

NEGOTIATING SUPPORTS ONE FAMILY'S EXPERIENCE

Sarah is nearly 25 and has lived in her own home for 5½ years. Before that she lived in an institution, so she has been the recipient of two very different types of support. As part of a six-pack with one support person, who could never be anything more than a minder, and as an individual whose support is person centred and built around her needs only. From a situation where we had no power to negotiate anything to where nothing happens without our say so.

The support we have negotiated around Sarah is not a blue print of the ideal model of support it is what we have found works best for her at this time. It is not set in concrete. But I am convinced that unless support is person centred, individualised and flexible, there is very little chance of anyone having a decent life. However money continues to pour into the large services where support is segregated, congregated and controlling, while small innovative services are struggling to survive.

So, who is Sarah? Sarah for most of her life has been described in negative terms. She has severe disabilities and is very vulnerable. Her biggest label is autism and all the stuff that goes with that. She used to be described as being challenging and difficult. Well Sarah's still all that but now her workers take great delight and pride when Sarah discovers something new she can do - they take the positive view rather than

the negative. Because they know her so well, they notice and celebrate the little achievements as it is so hard for Sarah to learn. I'm telling you this so you won't go away thinking "Well it's all right for some" but realise that the type of disability is no bar to a decent life.

I'd known for a while that I did not want Sarah to spend her life in an institution, but what was the alternative? The reasons she went to Basil Stafford hadn't changed, but very little had changed in government thinking and I knew of no one with the complex support needs that Sarah has, who was living in any situation resembling an ordinary life.

In 1992 I heard Nicola Schaefer speak. She is a mother from Canada and she spoke of how her daughter lived in her own home with people supporting her who respected and liked her. Her daughter's disability is very different from Sarah's but it hit me between the eyes - Sarah didn't need a 'specialised' setting with 'specialised' care - she needed people who liked her and wanted to be with her - Simple!

However it wasn't until 1994 that I got up the courage to do something about it. Early that year there was a CJC Inquiry into the abuses at Basil Stafford and I could no longer keep my head in the sand and pretend everything was all right. When I tearfully said to one of my co-workers "I've got to get her out of that place" she said "I'm on


board" and so started my circle of friends.

How we did all this is another story, suffice to say institutional reform came on the political agenda and rapidly went off it with a change of government.

However we didn't give up - the Housing Department stuck to the previous government's promises and found Sarah a house and I kept sending Family Services letters, asking for them to make the same commitment. Finally after being involved in rallies, public speaking, marches and media, Sarah's money came through. It was full steam ahead.

Our family had made the decision that Sarah would never again live with people she didn't know or like, so she is living on her own. This doesn't mean forever, but until the right person appears that is the way it will stay. This of course means that her funding does not cover 24 hour care so Dominic and I decided that we would provide support to cover the unpaid hours. This wasn't an easy decision - after all it was many years since we had looked after Sarah and she was quite a stranger to us. Also we were getting to the stage where our other 2 daughters were becoming independent and leading their own lives and suddenly here we were having to take on this enormous responsibility.

So, who was going to provide the paid support? There were some definite things we did not want for Sarah and we were very firm on what we did want. There were also some areas where we hadn't a clue. Because Sarah has very limited communication other people have to make major decisions for her - and we wanted that to be us along with people who knew and cared about Sarah. I must say we believe Sarah understands a lot more than she lets on. I had heard stories where support organisations regarded parents as problems or



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where support workers went against families' wishes. We'd already been there! We wanted a small organisation who would take the time to get to know Sarah, a very slow process, and where Sarah would be the focus and her family and networks would be welcomed and respected. I already knew of one such organisation, but they operated in the

western suburbs and Sarah was going to live southside. However, one morning I got a phone call from the co-ordinator of that organisation who told me that the committee had met and decided to do their bit for institutional reform by supporting a family going through the process. Would we like to be that family? I can still remember sitting there stunned with my mouth flapping and trying to get out the words "But Sarah isn't going to live in the western suburbs". However that wasn't regarded as a problem

and we became part of the Homes West community.

Leanne, the co-ordinator at the time, worked very closely with the family and circle negotiating the type of support and how it was to be delivered. I was very clear that I didn't want Sarah to have to put up with immovable 8-hour shifts, where I was told "Sarah can't do that because we have a staff change in the middle". I wanted Sarah's roster to be built around Sarah not Sarah having to fit in. To start with it was quite conventional looking - we had to start somewhere and we had seven people needing to know when they were working. However 5 years later our present co-ordinator, Helen, would be the first to agree that Sarah's roster is a nightmare - but works!

It was always understood that no one would be hired without one of the family being involved and Sarah is always there. Our first two workers were hired through networking. Then we placed an ad in the local paper. We didn't want the ad to be too formal, we wanted people to think that it would be fun to work with Sarah. Our ad read something like this - Wanted, a young, enthusiastic, outgoing woman to assist a young woman with disability to live the life of her choice - We got inundated with replies and Leanne did the weeding out and then we worked together to decide who we would interview.

What sort of a person did we want for Sarah? We listened to people who had been through this process and realised it was not necessary for that person to have been

'trained'. We wanted people who didn't have preconceived ideas about Sarah, but who saw Sarah as a young woman who had the right to a decent life' Some of our best workers have been students - they have a "Why shouldn't she" attitude rather than "I don't think she should". The down side of this is that we don't have them for long, but their contribution has been invaluable. Our workers (ages) have ranged from 19 to 60. We find a mix important. We try to utilise their strengths. Some are better working with Sarah doing general stuff, others are keen to try the new.

When we interview people we make it clear that they will be working for Sarah, not Homes West. Our workers are all part-time, some have other jobs as well, but no one who works for Sarah will work for anyone else in Homes West. This makes for a tight knit team and ensures confidentiality. It also means Sarah's support is very personal. We make it very clear that they will be part of a team, which includes family, friends, co-ordinator but with Sarah as the focus. We welcome input from workers and will often ask for their help when making decisions for Sarah. Especially decisions that will affect them too. This also shows the respect we have for Sarah's workers and it is certainly reciprocated. We like to know their hobbies as this might lead to something Sarah can try. We try to find the best worker for different activities.

One of the things we negotiated early on was Sarah's budget. After hearing some horror stories about

where some peoples' pensions went this was very important. Once a fortnight I draw a set amount of money out of Sarah's account, in correct denominations, so the workers can put money aside for Sarah's rent, Telstra card, Energex card, as well as her general housekeeping, medications and going out money. One of the workers devised a form which has to be filled in, like a petty cash book, together with receipts. This works very well, and although sometimes it is a little bit out, there has never been anything sinister. Any money left over goes into the 'blue box' to be used if one fortnight there are some extra expenditures, clothes, holiday etc. After Sarah's fortnightly budget has been drawn out there is quite a bit left over which is used for clothes, holiday, extra medical expenses, carpet cleaning, pest control etc. So far Sarah has managed to stick to her budget, thanks to the diligence of her workers.

Once a month we have a meeting, with Sarah, family, workers and Helen our co-ordinator. Workers are paid for two hours and are expected to attend. If the meeting is shorter, then that money is saved for a meeting with them and the co-ordinator, where they can perhaps talk about things they may not be comfortable talking about in front of us. So far nothing dreadful has come out of those meetings, so we must be doing things right! At monthly meetings everyone is encouraged to have their say. We

discuss the last month and find out what worked and what didn't and look to the future. Once thing we have found, Sarah's workers respect us and although we might have some lively discussions, we always sort things out. They are also very mindful of Sarah's health. She rarely gets sick but thanks to their vigilance, two potentially nasty situations were averted.

When Sarah started her new adventure it was necessary for all of us to learn as we went, to be ready to change. In our negotiations we made it clear that we wanted workers who could "think outside the square". Workers are expected to use their own cars and to keep a logbook so they can claim on their tax returns. Sarah can't afford to pay mileage, that would take too much away from her support hours. If Sarah is going on a long trip, perhaps to the coast then Sarah will pay some petrol money. Everyone seems happy with that. It always amazes me that some organisations do not allow workers to use their own cars, that they have to order one. How on earth can there be any spontaneity? Some organisations prefer that workers do not mix home and work. However Sarah has met most of our workers' families and enjoys spending time with them. I had some concerns at first about the worker relationship, but there has never been any conflict. I was also concerned about Sarah becoming too attached to a worker, and then that worker leaving. However she copes very well when someone leaves. I



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suppose she has been used to that throughout her life.

I'd now like to tell you the story of Michele and this story highlights what can happen when organisations are creative and flexible. Michele was one of our first workers and was living in Brisbane after her husband had been transferred for three years from Melbourne. Sarah and Michele had a very special relationship.

However Michele and her family had to return to Melbourne, much against their will, and Michele was devastated. She kept saying, Sarah must visit me, and I was thinking Yeah right. Sarah on a plane? Homes West to the rescue. Leanne was determined that Sarah should go and we began to plan. First of all it was obvious that someone needed to travel with her. We decided that because Sarah would go for about four days that meant a saving of her support hours. Some of that money could pay for her support worker's plane fare. Who would go with her? Well that was easy, Rita also comes from Melbourne and has a very large and close family. Her parents live in a large house near the airport, so Sarah would stay there the first night. We decided that Sarah would travel in the early evening when she is at her most mellow and we requested that Sarah be given finger food as soon as possible after the plane took off. I had a few sleepless nights imagining all the worst scenarios but everything went perfectly and Sarah slept all the way down and all the way back. Rita's family thought Sarah was wonderful and she had a great time with Michele. Michele continues to

keep in touch and hopefully Sarah will pay a return visit.

Another different type of support just happened. Deb had one overnight a week and her husband looked after their children. However there was some emergency and her husband had to go away. Deb asked if Sarah could spend the night at her place. I said "If you're game that's fine". Sarah had such a great time; she had dinner with the three kids (rowdy teenagers she loves all the noise that goes with teenagers) and slept beautifully. That has now become a weekly event. Of course it is important to make sure who's helping who, but the bottom line is that Sarah enjoys herself.

Sarah recently went on a long weekend up the coast with two workers. They stayed at a resort, visited the Australia Zoo, went shopping, went to the beach, out to dinner and had a wonderful time. A young woman Sarah knows who had also left Basil Stafford, went to Boys Town for her holiday.

One of the most important things we expect from Sarah's workers is to encourage friendships. Sarah finds this very hard as she doesn't know how to make friends and has little inclination to try. However one of our workers used to work with two young women and thought it would be good for them to meet. These two women took to Sarah immediately, even though their disabilities are far less than Sarah's. They are very protective and caring and Sarah just laps it up and thoroughly enjoys their fortnightly dinners. It is the first time that Sarah has had a friendship

where she reciprocates. We have recently compiled a list of the people Sarah knows and they will get invitations to dinner or lunch. Another way of keeping people in touch with Sarah and also another safeguard.

Sarah's life isn't anywhere near perfect. She still faces rejection, especially from disability organisations. We would like her to be more involved in the general community, but we are working on it. The most important thing is that she is welcomed and accepted. However she continues to make great gains. Things that were an impossibility five years ago she takes in her stride. There are still a lot of things that aren't happening for her but with the help of Homes West Sarah's life is changing all the time. They just do not give up on her. She is considered a valuable member of the Homes West community.

As part of our family's support of Sarah we have a family night once a week at my place. The five of us live in four different houses, so although we are a very close family, getting us all together at once is often difficult. This is also a good time for family arguments and Sarah finds all of us trying to get a word in at once very amusing. Of course this doesn't happen every time!

We also feel we are a family again. My youngest daughter was a baby when Sarah went to Basil Stafford and has no recollection of her at home. It has been hard for her to form a relationship with Sarah but we haven't pushed it and now we

find Nerida looking out for her at dinner making sure she is OK.

We have made a commitment to support Sarah on public holidays, when the wages are astronomical and have worked out a system where Dom and I share a few hours with Sarah. Homes West is very economical with Sarah's funding so we can get the best value for money. It's always hard to get people to work at Christmas and at Easter, especially if they have their own families, but one of our workers is Moslem so she is quite happy to put in a few hours!

If Sarah does not want to go out, then she doesn't. It's not a case of "Well we have community access between 9 and 12 and you have to be out of the house". If Sarah wants to go out she will make it very clear by picking up the car keys, bag or shoes, or just by standing at the door. However she is always encouraged to go out, the worker explaining where they are going, but it is still Sarah's choice. Sometimes she is offered two choices, using symbols and pictures, but this is still difficult for Sarah. In 5 years Sarah has got to know many shopkeepers in her area and they are patient, helping her to pay her bills or whatever.

Sometimes Sarah likes to be on her own in her bedroom listening to music. Her workers respect that and I have made it clear if that is what Sarah wants to do, you don't have to feel guilty because you are not with her all the time. Solitude is important to Sarah, as it is for me, and I sometimes think, supposing I had a support worker wouldn't it drive me mad at times? When


Sarah first moved into her own home it was very difficult to get her out of her bedroom. This was probably because her bedroom had been her only place of sanctuary. She' was encouraged into the lounge room by the worker bringing in her comfy rocker from the bedroom and her CD player and she gradually learned that hey! the whole house belongs to me. I can go where I like. Gradually she began to feel safe in her house. For a while she wouldn't go out into the garden but now she knows its OK to do that.

We have negotiated something else to make it clear to workers, not just what is expected of them, but what is important to Sarah. This year Helen and I got together and developed a job description just for Sarah. Prior to that the job description was quite vague, but it needed to be as we were all on a learning curve and slowly finding out the best ways to support Sarah. This job description doesn't just include the usual formal stuff but also sets out the no-nos. For instance, Sarah is not to be treated as a child. Although she enjoys picture books and soft toys at home, if she needs something to do in the car she takes a woman's magazine. That is stated very clearly in the job description. It is easy for workers to treat Sarah as a little girl as she requires so much support, but we have really stomped on that one. We have also made it clear that support is to be unobtrusive. Workers must learn when to step forward and when to step back. This job description

helps workers to understand how we want them to treat Sarah. This has been developed over five years of learning and it will change as Sarah changes. I wonder how many other people in other organisations have their own personal job descriptions? I have recently learned that someone from Disability Services in Victoria, who is looking at ways of supporting people in the community, has seen Sarah's job description (name deleted of course) and is recommending that their people should have individual job descriptions too.

We remind workers that although this is your workplace it is Sarah's home. Our workers take pride in how Sarah looks and in her home. Her home is beautiful.

When we first saw Sarah's house her older sister Joanna said, "Great it's near the pub" Last year for her birthday she welcomed 20 people to the pub to celebrate and had a wonderful time. Five years ago she would have been scared to death of the noise and who would she have had to invite?



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Recently Helen voiced something that had been at the back of my mind for a while. Sarah's Saturday evenings are very different from those of the average 20 something. We are now going to look into how we can link Sarah in with some young people so she can go out, with her support worker, and have a good time. Maybe some different groups so their commitment wouldn't have to be enormous. My dream would be that one day she

would have a group of friends to go out with and wouldn't need a support worker because they would know Sarah and feel confident and comfortable with her. This isn't going to be easy, but we have to try. It is becoming more and more urgent that we find some other forms of unpaid support. Recently there was a wage rise, but no extra funding from the department to cover that. I know there are so many people out there without any funding, but this has meant Sarah has lost paid support hours, and if it continues to happen people with packages will also end up on the crisis list. Small organisations have no way to cover those extra costs.

We have a long way to go - five years isn't a long time in the whole scheme of things but Sarah finally has a life and is facing the challenges. Sarah is a woman of courage. Hopefully Sarah will remain supported by Homes West and we'll keep on trying to make Sarah's life something wonderful.

Sally Barone