

# MY QUEST

## Will's Story



This story, as told to Catherine Raju, was written as part of the Story Project funded by Disability Services Queensland through the Community Enablers Project, 2013.



Will is a 22 year old man living at Maroochydore, one of the beaches on Brisbane's Sunshine Coast. Will directs his own funding and has control over the employment and supervision of his lifestyle facilitators. When Will heard about the Story Project he contacted me immediately to say that he would like to be involved. I met with Will a number of times. He talked about what it had taken for him to be living the life he has now. This is his story.

I am living the life of a twenty-two year old man. I make my own decisions. I have control over what I do. I won't go back to a life that offers anything less than this.

Since I was quite young I have had this driven quest to live the life of an independent adult, a life that is no different from my sisters or other people I knew. I think I have always had this ambition because of the way I lived at home. I was never treated differently from my sisters. If I wanted something I had to make it happen.

My school life was important too. I went to the local primary school at North Arm near Eudlo for the first three years and I was seen by everybody as just "Will who goes to the local school", not "Will who has a disability" or "Will who is different". Later I went to a bigger school with a special unit where the kids with disability were taught together in separate classes and mixed mostly with each other. My high school was the same as this. I changed schools because I wanted to see what it would be like to be with other kids with disability. Now I wish I had never left the local school.

I had not foreseen the consequences of the decision. What happened is that everyone began to see me as different. I had become just "Will who has a disability". Sports day was one example of how things changed. At the little primary school I used to join in the races with everyone else. I remember falling out of my wheelchair one day when one of the teachers ran pushing my wheelchair in the race. It was fun. At the new school, though, all the kids with disability had to go to

a separate “special sports day” instead of being part of the whole school competition. There were lots of examples of separateness like this. Even though these school years were difficult, the experience taught me to speak up for myself. I knew what I wanted in my life and was determined to make it happen. I was still determined to follow my quest.

I lived at home with my family until the age of sixteen. I have experienced a lot of change in my life since then. It’s a long story and I will tell it all one day but for now it is enough to say that the few years after I left home were very hard for me and my family. For one year I lived in a series of respite houses and then a place for teenagers who had behavioural problems. That was a particularly strange place for me to live seeing as no one in my life had ever considered that I have a behaviour problem. I survived, though, and even made friends with one of the guys who lived there.

It was hard having to move to so many different places during those years but I learned a lot. Some of what I learned came from very difficult experiences but there were some ridiculous things that happened too. One of the places I was sent to was a so called “wheelchair friendly house” but when I got there I found that it had two steep stairs up the front. I had been assured that the staff were experienced but I found that none of them had ever worked with a person with a disability. I had to teach them what to do. I learned a lot of patience during those years and I became even clearer about what I wanted from life.

When I was eighteen I moved to a group home at one of the beaches north of here on the Sunshine Coast. I had finally been given some funding from the state government but I still could not move to a place of my own. The funding was not enough to cover the amount of support I needed. I have cerebral palsy, use a wheelchair and need physical support for just about everything. I hated the group home. I just didn’t fit. I felt very isolated. I couldn’t have in-depth conversations with the people who lived there. I liked them and I still see some of them socially but the group and the house just didn’t work for me. Group living might work for some people but I didn’t like having to do everything with the others and having to fit my life around staffing schedules. I never went out at night like other people my age. I did learn how to connect with support workers, though. They were the people I spoke with most often. I suppose this has helped me now when I employ my own staff. I know what I want from people who work for me and I feel confident in negotiating with them.

I knew I had to leave the group home and I knew that I wanted to live on my own. There was no way I could afford private rental so I was lucky that I had applied for social housing from the state

government soon after I left home. You could do that then, put your name on a list. But the department of housing and disability services staff would not allow me to move to my own place. They told me I would not be able to live on my own with the amount of support funding I had. They suggested I try living in another group home, somewhere “more suitable”. This was not an option for me so I continued to fight for what I really wanted. Around about this time I met a woman in Maroochydore who has a disability and lives an independent life in her own home. Seeing what she had done with her life gave me extra courage to continue the battle.

I continued to email the department trying to convince them that I needed to live on my own and that I could do this with help from my family and other volunteers. My plan was to move in, if they ever agreed, and then advertise for a flatmate. The flatmate would provide me with some support, working the number of hours that would allow him to qualify for the Centrelink Carer Payment. This way I could make my funded support dollars stretch further.

Through all this there were times when I wanted to throw in the towel. People told me that it would never work, that I could never live on my own. But I kept going. I was brought up believing that if I wanted something done then I had to have the drive and determination to make it happen. And so I did.

Finally it all worked. My planning and advocating were successful. The housing department gave up on the group home idea and I was granted a place in one of these new public housing home units at Maroochydore. But there were still problems. At first I was told that I had to share the home unit with other people. There were two or three of us moving out of the group home and the department wanted us all to live together. I had had enough of sharing. I also knew that I was entitled to a two bedroom place of my own to store my wheelchair and other equipment and because I needed support overnight. I just kept emailing the department again with my request and eventually I was given this two-bedroom place by myself. I found a flatmate who supported me in the evenings and at night times and during the day I had support workers who were employed by the service who ran the group home I had lived in. I was finally living the life I wanted.

I soon realised, though, that there is a lot more to an independent life than just finding a place to live. All my efforts had gone into getting the two bedroom home unit of my own. Trying to make this happen had been all absorbing. But when I finally got here I thought, "Now what do I do?" I didn't know how to manage everyday living. I even wondered at times if it had all been worth it. But I soon began to learn how to manage the practical side of things and my life was certainly a lot better than when I was in the group home

I lived for three years like that with support coming from my flatmate and the workers from the service that managed the group home but I began to see that I still didn't really have control over how I lived. I met a girlfriend who lived in a group home at Caboolture. When I spent time there with her I began to see the difference between her support workers and the people employed by the service that supported me. At her place people engaged with me rather than just sitting around on the couch being present but not doing much. When I was with her, and the people who supported her, I began to feel a lot more motivated myself. The workers in my life were unmotivated in their own work and did nothing to encourage me to organise myself to be motivated. They did not give me options or choices or assist me to make decisions for myself. They were what I call "robot workers". They came pre-programmed with the attitude that they knew better than I did about what should happen in my life. They were not prepared to listen. This was not how I wanted to live.

It was all too hard and I came close to saying that I wanted to move back to a group home. I thought that living in a place like that might not be much worse than the way I was living. I was in my own place but I still had other people deciding how I lived.

I talked about all this with Carol, a friend of my family. She gave me the inspiration to hang on to my dream. She simply asked me if going back to a group home was what I really wanted and if I thought that all group homes would be like the one my friend lived in. She also told me that it was unrealistic to expect that I should know how to live on my own when I had never learned how to be independent. She encouraged me not to lose hope. We talked a lot and I realised I did not want to go backwards in my life and lose the independence I had achieved so far.

Carol was also the one who told me about the possibility of working with a host provider that offered a system of self-directed funding. Under an arrangement like that I could recruit and employ

my own lifestyle facilitators and would have more control over how my funding is used. The organisation would take care of the administration but I would pay a smaller percentage of my funding to them than I had been paying to the service I was using. I would have more money left to employ staff.

It was an exciting idea but it was also a bit daunting at times trying to imagine how it would all work. I was put in touch with an organisation based in Brisbane. Once I started working with them I could see that directing my own support and managing the funds were possible. The best part of all this was the planning we did. My family and I sat down together with a person from the organisation and we talked about what I wanted in my life. No one had ever asked me that question before. My mother never knew that I hoped to have a relationship and a family one day. It was really good to have that talked about and written down. It was great to have my family involved.

We also attended workshops about how to manage the funding and to set up processes for the paperwork involved. We do it all on the computer. It seemed complicated at the beginning but now that we have the processes in place it works quite easily and does not take a lot of time. My mother and sister are happy to manage the payroll and the paperwork at the moment but I am working on how I can manage all this in the future.

Self-direction has made a big difference to my life. It means that I can employ my own staff. I have control over who they are and what they do. The mix of paid workers and unpaid support has worked for me so far. On weekdays I have rostered staff during the day. I also have a flatmate, a university student, who assists me five days each week from early evening till early morning, including any support I might need overnight. We have negotiated that we will both do our own thing on the weekends so he is free to do what he wants then. My family help during that time. On alternate Friday nights I stay at my mother's place or with my sister.

It has not always been easy finding the right person for these lifestyle facilitation roles. I advertise on the GumTree website, on Seek.com or through the University. Often the best people are ones who have not worked at all in disability. They don't come with a service way of doing things. I have had a few different people in the role and have had to ask some of them to leave. They were "robot workers" again, people who had a set idea of how they think my life should look. They don't think for themselves or see me as an individual person. It's as if their work is all done according to some theory they have learned in a course. A text book view of my life. I have been the one who has

decided they should go but my family helped me with the process of doing it. I have a written agreement in place that outlines everything I expect from people in these roles. This makes it easier if I need to have the conversation with someone about leaving. Sometimes people leave because their university course comes to an end or just because they want to do other things in their life. I don't mind that people move on. Younger people like students don't usually stay in one place for long anyway and I quite like meeting new people.

I think communication is one of the big things that help these arrangements work. We have regular team meetings. My mother, sister and I set the agenda and then we meet with the staff. Sometimes things come up that are not working properly for either me or for them. I think it is important to clear the air straight away rather than let problems continue and get bigger. These meetings are also good for brainstorming ideas. The other day we talked about ways that people could support me to understand money better so that I can be more independent with my shopping. No one had ever thought that I might actually be doing my own shopping one day so I never learned about money or how to budget and shop efficiently.

I can see myself living here for a long time. Maroochydore is good because it is central. The home unit works well for me because it has enough room for storage and for someone to stay overnight. I can get to the shops and other places by myself. Even though I can do that, transport is still important. Buses are not frequent and taxis are expensive, even with the half price vouchers. I had help from my family to buy a second hand van. This has made a great difference to my life. The support workers drive it when I need to go somewhere. The van has been in repair for the past two weeks and it has been terrible without it. Not being able to go out whenever I want to.

I am still studying and am not sure yet where I will work. I am going to TAFE and will finish my Certificate IV in Disability Studies at the end of the year. I like to think that I can influence the other students in some way so they don't end up as "robot workers". If I can work somewhere in disability when I finish the course I could make a difference to how services relate to people. I am also interested in doing some motivational speaking so am doing a ToastMasters course at the university. I hope this might lead to opportunities to speak at schools or at conferences so people can see that, even if you have a disability, you can still live a good life.

I am proud of what I have done in my life so far. It has not always been easy and I know there will continue to be ups and downs along the way. I have benefitted from the help I have had from a lot of people. The planning we did with the organisation was one of the key experiences for me. The inspiration that I have had from my friend, Carol, and the mentoring from my colleague in Maroochydore have also been important. My family has always been there in the background encouraging me but in the end I have really done this all on my own.

I would like to show other people how this can be done, people who are just trying to live an ordinary life. It has worked for me so far. I was chasing a dream and a lot of that dream has become reality. I know that I will never go back to the life I had before. There's a lot still to do. My quest continues. But my life is so much better than I had ever imagined.

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