



Community Conversations:

TALKING ABOUT SURROUNDING YOURSELF WITH SUPPORT

'A good life is a human life. A human life is a social life, the essence of human nature is to be in the company of others."

(Al Etmanski —President of PLAN Canada)

TALKING ABOUT... SURROUNDING YOURSELF WITH SUPPORT

This short paper has been written to provide a platform for a Community Conversation about surrounding yourself with support. It is designed to offer brief, but important information and thoughts on the topic which will enable all who participate in the conversation to have a common starting place. It is not intended to answer all the possible questions about developing your support network, or to provide clarity for individual situations, it is offered in the spirit of 'a conversation starter'.

INTRODUCTION

This conversation covers the notion that you can develop your personal networks and increase your access to supportive and helpful people. It will focus on one particular method that many families have found to be very practical, 'Circles of Support'. This paper and the conversations that follow will look at the idea that:

- There are people within your local community who have a desire to be involved in the life of another person and also the competency to make a meaningful contribution. Many of these people will not know how to become involved and we need to learn how to invite them.
- Many disabled people are only connected with their families and paid service staff. It is possible to increase their relationships to include people who are not immediate family members, but nevertheless genuinely care about the person with a disability and have meaningful and mutually beneficial relationship with them.
- Individuals and families generally do better when they are connected with others who understand their particular needs and are committed to supporting them through the fullness of life, with all of its highs and lows.
- The formal service system often has limits to its capacity in a number of areas, such as genuinely connecting a person with a disability to their neighbours, community and fellow citizens. It may also struggle to provide meaningful support to the disabled person's main supporters, namely their family.

People with disabilities face greater risk of being isolated and lonely, of being harmed or having bad things happen, or simply missing out on the good things in life. They are likely to have fewer relationships and friendships (especially with people who do not have disabilities and who

are not paid to be in their life.) They have less financial security, are at high risk of having their lives controlled by others, are likely to lack the support they need to develop and grow and have limited access to the resources that could help. If these issues are to be properly addressed they first have to be recognised. Then thought needs to be given to what can be done to reduce the harmful impact that such situations can lead too. If we are going to be successful in protecting people from these situations this often means we will need the support of other people and agencies. Just knowing that there are others around for support can help families to reduce the bad things that happen and create positive change in the life of their family member. A strong personal network that supports your loved one and yourself can also have the effect of providing some balance to the control of the formal service system.

A CIRCLE OF SUPPORT

Families and systems look at all manner of ways to try and address the question of how best to safeguard a person who is vulnerable. We often turn to things such as services, procedures, processes, audits, legislation, service specifications, quality control, risk management strategies, segregation, congregation, withdrawal from the regular rhythms of life, surrounding people with paid staff and limiting opportunities to name but a few.

These are almost always done with the best of intent but often still fail to keep the person safe and can result in the person's life being controlled and managed

by others rather than supporting them to become the person that it is possible for them to be.

However, there is another starting point. We could simply start with bringing other people around who really care. What we have come to realise is that the strategies identified above, that are commonly found in the services, seldom work to keep people safe, we also know that people are safest when there are other people around them who care deeply for them.

People keep people safe.

Committed people are the most powerful safeguard we can introduce into the life of a vulnerable person. In fact, it is so powerful that the active presence of just one genuine and freely given relationship can be the single most important safeguard for a person. There are many ways to introduce new and genuine people into the life of a vulnerable person including developing a Circle of Support.

WHAT IS A CIRLCE OF SUPPORT?

A Circle of Support is a group of people who are invited to come together in friendship and support of a person who has a disability. Their role is to protect that person's interests now and in the future, and to help that person achieve their personal goals. The Circle members are usually people from outside of the service system.

No one is paid to be part of a Circle of Support. People are invited to join and through this process of invitation we share with them, what the Circle would like to achieve, how the Circle works, and why it is so important that the Circle members are there for one sole purpose: to look out for the disabled / vulnerable person. Experience shows that when people are paid to be in the life of another their loyalties are divided and at times compromised, so Circle members make their commitments of involvement directly with the person and their family.

A Circle of Support meets regularly and acts as a natural support network around the person (and or their family). Wherever possible, the disabled person is in control. Ideally this includes deciding who to invite to the Circle and where to direct the Circle's focus.

Having a Circle of Support can make a huge difference to a disabled person's life. It can be the difference between a life lived on the fringes of community and a life of inclusion and participation. It can be the person's strongest foundation for a meaningful future.

Forming a Circle of Support is one of the most important things you can do to start creating a better life for your family member, and to secure their future once you are no longer around.

GETTING STARTED

There are usually two hurdles or barriers that a family needs to overcome before they are ready to engage with the work of Circle creation. These can be summarised as the following two questions:

- 1. Am I ready to have other people come into our life?
- 2. Am I ready to put aside my personal fear of rejection?

Question one asks us to explore whether we

- are ready to try something new
- are open to the possibility that other people could care for and want to be involved in our life and the life of our son / daughter
- are willing to share our hopes and dreams for our family member with a disability with others and ask for their freely given assistance

Question two asks whether we are ready to take a step of faith. For many people the fear that they will ask and be turned down (rejected) is strong. However the experience of many people engaged with the work of developing circles, in numerous countries, with all manner of families has shown that this fear of rejection, as real as it may feel, is seldom what is experienced. In other words very, very few people say no to a good invitation.

When people are ready to engage with the actual development of a Circle there are a few practical steps to take.

Creating a Vision for the Future

Being able to have a clear picture of a good life for a person with a disability is really about being able to imagine for that person the right to the same kind of ordinary everyday hopes, lives and dreams that all people have. It means believing a person with a disability can have the same kinds of hopes and will need the same kind of opportunities in their lives as everybody else. It is important to keep holding on to these thoughts about hope and opportunities when you are thinking about the activities, places and people that might be involved in the person's life.

Clarifying the Purpose of the Circle

Having clarity about what would make a good life for the person with a disability will also give insight into the purpose for the Circle. Circles of Support have been created for many purposes including but not limited to assisting people to:

- Expanding their social networks
- Obtain social roles in their communities
- Join clubs / associations and groups that connect them with other citizens
- Move out of their paternal home to a home of their own
- Leave institutional living and obtain a home of their own
- Manage their paid service providers
- Recruit trustee's and advisors on Trust boards
- Prevent abuse and neglect
- Take on volunteer positions with the community
- Permit family members to take holidays worry free
- Engage in cultural, recreation, faith based and sports programmes
- Celebrate birthdays and other festive occasions
- Apply their ideas and connections in the community to the dreams and aspirations of the person with a disability
- Find employment and arrange job supports
- Share information, meals and rides to important events

- Monitor health and services
- Act as legal representatives in making decisions pertaining to legal, medical, financial, and personal matters
- Share hobbies and interests.
- Provide families with peace of mind

Relationship Mapping

Once there is a focus for the Circle we spend some time to map out the relationships and connections that already exist. These could include siblings, parents, extended family members, friends, neighbours, church members, co-workers, employers, friends from the past, teachers and former caregivers. Circles can include anyone who cares for and expresses an interest in the person with a disability.

By undertaking a simple relationship inventory a range of names will come to the fore. The next question becomes who to invite?

Decide on Who to Invite

At this stage you will have three core elements in place.

- 1. You will have a sense of what a good life for the person with a disability would look like.
- 2. You will have a sense on the area(s) that need to be focused on now to move the person towards their desired future and
- 3. You will have a list of names of people who could potentially assist in this pursuit.

This step requires us to consider and discern. The question is 'given the life we are wanting to create for the person with a disability, who out of the potential people identified would be the most beneficial to invite to the Circle'? The clarity of the Circle's purposes will aid this decision making process greatly, as the clearer we are on the Circle's purpose the easier it will be to discern which skills, talents, qualities, attributes and connections would be most needed and who, out of the people identified, would possess some of these.

The Invitation

The process of the invitation is the next step. There are many possibilities for the invitational process but experience has shown that the personal invitation usually has the most impact on the person invited. Invitations can be made in person, over the phone or by a formal written invitation, like you would extend for a wedding / birthday etc. Other people may benefit from a multi-pronged approach such as a personal conversation which is followed up by a written invitation. The core principle would be that a personal invitation is usually much more likely to engage a person than, for example a group e-mail.

For many families the idea of extending the invitation is a barrier. Personal fears of rejection can be very strong for some people so one of the easiest strategies to move through this stage can

be to get another person to do the asking. For a person who is one step removed from the immediate family the process of asking is often much easier. There are also many individuals who do not struggle with asking others, so if you are able to engage a person who has a natural ability to ask, then the invitations can be extended with ease.

The First Meeting

If the ground work outlined above is thoroughly undertaken people will come to the first Circle meeting with a good sense of what they are entering into. The first meeting is an opportunity to engage all parties in a dialogue around the practicalities of their involvement i.e. the aims of the Circle, the commitments of the members, that peoples involvement is voluntary (no payment), how often and when the Circle will meet etc.

Hospitality is a vital aspect of the first and subsequent Circle meetings. In fact it is a central aspect of all Circle meetings. By creating an environment of hospitality and welcome the Circle members will engage and be connected with one another in a very ordinary and typical way. This will greatly aid the group process. It is also a good idea to have one person summarise the Circle gathering by writing a brief summary as a record.

Nurturing the Circle as it Develops

Once a Circle is formed, it needs to be nurtured and maintained. This is accomplished by regular meetings which include all Circle members and the person with a disability. Maintenance activities will vary from Circle to Circle but all will include regular planned contact between the members of the Circle, hospitality, fun and the building of trust and relationship that comes from spending real time together.

The Role of a Circle Facilitator

There are some skilled and experienced Circle facilitators in New Zealand, however they are not in every town or city. If you are unable to locate an experienced facilitator within your region then it is possible to engage a person to undertake this role for you, either in a voluntary capacity or perhaps you could purchase their support with your Individualised Funding.

If you are thinking of securing a facilitator to manage your Circle then it is important to consider the following. Great facilitators are those individuals who are naturally community connectors. They naturally and easily build bridges between people. They are the people at parties and gatherings who introduce unfamiliar people to each other and ensure all people feel welcome and included. A formal education in not required to be an effective Circles facilitator.

First and foremost look for individuals who share the family's values. Engage people based on their knowledge and connections to the community and their compatibility with the individual for whom a Circle is to be established. Look for people who are good listeners, who can see the strengths of others, and believe in the richness of their communities.

QUESTIONS TO GUIDE YOU IN CONVERSATION ABOUT SURROUNDING YOURSELF WITH SUPPORT

- Do I have a good idea on what a good life for my family member would look like?
- Am I ready to have other people come into our life?
- Who might be willing to come into a closer relationship with my family member?
- What role(s) do I want the Circle to take on?
- What am I currently doing for my family member that I would be willing to let someone else do, or that I could use some help doing?
- Would I be able to extend the invitations or would I need some help with this?
- Who do I know who is a natural connector of people?