PEARLS OF WISDOM

Self-direction in regional Queensland – making it work

Jane and her family live in a small town in western Queensland. She has been directing the support for her daughter, Sarah, for eighteen months now. She says that life just keeps getting better since she made the decision to direct her daughter's funding herself. Jane's story describes her experience of what it takes to be engaged in self-direction when you live in regional Queensland.

The starting point.

The idea of directing Sarah's support ourselves started with discussions at our support circle meetings. We have had a circle around Sarah since 2006. (You can read about how we did this in the story, Sarah's *Support Circle – a regional story*) In the early days, every meeting included a debrief session from me which was usually about the difficulties we were experiencing with Sarah's support arrangements. The circle would then try to work out strategies to improve the situation.

Sarah had left school after completing year 12 and I had thought life was going to get better for her then. However I soon started to feel that I was back on the wagon of talking to people who just did not get it. The people in the service were unable to understand some of the most basic elements of what it would take for Sarah's life to work well. I felt that my role as Sarah's mother and her primary carer was not understood. The whole notion of the "natural authority of families" seemed to be foreign to people in the service at that time. Communication was difficult. I had a full time job so it was important that we were all on the same page and that the communication was clear and precise. However, I often had to approach two or three people just to get anything organised.

Another problem was with the organisation of support staff. We would never be sure of who would be doing the shifts and when changes would occur. This was difficult for Sarah on a personal level and, without consistent staff, it was also hard for me to train support workers to understand Sarah's particular needs.
The main problem, however, was that we felt the staff did not share the vision our family had for Sarah's life. They had no idea of where we were heading and so they were unable to understand the type of support that would help Sarah achieve the life we envisaged.

After many years of frustration it was a conversation with a friend that finally prompted action. This woman, also from a country town, had been directing her son's funding for some time. Her advice to me was simple. She said, "You just need to DO THIS. It's not hard."

When I look back at this time of our life I realise the value of being connected with people, especially when we live in a regional town. Once I decided that I could, perhaps, "do this", my friend gave me the number of an organisation in Brisbane which works as a Host Provider for people who are directing their own funding. Another friend then put me in contact with a woman who works in that organisation. She explained to me how the Host Provider arrangement works. After talking with her I realised that self-direction would involve quite a shift in my thinking and that it would involve work but, in the end, it was all much easier than I had imagined. I had no hesitation in saying, "Yes!"

KEY POINT: *Connect to families and friends on a similar journey. Ask for help. You will not look stupid. People want to share their successes.*

The hurdles.

Like most people who live in a small rural community we have only one service in our town. I was terrified that if I pulled out of the service and things didn't work out for Sarah we would be up the creek without a paddle. We could even be worse off than we were before.

I imagine that it is not always easy to change services even when you live in a bigger town or city and have other organisations to choose from. There are particular, issues, though when you have only one service in a town. It is difficult on a social level because you know the people who work in the service; you see them regularly downtown. They may feel personally confronted or offended by your decision to leave their service, not understanding your strong conviction about the kind of life you want for yourself or your son or daughter. Other people might appear to agree with you but it is clear that they, too, do not share the vision you have and do not really believe that what you are striving for is possible.

On another level, when you have only one service in your town, it is truly scary to contemplate leaving the security of having at least something in place, even when you are not happy with the situation. I was constantly told that Sarah already had the best service on offer; the best possible under the current system. You begin to doubt yourself when your belief is constantly questioned.

But I knew that the support my daughter was getting was truly putting her at risk. I could look at the situation from many different angles but the facts remained the same. I knew I had to change and not settle for second best. I had to ask myself, if I would not be happy to accept a second rate service for any other part of my life, why would I accept a second rate service for Sarah?

Despite all this, it was still not easy making the decision to leave the organisation in order to direct the support ourselves. I had a million questions racing around in my mind. Would I find someone to work with Sarah? How would I find someone? Would it work well? What if it didn't? But in the end the question that remained with me was, how do you know if you don't have a go?

KEY POINT: *Stick to what you believe in. Don't be over concerned about what other people think of you. Keep the big picture in mind. Be brave! Take the first step; it is always the hardest.*

First Steps: choosing our method of self-direction

After talking with other people who are directing their own funding, we decided to work with a Host Provider rather than using a system of Direct Payments. This meant that the Host Provider would actually receive the funding from the Department rather than the money coming directly to us. At that time there was no service in our town that works as a Host Provider for people who are self-directing. This is the case for a lot of people in regional Queensland but it does not necessarily mean that people in our situation cannot be involved in self-direction. We could have chosen to do Direct Payments but we wanted the extra layer of support from a Host Provider.

We were happy with this idea because it meant that the Host Provider would do as much or as little as we wanted in terms of helping with administration, recruiting, payroll etc. I knew that I wanted to concentrate on getting the right kind of support around Sarah rather than worrying at that stage about acquittal of funds and other administrative parts of the business. Now, after a year of self-direction, I would feel more confident to take on other responsibilities. I know that I can negotiate this with the Host Provider if I want to.

KEY POINT: *Be clear about how much or how little you want to take on; research Host Providers so that you feel comfortable with the people you will be working with; take charge from the early stages.*

Finding a Host Provider

Our early contact with the Host Provider in Brisbane, the one that explained the system to us originally, proved to have been a useful contact. From my first meeting with them I felt comfortable in the relationship. I felt that they really did share the vision we had for Sarah's life and the values and beliefs that this was based on. I

think it is important when people are looking for a Host Provider, that they have this confidence in shared values and the working relationship.

The organisation was happy to take on the role of Host Provider with our family even though this meant working with us over such a distance. They had worked previously with a family in a country town and had learned some lessons about what it takes to be a Host Provider for people in regional and remote areas while they, the organisation, are based in Brisbane. One of the crucial elements was that people should not be left unsupported in their self-direction efforts. For us, this was not a problem. We had good contacts with other families who were thinking about self-direction, with the people in our support circle and with a wider group of people throughout Australia, and even overseas ,through my attendance at workshops and other events over many years.

Organising the change

Once the connection with the Host Provider was made the next step was to contact the Department of Community Services to find out how much funding Sarah actually had. Once I knew this I could work out a plan of support for Sarah with the Host Provider. The next step was to put in a Change of Service Request, again by contacting the Department. The person I spoke to there was very helpful and understanding. His response to me was, "Yes, you absolutely you have the choice to make this change. Some people shop at Woolies, some at Coles". A good approach, I thought. I was told that this paperwork would take up to 6 weeks and that we could not make the change before the funding quarter ended.

Finding the right person

While we were waiting for the process to go through I was actively looking for someone to work with Sarah. Because I knew the amount of funding we had and had worked out the contract with the Host Provider, I had a pretty clear idea of what I could offer someone in terms of hours of work. Finding someone seemed to me to be one of the scariest parts of the plan, I needed to get out there and start asking.

My approach to finding someone was simply to 'put it out there'! Sarah is well known in our town. Perhaps not fully a part of the community yet but certainly known by a lot of people. My strategy was to work on this level of knowledge. When people asked after her I would no longer give the simple reply of, 'she's doing okay". I would actually tell them that yes, she is okay, but that we were looking for someone to assist her. And it worked. What I thought would be the hardest part, finding someone to work with Sarah, was not really hard at all.

Our first recruitment story:
I put my strategy into place one night when I was buying fish and chips in town. The person working there knew us from Sarah's primary school days. When I told her about looking for people to assist Sarah, she gave me the name of someone who worked in aged care in the district. I thanked her politely and pocketed the name, firmly believing that someone with a background in aged care could not possibly be a suitable person to work with my daughter. But at least this experience showed that the strategy had potential.

At our next circle meeting we talked again about how to find people to work with Sarah. We decided that the next step would be to put an ad in the local paper. As it turned out, this would not be necessary.

We followed the circle meeting with our usual dinner at the pub. By coincidence the woman I had spoken to about Sarah was working there that night. She was delighted to tell me that the person she had suggested was actually in the pub and asked if she could introduce us. It was all a bit sudden but we met her and I felt instantly that this woman would be the right person to work with Sarah. I made arrangements for them to meet as soon as possible. Sarah liked her too and from that time on the arrangement has been working well.

It sounds too simple, really, but the strategy of putting it out there and ASKING really did work. Everything I had heard over the years about being clear about what we wanted for Sarah and using this vision as the starting point for our planning was working a treat. We were pretty clear about what we wanted and we certainly knew what we didn't want.

KEY POINT: Start with a clear idea of what you want to achieve. Don't be afraid of sharing your vision with people. Put it out there!

Making self-direction work

The next step in the story was all about changing from working within a service to being able to direct Sarah's funding ourselves. We had found the first person to work with Sarah but now had to put in place the arrangement to be able to employ her ourselves – to actually begin the process of self-direction.

Despite the problems of distance the arrangement with the Host Provider is working. I know that I can have as little or as much contact with them as I want. Mostly, it is simply a matter of submitting my invoices monthly and then receiving the next month's allocation of funding into Sarah's account. The organisation is always there when I need them. We make contact via email and their style of communication is simple and concise. We feel confident working with them because they seem to have their processes worked out and they know what they are doing. But perhaps the most important thing is that, no matter who I talk to in the organisation, I know I am talking with people who believe in me and respect me as the person who is helping Sarah have a real and true life.

KEY POINT: Be organised with your paperwork – Keep it simple; set up systems that work for you; keep lines of communication open.

What's happening now?

The past eighteen months have seen significant changes for Sarah. She has become more her own person and I am sure that she feels in more in control of her life. She and her support person have worked out their own way to communicate and Sarah makes it clear when she wants her there and when she doesn't. There is total respect from both sides.

We notice that Sarah is now thrilled to dress up and put make up on to go shopping Her profile in the community is lifting with people seeing her now as an adult, an individual in her own right, no longer a child with a disability.

We are delighted to still have the original person working in the support role with Sarah but we realise now that we need to look for a second person. This is one of the safeguards that we need to introduce to ensure some continuity for the arrangements. We continue to grow and develop in our understanding of what is involved to make self-direction work well.

The journey has begun but we know that it is a long one. I was terrified at the beginning that it might fail and that I would be left with egg on my face. But we are all confident that this is the best thing we have done for Sarah and for the family. I have always seen Sarah as a leader and change agent in all that she has done in her life. In many ways she is an ambassador in her community. This is not always an easy role to play but we are delighted that there are now other families in our region using self-direction.

KEY POINT: Realise that self-direction is an ongoing journey; think about safeguards; celebrate the good things.

PEARLS OF WISDOM

From my experience

Starting something new can be an isolating experience, especially in a small town. For me, being connected with other people on the same journey, people who share our vision for the kind of life we want for Sarah, has been a life saver. For anyone considering a change to self-direction I would recommend it thoroughly as a way of achieving the kind of life you want for your son or daughter but I would strongly recommend finding ways to connect with ideas and information and especially with other people. While I have professional connections in the disability field it is the personal connections through friends and other families I have met on the journey that have been important to me. It is not easy making connections, especially when you live in a regional area. But in some ways I think this means we have to make more of an effort to take the opportunities that are offered and to use technology to its full advantage even if this means moving out of our comfort zone. It is the connections with people that have kept things together for my family so far and I know that it will be crucial for us in the years ahead.

Making Connections

Some of the places and organisations that have been important for me in making contact with other families and gaining up to date information are:

Community Resource Unit
Qld Parents of People with Disability
Pave the Way
South West Training Coalition
Peer Support
Facebook – Advocacy group, support network groups
Online web groups – Mailing lists