Re-shaping a Life: Changing the Hole to Fit the Peg

By Jan and David Goldsmith

- *Hearing words like family governance and the possibility of David living in his own home was a revelation. We learnt that we could have a plan and a vision for David and the future became something we had control over and not something to dread.*
- *Until we did this ourselves, money was spent on things I wasn't interested in and that is a waste. I used to feel like a square peg in a round hole; now I'm making the hole just my shape.*

……

***David Goldsmith** is a young man in his late 20s who lives in Boondall and is assisted by his parents, two sisters and support workers to have an interesting and challenging life. Bespoke Lifestyles supports David and his family to manage his funding and provides advice and education on family-managed arrangements for example employing support workers. David and his mother Jan write of their experience with self direction.*

……

I remember when David was at school, I didn't want that part of his life to finish. During those years, I knew exactly what was required and that he was in a safe and nurturing environment. Leaving those school years behind in 2001 felt terrifying and we felt unprepared for the future. With support and advice from his school, we secured some post school funding and over the next 8 or 9 years, David attended programs under three different service providers. As we moved along this journey, we learnt more of what David wanted and needed to be the person he felt he could be.

In 2005 David discovered Facilitated Communication (FC) which enabled him, for the first time, to articulate what he wanted to do with his life. Before this, he had been limited by his verbal communication to very basic needs and wants. This meant we were only really guessing what he wanted but with FC, he could convey his deepest feelings about self-worth and participating in society. There was a huge readjustment in everyone's expectations. It took a year or more to adjust to this new skill of David's and to become accustomed to his voicing his own opinions. There was no place in his new world for sitting on buses and going to the movies with a group of people not of his choosing to fill in the day.

I found it frustrating when I was at the day centres. They would choose an activity that the majority would like and usually I wasn't interested in that, so I spent the time being quite frustrated and cranky inside.

FC was a great awakening; it let the light into my life. I could now participate in decisions about my life.

Our family, including David attended conferences and workshops over the years which showed us a future for David we never thought possible. Hearing words like family governance and the possibility of David living in his own home was a revelation. We learnt that we could have a plan and a vision for David and the future became something we had control over and not something to dread. We applied for funding to support David in this new plan and have been successful in securing a small amount of ongoing funding for this purpose.

David is well supported by three terrific support workers who all contribute something unique to his life.

I would like to add that I really feel well supported by my workers because they know me so well and we don't do things that don't interest me. FC has given me the opportunity to speak up and express my desires.

David always wanted to be a mower man so he is now mowing on Mondays and Fridays. He goes to TAFE on Wednesdays and Thursdays. He also contributes by volunteering at a school and in a community garden and being a member of a writers' group. He finds time for golf; has tried sailing and is open to other adventures. Grocery shopping and cooking are also part of the week.

© Community Resource Unit. 2013

As you can see, there is a rich mixture of education, work and pleasure in his life – something we all aspire to. There has also been the chance to gain confidence and make friends. He isn't doing anything just to fill in his days idly, in fact he craves being busy and useful. David has voted in the last few elections and is proud of his status of being, as he says a "fully fledged member of society".

It was challenging to work out where to start so that David could have a home of his own. His name was on the list for Public Housing for some years, but we realised that this wasn't going to be a reality for some time. How could we plan for him to be in his own home when we didn't know when and where that would be? There was also the issue of support. He needs someone with him and there will never be enough funding for that to be a paid worker. We thought about flatmates but knew that public housing had stipulations about who is eligible.

We made the big decision to purchase a property for him, close to our home. This was a huge commitment, but we felt it was best as the family is totally in control . Currently his sister Lisa is sharing with him. Their home is 800 metres from ours. David is spending about half the week there and lives the rest of the time with Mum, Dad and the cat. Having two homes has its funny moments. If I don't keep an eye on things all his pyjamas, jeans or socks are in the wrong house! However, plans are on track for David to be living full time in his own home with Lisa by the end of the year.

David still needs lots of support and reminders to get ready for each day. We are trying to get a mixture of paid support and natural, family support. If and when Lisa wants to move to the next stage of her life, we plan to advertise for a flat mate to share his home and be there at night. He wouldn't be a support worker as such, just someone to be there and provide security. David would still have paid support to work and participate in the community the way he is now.

While this all sounds wonderful, it is constant work to oversee it all and a large commitment from the family. If one of his workers has holidays or is sick, back up has to be arranged by us. However, we are learning from our mistakes and growing in confidence with our planning and coordinating. I'm relieved we started this process while we are nearby and young enough to work this out with our family. Our daughters have been involved from the beginning and are committed to David as well. They will take over from us when we are no longer able to do it.

There are many things I want to try and learn about and I have more confidence now that it will eventually happen. I was on the edge of society but now I'm more mainstream and not so marginalised. I like to be part of what's going on and not stuck away doing something different from everyone else. There are days I don't feel very strong and my workers provide that extra power for me to contribute to the world in my small way. So, yes, I feel much more a real person and not just an autistic twit. I like my workers very much and look forward to each day which brings something different with it. Until we did this ourselves, money was spent on things I wasn't interested in and that is a waste. I used to feel like a square peg in a round hole; now I'm making the hole just my shape.

© Community Resource Unit. 2013