

# CIRCLE OF SUPPORT, CIRCLE OF FRIENDS, PERSONAL NETWORK AND OTHER THINGS WE CALL IT!

by Jayne Barrett

Jayne is a strong advocate for families and people who live with disability. Her work has been to inspire people to think that a better life is possible when people are embedded in their own homes with family and friends, included and participating in their local communities, filling roles and having the same lifestyle opportunities as any citizen. Over the last eleven years, Jayne has been Manager of the CLP-Circles Initiative which is a funded effort that works to create ways for personal networks to be involved in safeguarding and to 'look out' for their friend or family member into their future. Security through freely-given relationships, along with peoples hopes and dreams, are at the heart of this work. Amanda, the eldest of Jayne's three daughters lived with severe and multiple disabilities until she was 27 years of age; she died in December 2000. Growing up with Amanda, seeing and being part of her achievements and contributions, Jayne says has been the motivation for her work.



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## WHO'S IN YOUR CIRCLE?

Friends give us so much. They take interest in us, know our history, often share similar interests and passions, know what makes us

two special friends with others that take on different roles in our lives. It might be a friend you party with, a friend that rings often or someone that is called on for a chat and catch up from time to time.

A common perception is that the needs

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happy or sad, care if we are sick or down or just haven't been around lately, will often just hang out together, inspire us to do more or do less, offer us advice and cautions, help celebrate our and their achievements. Whether we see



them daily or have contact weekly, monthly or occasionally, we know they are there for us and we are there for them. Often some are closer than others, some of us have one or

of people who live with disabilities will be completely met by paid support services. Families and people themselves often fear they will be a burden on others and are grateful for good and not-so-good paid service. Service providers both consciously and unconsciously reinforce this message to community members, family and friends. However, those supporting the Circles Initiative think that people who live with disability need 'good' paid support services in their lives, but see that most service providers very quickly seek to 'own' the person. There is often a loss of personal autonomy and control of their lives and family and friends are not encouraged to retain an important role in their lives.

We have learnt through our work and

involvement with Circles that we move in messy territory as our Circles are about freely given relationships. This often means we act as a third party facilitating a relationship. We believe people who live with disabilities have the need for friends and allies just the same

as any of us. The intentional inviting and drawing together of a person's freely given relationships brings many challenges. We wish to respect the things that friends bring to our lives and that we give back to our friends. So we have learnt that our intentional efforts to bring people together firstly must do nothing to harm their friendship but rather build and strengthen it.

The Circles Initiative aim is to:

- Build and strengthen the personal networks of a person who has disability,
- Assist the person to identify their hopes and dreams for their future and share their interests, gifts and talents,
- Ensure each person has a coordinated plan to achieve their lifestyles, hopes and dreams,
- Facilitate personal networks to come together to form a Circle of Support,
- Build future personal security in a person's life through people (freely given relationships).

The Circles Initiative identifies a Circle of Support as a group of people who are intentionally invited to come together in friendship and support a person who has a disability, for the purposes of protecting their interests into the future. This is not with the expectation that this group might have a responsibility of "caring for" the person, BUT with the expectation that, if asked, people

might be pleased to make time and agree to join the Circle to "look out" for the person.

## WHO IS INVOLVED IN A PERSON'S

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## PERSONAL NETWORK / CIRCLE OF SUPPORT?

People who care about the person and are prepared to commit to friendship and become involved in the Circle for the long-term, this could include:

- Close or extended family members, such as brothers, sisters, uncles, aunts, cousins,
- Friends of family, friends of the person, or past support staff,
- People who are in the person's networks, such as sports, hobbies or faith groups,
- Advocates and others who have been identified as interested in being involved in the person's life for the long term,
- No one is paid to have ongoing involvement in a Circle of Support.

## INDIVIDUAL SOCIAL COMMITMENT

Each member of the person's Circle endeavours to spend individual and regular time with the individual, getting to know them well, and learning about their aspirations in life as well as their daily, changing and evolving needs and opinions, their vulnerabilities, strengths and gifts, hopes and dreams for their future.

## WHY IS HAVING A CIRCLE OF SUPPORT IMPORTANT?

- If a person is vulnerable, it may help to have someone to "look out" for them; assist them to advocate; offer advice and defend

- their interests,
- To provide support for parents who have done this “looking out for” alone. When parents are no longer able to fill these roles, there will be people who will retain knowledge of the person, their history, ambitions and lifestyle choices,
- To encourage people that may be in the person’s or their family’s network but have never been invited to have a role in the person’s life. They have often been led to think that there is nothing required of them,
- To have someone to hold paid service workers accountable for their support. Some people have no one filling these roles except paid service workers,
- To have people around you who are there because they like you.

**‘IF IT WASN’T FOR MY CIRCLE FRIENDS AND YOU, I WOULD NOT WANT TO LIVE ANYMORE’**

*I received this text message from Susie who had just returned to her home after her father John’s funeral. John was in his late 80s and had been Susie’s primary and sole care provider for most of her life. We met Susie in an aged care nursing home, with her Dad John visiting her about a year earlier. Her room had no windows and she spent all day in bed just waiting for her daily visits from her Dad. Susie had been living in the nursing home for several years when her Dad himself needed to move to an alternative care*

*breakdown and had little to do with them for many years. She felt totally alone except for her Dad. Initially, we managed to find three people who had been personal care workers some years previously and who Susie and John identified as*



*‘good’ people. We contacted them and invited them back into Susie’s life as friends; they were thrilled to be asked. Two years on, Susie has a bunch of friends, who call themselves her Circle of Friends, which also now includes her hairdresser, an advocate and an old friend from school days. Susie gets together with them individually and as a group on a regular basis when she shares her hopes and dreams and sometimes they just enjoy sharing the same interests. An invite to their homes or a café for lunch and/or a cuppa happens often.*

**SOME OF THE CHALLENGES AROUND CIRCLES OF SUPPORT**

In some respects, the Circles Initiative is fortunate to be funded to provide people with Facilitators, but we are aware that funding can be lost at any time. Building a framework for continuing this work and being able to sustain it over time is critical for us. We currently have four facilitators in full-time positions involved with 10 to 12 people each. We are involved in lives of about 40 people and their friends. Most people have a group of friends, while some have a small group of two or three. Other

people have many friends. We are seeing examples of micro-community working around most of the people we are involved with.

When inviting or asking people to get involved in

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someone’s Circle, it is important to find ways to allow people to say no, because it is likely they will still be somewhere connected in the person’s life and our experience is that some of these people will involve themselves at some time anyway. Often people are only too pleased to be asked to get involved, but this also needs to be thoughtful and put in terms of the business of their own life, such as, what role/s might fit for them? We have found that friends are there and are generally pleased to accept an invitation to be involved. Circle members agree on their mission and to be guided by the person’s hopes and dreams. To keep the person at the centre of all discussions is the ongoing work of a Circle. Just because a person agrees to step forward does not mean they are clear about the role/s they can fill.

Mostly, we see that people who live with disability have times of major need and then have periods where life seems to just happen. A Facilitator needs to tune in to the rhythms of each person’s life and assist Circle friends to play the roles. The Facilitator can advise, advocate, take action or just be there for their friends.

A person who lives a life of segregation and does not engage in everyday community life is less likely to have any people who will step forward to the invitation to become involved. However, we do find that some past support staff are often only too pleased to be invited to take on a role of friend and are happy to be

welcomed back into the person’s life.

**THE FACILITATOR’S ROLE**

Helping the person manage their get-

togethers of Circle friends and ensuring that things are happening is the role of the Circle Facilitator. The Facilitator may help the person stay in contact and catch up with friends as well as assist the person to host their Circle get-together. Get-togethers are often quite social and informal affairs where food is always present and can happen in people’s homes, cafés, pubs or halls, but never in service settings. The Facilitator ensures that despite the informality, an agenda is addressed and that notes of the get-together are kept. When there are pressing matters to be addressed, or follow up, or some serious brainstorming of ideas is needed, the Facilitator ensures the group is clear about the agenda.

We have walked beside many people over the past five years whose friends have helped to make some pretty incredible and seemingly impossible things happen for their friend or family member. Some things that have happened:

- A trip to the Grand Ole Opry in Memphis, USA
- Moving from the institution to a ‘home of my own’
- Swimming in the sea again
- Going on an interstate holiday
- A girls weekend in Melbourne
- Moving into ‘my own home/apartment’
- A bedroom makeover
- Spending more time with her son
- Home renovations
- Making sure the person has good support staff

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facility.

*Susie had a disconnected relationship with her sisters, brother and mother due to a marriage*

- Getting a job that the person wanted, not in a sheltered workshop
- Having friends and spending time with them
- Having trusted friends around to do things with when Mum goes overseas

#### CLARITY OF THE CIRCLE'S PURPOSE

The Circle members need to be clear why it is that they have been invited to come together and what their mission and purpose is. In some services, I have seen multi-disciplinary staff teams with no friends, family or even the person themselves present and call themselves a Circle of Support. This would not be a Circle of Support by my definition.

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Paid staff often get very confused, and this confusion is passed onto the people they support and their families. Staff are paid and accountable for good support and care work; I would hope they are friendly and caring workers, but too often I hear staff identify themselves as ‘friends’. My challenge is to ask how much of their own personal time is spent with the person, and how often the staff member includes the person in their private life and involvements when they are not getting paid. When they resign, will they still spend time as a friend with the person? Many people and their families who I know are continually devastated when a worker leaves. A good worker can leave so much more behind if they have worked hard to welcome and nurture freely-given relationships in a person's life.

Some things to clarify that may help in identifying the purpose of a Circle are:

#### Who will manage the affairs of the group?

Some parents may take on this role; for another group, an individual member may take on this role; or different members may share the role from time to time. For the Circles Initiative, we have a paid Facilitator who works alongside the person or their parents.

#### For how long will the group meet?

Some groups decide to meet while there is a specific need to be addressed; others while there is energy to keep going, or for a nominated period of time. For the Circles Initiative, we invite commitment for the long-term.

#### What does the group want to achieve?

I know some groups who come together to help resolve a particular matter, such as a better social life for the person, getting them a job, to get better support services, or to keep the person in their own home. The Circles Initiative is focused on ‘looking out’ for the person and seeks a commitment from friends to bring long-term security to the person's life.

#### CLARITY ABOUT LIFESTYLE AND VALUES

Finally, I believe it is critical to be clear about the lifestyle and values that the person aspires to. The future hopes and dreams of the person and their loved ones need to be the driving force of the Circle group. We are clear that our involvement is with people who aspire to live an ordinary life in a home and community just like all citizens. We spend a lot of time helping people think about their hopes and dreams for their future. Their interests, gifts and talents lead us to helping them participate and share in community involvements with friends and other citizens. These aspirations need to be clear so that Circles friends can be helpful in

pursuing these lifestyle choices. Providing opportunities to get ‘good’ information about what is possible, to be inspired by other like-minded people is a powerful way to help the person, their family and Circle friends to think about answering the

question: What will it take to have a person's hopes and dreams come true?

#### FOR MORE INFORMATION:

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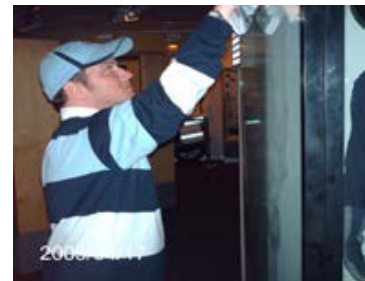


## TALKS THAT MATTER

### Warren O'Brien Trilogy

Warren O'Brien is leading a full and inclusive life thanks to his own endeavours, his supportive family, and a number of loyal friends and allies. Belonging Matters have documented three key areas of Warren's life, his volunteer role at the Victoria Police Museum, his variety of roles with the Salvation Army in Box Hill, and his own home. (The final in the trilogy, documenting Warren's homelife, is in post production and will be available in the coming months.)

#### Going Above and Beyond



#### The Salvo



To watch **The Warren O'Brien Trilogy** visit the Talks That Matter Page on our website:

[www.belongingmatters.org](http://www.belongingmatters.org).