, not to be the solution.

This is not to say that individual members of support circles do not provide practical support to the person with a disability. Many do. However, such support best grows out of their relationship with the individual and the family, rather than from a particular expectation, perhaps unspoken, that it is implicit in their role as circle member. It grows from personal commitment. As the support circle develops and the dreams of the individual and the family are shared, circle members see natural opportunities to offer their particular experience, energy and skills.

As with all aspects of succession planning, the development of a support circle is part of family

business. It is private to the family and needs to remain in the control of the family. This is not the business of services. It is not service planning. The aim is for support circles to assist and support people to live a good, safe and secure life. Good service planning is very important but services are just part of the picture to achieving a good life. Services do not make a life.

Family-support agencies might play a role in supporting families to embark on succession planning, including discussing with them the value of developing a support circle or network and how the service might best be of assistance. But it is not service business to do this for families.

Other services have developed ways of “arms-length” support through employing facilitators whose

work is distinct from other parts of the service. For example, an accommodation support service might employ facilitators to assist families with these issues and report directly to a Board of Management, rather than a service manager. This means that the work of the facilitator can remain with the family and not be confused with service business.

So, what have support circles got to do with succession planning? For increasing numbers of families a support circle is a key strategy in their planning, offering all family members some peace of mind. While this strategy requires the building of trust and comes at a cost – in time, commitment and energy – it provides a practical answer to their question: ‘*What will happen when I’m gone?*’

ON BEING SOMEWHAT ‘PERSON-CENTRED’

Michael Kendrick is a regular contributor to CRUcial Times. With nearly 35 years of experience, he has made a very significant contribution to the field as an educator, consultant, and advocate. He is well known for his work on Leadership, Quality, Advocacy, Safeguards and the promotion of community living for people with a disability.

Many individuals, agencies and even systems claim that they are in some manner or other entirely focused on the well-being of the people they support i.e. that they are ‘person-centred’. This would normally be something to welcome and admire, were it true. Many such claims may be offered with good intentions, insofar as the party responsible believes themselves to be in a deep and significant relationship of apparently bountiful assistance to the persons they support. Nonetheless, wiser souls would be well-cautioned to be wary of announcing that their every thought, concern and effort is inspired and guided only by the wants and needs of the people they support. The reason for this is that it is humanly impossible to be completely centred on another and their best interests and needs.

Human beings can ‘be there’ for others, but there are always limitations, constraints, competing interests, priorities and responsibilities that condition any involvement with another person. A more accurate depiction of our innate capacities would be, that when we are able to be attentive to others, we can sometimes do so sincerely and with respectable amounts of fidelity, commitment and quality. In this regard, being ‘person-centred’ is a moment-by-moment matter and clearly, there must be many moments during which we are very much not centred on others. We may be surprised to discover that such ‘non-person-centred’ moments are quite plentiful and the moments when we are deeply attentive, responsive and committed to others may be somewhat rarer than we might first imagine them to be. We are flattered by the idea that we are

committed to people, but is this really the case and to what degree?

A better approach might be to not be so quick to define ourselves as being wholeheartedly ‘person-centred’, as so many individuals and agencies these days have conspicuously announced themselves as being, but rather to recognise that when the conditions are right, we might well do and be things that are very ‘person-centred’. Albeit that these would be highly conditioned and qualified by the many limitations any of us bring to our roles in regards to the support of others. The advantage of this approach is that we can examine and improve on our available capacity to be there for others without having to take the fatal and immodestly grandiose step of declaring ourselves to be comprehensively an ally of others, when the chances are quite high that we are anything but that a good amount of the time.

It is really in doing ‘what we can with what we have’ on behalf of another person that makes us momentarily ‘person-centred’, because this claim of attempted, incidental ‘person-centred acts’ better illustrates that we are genuinely devoting our modest contributions to the advantage of others, because there is no pretence that something of limited benefit to others is somehow automatically of great benefit to them. In fact, even when we think we are making a good contribution to others, we may need to remember that this may only be our sense of what has transpired and will need to be verified by evidence other than our own self-affirming opinion that we have been useful to another. Nonetheless, the fact that a genuine attempt to serve and support

others has taken place is valid, irrespective of whether such acts ultimately proved to be beneficial.

'Person-centredness' is revealed not simply by the intentions to be of assistance to others but rather by the genuineness of the efforts taken to do so. Though it would be better if such acts were always fruitful, such acts can be meaningful simply because they are taken for the right reason. However, this alone is insufficient if there is inadequate regard for the person to be assisted. This 'person-centred regard' is a complex ethic, but it essentially means that the person seeking to assist be deeply committed to the person, their autonomy, their well-being, their dreams and the meaningful address of their needs and potential.

The capacity for any person or organisation to 'be there' in this highly demanding way for another person is predictably quite variable. In fact, some people may be woefully unsuited to such roles and others may be quite inspired, gifted and effective. However, even if one has the evident capacity to 'be there' for another person, it would be a stretch to suggest that in any given moment one is maximally doing so.

This understandable variability in the ability of people to 'be there' in an enhanced way is not a fixed matter, as it is quite possible for people to concentrate themselves on the task and thereby conceivably extend their ability to be responsive to people. So, the question of 'being there' is not simply one of innate aptitude, but also of the degree to which one applies oneself in terms of the ethics of being person-centred. This is essentially a moral or ethical accomplishment that could be seen as being somewhat separate from whether one has been effective.

When the effectiveness of one's 'acts of person-centredness' are critically evaluated, it could provide an opportunity for becoming much more relevant to what the person needs through both one's own efforts and those of others. A thorough and abiding commitment to the person should result in the kind of soul-searching and critical evaluation of what has and has not been helpful for the person, so that scarce energies can be most fruitfully deployed.

In reality, it is inevitable that almost everyone involved in trying to be meaningfully 'person-centred' will have to conclude that they are only 'somewhat person-centred'. On the face of it, such a declaration may seem a bit disappointing, at least in contrast to the rather improbable claims from many persons and agencies that they are comprehensively 'person-centred'. Nonetheless, if in those moments when one is actually trying to be genuinely person-centred, one is doing so with admirable intent and effort to 'be there', then at least one has been authentic, even if the meaningful differences made in people's lives have been elusive.

CIRCLES OF SUPPORT INITIATIVE

Jayne Barrett coordinates the Circles of Support Initiative, a collaborative project in South Australia. This initiative grew out of the recognition that many of the people with a disability, supported by a small service provider, had ageing parents. After many years of trying to help extend people's personal networks by including this strategy in the general responsibilities of the service coordinators, the service provider concluded that a different strategy was required if genuine success was to be achieved. Jayne describes how the Circles of Support Initiative attempts to build circles of support and increase the social networks for a number of people who had been institutionalised or were at risk of being institutionalised.

Parents are often the only people who take a great interest in protecting the interests of their sons and daughters. Yet we know that in order for people to have good lives into the future, it is desirable that they have friendships and relationships with other people who take a real interest in their lives.

One of the core beliefs behind the Circle of Support Initiative, a collaborative project between a small service provider and a large residential institution in South Australia is that the presence of unpaid, interested others in the lives of people with a disability is an important safeguard, with the potential to increase the opportunities for people to lead ordinary and good lives as members of their local community. This initiative has taught us much about the role of circles in a person's life; the following examples illustrate what has happened for two people involved in this initiative who have been living in institutional care.

Bill is a middle-aged man with a disability who had lived in a country town all his life. He tells us he lived at home with a wonderful family and was an integral member of his community. When Bill was in his mid-thirties, his father died. Bill and his mother designed and built a house for him to enable him to have a more independent life. Bill's mother died some years later.

Bill tells us that he was very happy, although he did feel lonely sometimes. He had some paid support to help with shopping and household chores and continued to meet with his friends and acquaintances regularly. He had always been an active community member and continued to volunteer with the country library, was a committee member of a local conservation and sustainable living lobby group and he also enjoyed sailing and play chess.

Following a series of falls and some surgery and time in hospital in 2004, Bill was no longer able to walk, use his hands and arms and his speech became more difficult to understand. Unable to see how he could return home after leaving the hospital, his sister found him a place in a large nursing home with over one hundred residents about twenty kilometres from his hometown. Friends would visit him regularly and they became terribly concerned for him as they saw him becoming more and more depressed.

One of Bill's friends learned about the Circle of Support Initiative and approached us for help to set up a circle

for Bill and possibly get some help to find out if and how they could get him out of the nursing home and back to his home community. As Bill had been such an integral part of that small community, we decided to invite the local community to a gathering in a local church hall, which was owned by one of Bill's friends. Fifty people came that evening; there was food and singing and people were invited to join together as Bill's circle of support. Over the last eighteen months, eight people have become key members of his circle and meet with him every month to discuss issues in his life and to help Bill think about having hopes and dreams for his future. Nearly one year ago, Bill moved back to his hometown and now uses a motorised wheel chair to get around his home and in town. He is supported by one of the smaller service providers which assists him to choose his own support workers and to make decisions about his life and how he is supported. Bill still meets with his friends socially, plays chess, goes sailing and continues to serve as a committee member on the local conservation group. Most recently, with good advice and assistance from friends, Bill became the proud owner of his first motor vehicle.

Bill and his circle friends have achieved these positive changes in this time with the guidance and facilitation of the Initiative, which helped them learn how to negotiate the maze of government funding, secure on-going funding for him and assisted the circle in planning his move from the nursing home. The Circle of Support Initiative has supported Bill and his circle friends to continue to hold a vision of 'a good life' for Bill in the community.

Rose is fifty years old and has lived for about thirty years in a very large institution in Adelaide for people with the most significant disabilities. Her parents, who are now in their late eighties, placed her there so she would be well cared for. Rose has physical and intellectual disabilities and uses a wheelchair to get around. About two years ago, she started saying she wanted to leave the institution. Her parents and sisters were very unhappy and they did not want her to consider this option. One of their concerns is the stress this would place on their ageing parents.

In the institution, Rose had made great use of volunteers and particularly those from church groups. When we met, she was going to four different churches a week, including their weekly bible study nights and other social activities.

As we got to know Rose, we discovered that there was one group she particularly enjoyed and where she spent a bit more time than with the other groups. We talked with the people in this group about setting up a Circle of Support for her. Several people, who Rose had particularly identified, were excited to be asked and agreed to being in her circle. Rose has seven people in her circle who regularly come together for food, fun and to talk with her about her hopes and dreams and a vision for her future. As her circle friends they are committed to try to make these dreams come true. Rose wants to get a job and spend time doing fun things with friends. Her Circle friends give her advice and help her to do these things.

Recently, Rose and her friends have found an ideal two-bedroom, wheelchair-accessible house near her church and friends and together with staff from the institution,

they are negotiating for a funding support package. Eventually, it is envisaged that Rose will find a flatmate to share this home, someone who might also be a companion for her and perhaps provide some overnight support in return for a reduced share of the rent or similar. Rose does not want to live by herself; she is a very social person, so the circle friends are on the hunt for someone who might be a good match with her, perhaps a mature-age female student, who, like Rose, has a strong religious faith.

The role of the Circles of Support Initiative has been to assist Rose to have her voice heard and to help her, together with her friends, to get a clear understanding of what 'a good life' included in community might look like. This has involved helping to navigate the service and funding systems and find out about community resources.

It has also involved keeping the door open to Rose's family and addressing the challenges of their attitudes, expectations and assumptions about what they believed to be the right life for someone like Rose. Hopefully one or all of her sisters may consider the invitation to join her circle in the not too distant future. Recently Rose's parents decided to celebrate her fiftieth birthday with a party and they extended an invitation to Rose's circle friends, who they had not been pleased to engage with until now. Rose's mother said that all she wants is for her to be happy and safe and if this could be achieved by leaving the institution, then she would be supportive.

As I lead this Circles of Support Initiative, I am coming to understand that having support circles in place involves conscious consideration of the following points:

- Developing a circle can be messy and complex, and may take weeks, months, even years to create, because each circle is as unique as the people involved;
- It can be relatively simple to draw a group of people together, but it is essential to guide the group's efforts so that they do not lose direction and fail to 'do good' for their friend, even with the best intentions;
- Individual circles are not static; they are likely to move from being robust to fragile and vice versa time and time again;
- Inviting people who are friends and family sometimes provides particular challenges that need careful thinking and planning;
- Parents have often held life-long, protective, practical roles of all kinds and often need a great deal of time and reassurance that someone else might care, be differently capable and may be interested to learn how to take on some of these roles;
- Paid support staff need help to understand how to make room for others to develop freely-given relationships and have a role in the person's life, and to learn how to provide support to people and their friends so that doing things together works well.

People who have disabilities are more vulnerable and will be for the whole of their lives. They will need people in their lives, who like and know them well and even love them, who will stay close to them, advocate for them and ensure that their dreams for 'a good life' are fulfilled.

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.

CIRCLES OF SUPPORT

In the last issue of CRUCIAL Times, Sally Richards described the key elements of the family-governed structure which she and two other families set up to support their sons to live a good life in the community. In this issue Sally discusses one of these elements, the circle of support, in greater detail. Most people who are involved in the world of disability have heard of circles of support, sometimes called circles of friends. Sally prefers to use the term 'circles of support' as she believes that support can come not only from friends but also from extended family, acquaintances, teachers, support workers who may or may not already work with your family member, business owners or youth workers.

Sally also reminds us about some of the essential building blocks of a circle of support and alerts us to remain aware of potential pitfalls which might hinder the circle of support from assisting the person to achieve a good life.

A circle of support is a group of people who gather regularly to talk about, improve and expand the life of the person at the centre of the circle, who is usually a person with a disability. Indeed, the first thing to establish is who is at the centre and who the circle aims primarily to benefit. Others will naturally benefit as well. For example, the family cannot help but benefit if their family member is happier and more engaged and included in their community and has a more interesting life.

The person who has a disability should be present at and participate in every circle; after all it is their life the circle is discussing. When the person does not have the ability to do this and someone else needs to act as their proxy, it is vital that that person is someone who knows the person well; for example, I represent my son, his interests and his life at each circle meeting.

So what are some of the potential pitfalls of circles of support? A major issue is that circles of support may be seen as some kind of panacea; one that will solve all the problems, sort out all the dilemmas and make a life valued, interesting and included and that it will all happen quickly.

This is not so. Circles of support are hard work and may take some months or years before they achieve positive changes and they can be difficult to implement in a sustained and meaningful way. Sometimes they become just one more thing that has to be organised, facilitated and maintained. Circles can languish and eventually dissolve if they are seen as an onerous task that *should* be done instead of a

means of providing practical advice, solving or unravelling problems, generating ideas or emotionally supporting the people at the centre of the group.

It is important to find the right people to be members of the circle. The group needs to consist of people who know and understand the central person and their wants and needs. If someone on the group has the best interests of the central person at heart, but their ideas of what is best, do not align with that person's, then there is the potential for disagreements, alienation and fracturing of the group. So be very careful who you invite to be part of the group and be very clear about the values and philosophy from the beginning.

Another difficulty people have, is asking friends, family, colleagues or acquaintances to be part of the group. Asking is not something that comes easily to many people, including myself. It can be helpful to give this role to someone else. This is a contained and well-defined role; you are not asking someone to devote their life to the central person or to commit to being on the circle forever; a good friend or empathetic family member who might otherwise be fearful of taking on a more central role in the circle may be happy to take on the role of organiser or facilitator and do the asking.

It is important to establish what is expected of circle members at a very early stage. I used the first meeting as an opportunity to 'set the scene', for example, to confirm for the group my own values and hopes for a good life for my son, to discuss the purpose and proposed values of the group and to establish what we might discuss and strive to achieve.

Membership of the circle may be fluid. For a start, life is fluid; an ever-flowing river of changing directions, wants, needs, achievements and set-backs. This is true for all lives. Circle members may be genuinely interested in and committed to the circle but at times their own life gets in the way. So they might be unable to attend all the circle meetings. However, just because a person is not physically in the room, it may not mean that they are ineligible to be part of the group. Nor does it mean that they don't care.

Circles need to find their own dynamic and they do not always develop in the way that might have been anticipated. Setting goals and targets which are too high or having unrealistic expectations of the group can lead to disillusionment with the process. Marking achievement and progress, no matter how small or seemingly insignificant, will provide encouragement and build enthusiasm and by meeting regularly, though not necessarily frequently, members are encouraged to have faith in the process.

Keeping the purpose of the circle at the centre of the process is vital. The formal processes and procedures should not overshadow the purpose of

the circle. The circle does not exist for its own sake or to be a wonderful example of how to run an efficient circle meeting, but as something which should seek out, create or foster meaningful experiences and relationships for the central person.

Having a note taker, however, is essential. Someone needs to take brief notes and ensure all members of the circle, present and absent, receive them. This could perhaps be one of the roles of the facilitator, if there is one. This informs all circle members what was discussed and decided at meetings and is a crucial element of maintaining a strong sense of purpose for the group.

One way to prevent meetings becoming overly formal is to make them fun. Turn each meeting into a celebration. Celebrate achievements with food and drink; coffee and cake, tea and cucumber sandwiches, champagne and finger food, beer and sausages. Start each meeting with the good things. Talk about what positive changes have been made, what is good in the life of the person or ask each member to speak of something they admire or enjoy about the person with a disability.

Move on to the parts of the person's life that need to change, so that their life will be better. Work this out first so that the meeting has a real focus. For example, the best circle meetings I had were when I asked the group to brainstorm work experience opportunities for my son and when I wanted to plan my son's business launch. People are happy to contribute their ideas if they are given a specific problem to discuss. If group members don't know why they are there or told something vague like 'I want my son's life to be better' they can feel inadequate and foolish and are unlikely to want to be involved in the future as they feel there is nothing they can contribute. This is another reason why it is important that the people involved in the circle know the person and their needs well.

Maintaining a circle of support is a vexed question. Has this circle been formed to explore a longer-term role or a short-term goal? Different people with different skills will be required in each case. For example, when I was planning the business launch mentioned above, I invited a very good friend who is a caterer and an events manager, but who is not part of Jackson's regular circle, which has the longer-term focus.

Circles of support are not for everyone. Some people may not need one; others simply do not like them. It is not mandatory that every person with a disability has one. But if this is something you decide to pursue for your family member, then find an ally, take it slowly, celebrate the gains, big and small, and give the circle time to develop. Circles provide an opportunity to develop and improve the lives of a person with a disability and their families; the opportunity is valuable and cannot be hurried.