Jacy’s Story:

Jacy told her story during an interview. This is the transcript.

Living a 'normal' life with disability

I live with Cerebral Palsy (CP) and a hearing impairment but I am a very good lip reader. I have an 11 year old son, Luke, and a partner, Brad, who also has CP. Brad and I have been together for seven years. My son and I have been living independently in a ‘rental’ Unity House for eight years and Brad moved here from Sydney a year after we moved in. We would like to get a bigger house so my son can have his mates over without taking over the lounge room, as his bedroom is very small. I have put my name down with the Housing Trust and the waiting list is quite long but hopefully our turn will come in time.

I used to live on my own until I had a baby then I lived with my mother for four years after which we moved out on our own. I have a couple of close friends and a lot of acquaintances - having a baby changes who you are friends with because you have to put the child first. I needed a carer when I had the baby because things got a bit harder. I still have a carer who comes for seven hours a week over three days doing the cooking, cleaning and a bit of housework to make things easier. I can, and do, cook sometimes. I’m teaching my son to cook now and he is starting to enjoy it. Having a little help goes a long way right?

I like having a ‘normal’ life, being independent, having a car and a job. I have been driving for almost 18 years and I love it. I manage to drive with a normal automatic car with no modifications. Brad has a car too. I like being on the computer, especially using Facebook because I only have to type what I want to say once! Not three times or struggle to talk with this terrible speech I have. I would much rather do typing than talking!

I sometimes have pain with my disability, usually in my neck and lower back when I walk or stand for long periods of time and also my hands get a bit hard to control because of spasticity. I receive a disability support pension because I don't earn enough from my work to live. I would like to have self-managed funding so that I can organise my own carers.

Becoming an author

I am proud of having written a book titled *If Only You Knew*. It's an inspiring and educational book about the first 20 years of my life living with CP in the real world. The main message of the book is for ‘people living with disability' to get out there and for the general public to ‘never assume anything’. I received a $1000 donation from ZONTA to help with the cost of printing my book. Inprint Design and Hyde Park Press also assisted me. I wrote the book independently using the computer. I had help from a professional proof reader before the book was finalised. I have an electronic version of the book which is very good for people living with disability who have bad hands like me.

Flinders University has purchased 200 copies and they are going to use it for the courses in disability studies. I'm fortunate because I know the lecturer there. The feedback from the students was that they were truly inspired by my book and really enjoyed reading it. I am in the process of writing a second book called *If Only I Knew!* which is based on the second 20 years of my life. I am turning 40 this year and aim to climb the Sydney Harbour Bridge!

Employment

I work at Inprint Design part-time on Monday, Wednesday and Friday. I feel fortunate to have paid employment. I've been there since 1997 doing design work on the IMac which I love.

Holidays

Brad and I like going on road trips. Two years ago we drove from Adelaide to Canberra and had an absolute ball! Next year when my son goes to his first Jamboree camp with the Scouts, Brad and I are going to Sydney. We're going to fly to Sydney and hire a car, then drive the car from Sydney to Brisbane. We are looking forward to that. The reactions from people wherever we go are hilarious! We always surprise people!

Determination- "never give up"

I am a very determined person. I never give up. It is a little different for me to walk and do things but I am a very positive and happy person. If there's anything I can't do, I find another way to do it. I think I have learned this from my family because they raised me in the country at Broken Hill. My mum and dad were a little tough for my own good, they would say "toughen up" "You can do it, just try it in the way you know how!" and "get a move on". You just get on with it. There's no complaining about it.

I believe the problem for a lot of people with disability is they may have been 'wrapped up in cotton wool'. Perhaps when they were younger everything was done for them because it was easier. Some children with disability were never taught to do things for themselves and I think that is so unfair! In life I have had to go out and get what I want because nobody's going to do it for me; I have to get out there and do it myself to get things done my way! Of course there are times when I am feeling tense in my neck. At these times I have a bath or I go for a drive to relax or have botox! Botox is like a magic drug that would totally take the pain away but only for a few months at a time.

Suggestions for other people in a similar situation

The suggestion I would make to other people in a similar situation is listen to your heart. Don't give in. Get out there. Think differently and know what you can do. You've got to keep going and it's okay to ask for help. I used to hate asking for help but now I'm getting better at it. My other suggestion is don't judge a book by its cover. There are a lot of people with disability who they think they can't do it … but they can. They just have to find a way.

For example, I want to promote my book, so I am doing things like attending a business course and showing my little advert on the 'postcard' I designed for people who always asked me what I do. I have learnt what I have to do to promote and sell my book and I am getting there. At my first Disability Expo I met a lot of people. One girl had read my book and she was so happy she had finally met me. She asked if she could get a photograph of us together. I felt 'famous!' and I was gob smacked! I sold heaps of my books on my own and was very surprised at myself that I could do this! No more excuses! "I can do it!"

My motto is "I can do it my way". Some people look at me, and they think I'm 'dumb'. They look at you as if you are a little girl. But I believe I can do anything whatever I put my mind to. Other people living with disability can do it too. They don't have to sit at home, in the corner, and say "Why me?"