

CIRCLES OF SUPPORT INITIATIVE & SDA

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.

[What is a self directed approach?](#)

A self directed approach gives people with disability and their families more choice and control over both informal support and government funding which is directed at their support. It is designed to enable people to direct their own supports rather than attempting to fit within pre-existing service systems.

As a concept, a self directed approach places the individual at the centre of decision making and treats family members as partners. The process focuses on discovering the person's skills and capacities, and identifying the priorities of the person in terms of their hopes, goals and lifestyle choices. The individual and their family are then able to design the supports that will meet their own needs and goals, rather than being limited to choosing only from a predetermined list of service options.

A self directed approach is underpinned by the values of independence, choice and social inclusion. Some of the current opportunities for this approach do not yet cover the full range of these values. While they represent encouraging signs of an emerging trend towards giving more choice and control to people with disability and their families, there is still some way to go before it can be said that they include all the elements of a truly self directed approach

[Self Directed Approaches by NDS](#)

LIFESTYLE IN SUPPORTED ACCOMMODATION (LISA) INC.

Tel: 03-9434-3810: Email: info@lisainc.com.au or vk3qq@optusnet.com.au

Web: www.lisainc.com.au : www.lisa-aus.blogspot.com

NOTE: We are always interested in feedback and information; general, specific, good or bad.

If you wish anonymously: Our mail address is, 73 Nepean Street, Watsonia, 3087