

Let's start now: embracing today's opportunities

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I started thinking about a circle of support for my son Jacob about 7 years ago when he was 11.

I had heard about the concept and thought it could be helpful but, somehow, the process lost momentum.

Momentum was recently regained when a friend simply said, "You better start now". Jacob was about to finish school and I was sharing my ideas.

I realised that Jacob needed bigger ideas than I could manage and more people involved that just me.

I thought about how the circle would work and decided that working with a facilitator would work best for us.

The facilitator is not paid. She is a friend who shares the same values about the importance of Jacob being included and valued in his community. She doesn't have any particular expertise in being a facilitator but she is happy to listen, learn and read. She also has other skills in leading meetings from her work role.

When I asked her to be involved she said she would be "delighted".

Both myself and my friend, the facilitator, spent about two months before the first meeting actively reading, thinking and talking. I contacted Family Advocacy and they sent me some articles, planning frameworks, draft meeting agendas and invitations. I also attended a planning course.

It wasn't hard to decide who should be involved. We invited our nearest and dearest plus one person who provides Jacob with support. I made it clear to the workers we asked that their involvement was voluntary and that they wouldn't be paid for their involvement.

Some of these people already had a range of roles in Jacob's life.

Most jumped in and wanted to be part of the circle. One person who lives a long way away usually joins over the phone. When she is in town we have a circle social to keep the face to face relationships alive.

I had talked to most people about what I had in mind before sending the formal invitation. I sent the email and asked people to respond to my friend who was to be the facilitator.

I thought it was very important that people in the circle have a clear and shared view about the type of things that would make up a good life for Jacob. People needed to be clear about how vulnerable Jacob is because of his disability, the usual limited options for people with disability and the benefits of him having many and varied relationships and connections.

The first meetings were more formal because this foundation involved serious conversation and reflection.

Our meetings go for about one hour with the first hour of our meetings formal and the second more social involving wine and pizza. The social part allows a time for more relaxed discussion of things we talked about at the meeting.

It can be difficult planning meetings at a time that suits everyone but that's just a fact of life.

We meet every 6 weeks.

There are 9 people in the circle and 6 at most meetings.

The facilitator takes notes and minutes are circulated after each meeting.

The meetings take place at our house.

Jacob is not involved in the meeting when we talk about devaluation. We tell him that we are going to be talking about some things that make me sad. He goes and does his own thing.

That way we can be frank and talk about things bluntly.

For the rest of the time, Jacob loves it.

A problem we have is that most people in the circle are middle aged. We need to work on that.

Because the circle facilitator and I are friends, I have always caught up with her fairly regularly and these times give us an opportunity to discuss circle happenings.

We have started using an action sheet because some actions were not being followed up. The action sheet makes it clear who is doing what and helps control my inclination to do everything.

I made it clear to people that being in the circle wasn't about providing support like personal care for Jacob.

I also made it clear that if they were to be involved they would need to be prepared to advocate when needed and if I could not.

So what has changed?

Jacob spends more time with people he likes, including his aunties and uncles and he loves it.

We now have a clear vision for Jacob's future. This vision is loosely based on a vision I had prepared. The group critiqued and added to that vision. It is about what we want rather than what we don't.

It took three meetings to refine this vision but I felt that nothing will happen unless we have a shared consciousness.

We are starting with some small but significant things. Some time has been spent focusing on a great birthday party. A party can be an excellent way of expanding social circles and marking significant rites of passage.

We are also thinking about 'Schoolies' week. I can be very risk averse so it is good to have others questioning my assumptions.

We are making plans for next year.

We have a new dog that suits Jacob rather than one I would normally get.

I'm not making all the decisions.

I and the people who care about him are thinking differently about Jacob.

People really do like being involved. They follow up with me about when the next meeting will be.

Jacob could have continued without a circle. It wasn't something he needed right now.

In a lot of ways we already had a very informal network, so starting a circle of support was little like gathering them all up and pulling us all together.

The circle is already resulting in shared thinking about Jacob's future and I can sense that it will be something that really pays off in the long term.

We all know that there will be ebbs and flows in how much we achieve.

I think if I was to say anything to other people starting a circle of support, it is the importance of people in the circle understanding the way people with disability are devalued.

Most people can understand that they wouldn't like negative things to happen for their child – like not having friends. For people who are not familiar with the life experiences of people with disability, it is the ongoing nature of this devaluation for Jacob and for other people with disability that needs to be stressed and understood.



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