

BONNIE'S STORY

On meeting Bonnie you instantly have the feeling that she is a passionate person who has high expectations of what she will achieve. Her story is testimony to this.

I am 28 years old. I live with my partner Richard and my three children, Ryan, Caitlin and Lucas. We also have two cats and a rabbit.

Family and motherhood

Ryan, my son, lives with hearing impairment, as do I. We have a syndrome called Enlarged Vestibular Aqueduct Syndrome (abnormal fluid in the ear). We each wear a cochlear implant in our left ear and a hearing aid in our right. I received my diagnosis when I was at Kindergarten and Ryan's was spotted at birth – he started speech therapy straight away. Ryan began school this year. He is a mainstream student and has settled in beautifully.

I believe it is my role to teach my kids to become advocates for something they are passionate about. Ryan is already a strong advocate for his disability and I will nurture that in him.

Employment Experiences

My passion is disability advocacy first and foremost. I am passionate about rural and remote disability issues, inclusive education and the rights of women and girls living with disability.

I work with Carer Support Respite Services as a NDIS Coordinator. My role is about assisting families in coordinating and financially managing their NDIS plans. I am also the Executive Secretary for the Board of People with Disability Australia (PWDA) and volunteer with Girl Guides - I would love to see more girls living with disability get involved in Guiding.

Self Advocacy

I advocate for myself and my needs. It was tough at the beginning of my working life. I apologised for my disability and worked around others! Never do this – always stick up for yourself and say when you can't do something because of disability. But always give it a red-hot go.

In my previous jobs I had to answer phones. I would often tell my colleagues that I couldn't understand the person on the other end due to their accent or speaking manner. I felt I was scorned for expressing this, as if I did not want to do this part of my job or that I was trying to get out of it. So now I ask during a job interview "What are your phones like and do you accommodate equipment to aid me?" For me it is saying "Well I have a disability if you're going to interview me let's not waste anybody's time". I can often tell how supportive the environment may be by the response I get. A supportive working environment and team will go out of their way to ensure you are fully equipped to do the job you are hired to do.

I have been discriminated against in several workplaces, but not bullied. I've been treated like I'm stupid when I've said "I can't hear at the present time" or "I misunderstood that". My best advice for Hard of Hearing in the workplace is explain that what may be the THIRD time a person has given an instruction or question, may be the FIRST you fully hear it.

While there are a lot of people in the workforce living with disability I really think there should be more acceptance by employers to employ people living with disability. We need to look at the ability and not the disability. I'm very strong about that.

No doubt, I've had some fantastic support with my time in workplaces, including government. One department offered me technology to help me on the phones but it's a lot of fiddling around. There's somebody to test it, government regulations on how things are installed in the office, people asking you "What is that? How do you use that?" I have a neck loop that I just talk into and basically it's hand-free. I don't have to lift up the handset. It made me look like I was talking to myself. I no longer use the loop in my current role as the phones are just right and I have a supportive environment – I can hear clearly with the phones. It is about trial and error – finding the right technology that suits YOU, not somebody telling what you should use. Always try something and be honest in your feedback.

One thing that really annoys me is when people say, "You don't sound like you're hearing impaired, you don't sound like you have a disability". Disability does not have to be SEEN or HEARD. It just is. I don't know what I am supposed to sound like – and have no idea about what normal is like. I also have to remind people that however normal I sound, I still can't hear them sometimes!

UN Conference

In June 2014 I was chosen as part of the youth delegation to attend the Conference of State Parties (COSP) on the Convention on the Rights of Persons with Disability (CRPD) at the United Nations (UN) Headquarters in New York. The delegation was mentored by the Australian Centre of Disability Law and People with Disability Australia (PWDA), who I represented. The opportunity provided me with a rare voice as a young person to speak to top government and disability representatives from around the world on youth disability issues. It was an opportunity that cannot be forgotten easily as it has fuelled my direction to work with young people in making change.

Interests

In particular, I am most interested in education for young people with disability. Those who are transitioning from primary school, to high school and then into post-high school face the most issues. Early intervention is currently the focus on young children with disability but there is a large drop-out in students past Year 10 that graduate without future prospects,

encouragement and skills. I would love to eventually work with rural and remote families of children with disability.

My passion for change also lies in my advocacy for social justice. After working for SAPOL, I would like to see mandatory education for police officers and court officers about disability and changing the perceptions faced by police officers in assisting a person living with disability in the legal system. I am most interested in the incarceration rates of people living with disability and mental health issues in our prison systems and how rehabilitation and support can best aid them, starting from high school students having better prospects.

I think our social justice system needs a massive overhaul in the way people living with disability are treated. We need a liaison. We need a central disability team in our legal system that isn't reliant on social services and advocacy organisations.

'Handbag Analogy'

In the past when I was working, I had a 'Handbag Analogy' - all my interests for disability advocacy were all stored into a handbag on my arm and over time I would keep on putting interests into the bag that I wanted to tackle and it just kept filling up. The urge to step away from an area unrelated to disability and government was beginning to become heavy as the two cannot be done in conjunction to each other. So when I landed the UN opportunity my contract with SAPOL was coming up and they asked me "Do you want to renew it?" and I said "No, I want to try something different".

So when I came back from New York, I was jobless and it was fantastic! Everything out of the 'handbag' tumbled out – oh, the things I could do! I have been approached by several organisations to represent them and have chosen few. I am a mentor with Julia Farr Youth Mentoring, part of JFA Purple Orange and participate in workshops for youth. I am also a Families Can: Do Group Ambassador as a former client. They're a terrific service for children living with hearing impairment and hearing loss. I felt very proud of being asked to be a family ambassador. I have been approached by interstate organisations as well as the Civil Society – I cannot wait to get moving on new and exciting projects!

Study

I have completed a Bachelor of Arts, majoring in Sociology and Australian Politics. This was meant to go with a Bachelor of Criminology and Criminal Justice to aid my work with SAPOL, but I have decided not to continue with that. I have also completed an Advanced Diploma in Community Sector Management via TAFE SA. I am thinking of going for a Masters' Degree in Social Work or Human Rights.

Each individual is different, but I chose not to disclose my disability when applying for my university course with Griffith University via Open Universities. Purely because it was irrelevant to me – all of my course requirements were in written lecture format to

download in advance, discussions were online in a 'chat-style' and email was the choice of communications for both myself and the lecturers. I chose not to involve disability liaison as I felt that the online study worked for me as it was.

It is a great achievement to complete university via correspondence. It depends on the motivation of the person to complete it. You have deadlines but no classes to attend, just a lot of paper to download and read weekly. It is very easy to become side-tracked!

Early Influences

My Mum has always been a big advocate for working. I had no excuse unless I gave it a go and she wanted me to get a part-time job outside of school, but I always responded with, "I can't hear in Hungry Jacks ... I can't do this, I can't hear on the phone." I made excuses. One day, as a way to 'prove it', I applied for a job at Hungry Jacks – and got the job! It was the best experience as it forced me to talk to people; it forced me to adjust to loud environments; it forced me to think on my feet and those were things that I wasn't really comfortable in doing. I was 16 at the time and so being 16, I felt a big sense of independence working and haven't stopped.

The Reality of Hearing Devices

Having to wear hearing aids has been a challenge and it was a shock to my parents. I've grown up in a hearing family, but the hearing loss does run in my family. My grandmother's sister had the mumps and became profoundly deaf. But they think there's a gene which causes deafness and it's inherited. My parents are both hearing and my two sisters, Anita and Dana are hearing. I've always gone to a mainstream school and feel like I have come out on top because of it, as it forced me to communicate and get a footing on being 'normal', particularly growing up in rural towns.

Growing up in the hearing world, I was late in learning to use AUSLAN. I use it in very basic terms as I have not been able to use it as much as a communication method and am now very rusty!

I got my cochlear implant when I was 22 old. On my 21st birthday I woke up to no sound in my left ear, which was my best hearing ear. I was naughty and stopped wearing a hearing aid in my right from my teens and was reliant on my left as one hearing aid. I thought my battery was flat, so I changed it and nothing. Tried the tube and mould, nothing. Then I began to panic and needed to call Mum – I couldn't hear her and she couldn't text! I rang my Youth Coordinator at Can: Do4Kids and she was able to advocate for me by calling Mum and explaining. She came to get me for an emergency appointment at Australian Hearing and the ENT and acted as my interpreter using AUSLAN. Godsend! The ENT determined that I had fully lost all hearing in my left ear and was placed for cochlear implant. In the meantime, karma came in and I was forced to re-train my right ear to become my dominant hearing ear. It impacted on a lot of aspects of my life, including work, study and social life.

When I first used my cochlear implant, I felt intimidated and stared at. A lot of people had asked me “Is that screwed into your ear?” or “Is that attached to your head?” They didn’t realise it’s just a magnet. So the first couple of times I would carry around a plastic screwdriver, one of Ryan’s plastic builder toys and I would pretend to screw it into my head and it would freak people out! People would just be like “Whaaaat?!” I attached a little magnet to the end of it that would attach to my cochlear magnet. I began to enjoy this little party-trick for the curious.

I have now had my cochlear implant for seven years and it took five of those years to adjust to it. It is a strange sensation and can often sound mechanical in some places. I hated hearing things that I never heard before such as light switches and the fridge light, as it felt more natural not to hear so much!

Family Support

In my family, I wouldn’t say I had the greatest support growing up. My parents raised me as hearing and often forgot that I could not hear in loud situations or felt left out at times. As a way to fit in with her own social identity, my sister would occasionally bounce between contributing to bullying behaviour at school to sticking up for me! I was laughed at if I pronounced a word wrong (I had been educated early to say words ‘as I see them’ by teachers’) or misheard a direction. I wouldn’t say I had NO support, but I was misunderstood and forgotten in terms of my needs.

Experience of School

Throughout school the necessity to advocate for myself kicked in heavily. Nobody was going to do it for me! When you are 13 and you have to educate somebody when they do a ‘retard’ imitation or a mock sign language action at you, as well as calling you names like ‘retard’ or ‘spastic’, it is incredibly difficult to fit in, you roll with it. It was a very hard thing to do and it was never easy to ‘simply walk away’. Nowadays, when I see the action by kids in school grounds or wherever, I speak up. I actually walk up to them and I say “not acceptable” and they get a little bit of a shock because it’s an adult that they don’t know having a go at them. I don’t like doing it; I don’t enjoy it but I think that by shocking kids into knowing that I saw that teaches them that it is not a socially-acceptable thing to do.

When I was in Year 11 I went to Windsor Gardens Vocational College when we moved back to Adelaide. It was the first time in a school environment where I was situated with hearing impaired/deaf children. While I was open to the experience I was placed in a class of deaf/hearing impaired students that were in specialised units. I hated it because I felt my independence was being stamped on. I didn’t like what was being taught as Math and English at a Year 8 level. I felt advanced as I had already experienced a mainstream education culture that pushed me and I felt the environment was too easy. It was my first

exposure to the difference in mainstream and specialised education. I was experiencing both perspectives and felt segregated.

I hated support workers (SSOs) as I felt they did the work for me and I argued this with them. I simply wasn't pushed to learn; I felt watched and as though I couldn't have an opinion in my learning. Instead of learning, I was becoming reliant on help and the easy pathway.

I wanted to do history and legal subjects. I was told "Oh well Bonnie the specialised students don't often get to do that. Why don't you try art? Why don't you try multimedia?" I thought "I don't want to do that; I want to do History; I want to do Australian Studies; I'm interested in Politics; I want to do Legal Studies." But I was enrolled into Art. I argued hard with mum who, with the Coordinator, agreed to enroll me in hard English, Math, History, Australian Studies and the like. What is strange is that I felt 'academic' but looking back in my class reports from Year 7 to Year 11, I was labelled as 'distracting', 'class clown' and 'difficult to teach' I wish I tried harder to demonstrate my ability to learn despite my hearing. University has proven that I am somewhat academic!

During school in Victoria, a support worker was not available because of our rural location and lack of services. A Deaf Educator would occasionally come out as part of the Victorian Education Department but it was rare, at least once a year. When we came back to SA, we were handed services left, right and centre! Youth programs were on tap! But during school with one or none other hearing impaired students in the same school, I didn't want to be associated with the hearing impaired/deaf community for a while as I couldn't identify with them and their perspectives.

So when Can: Do4Kids became involved and wanted me to join their youth program for youth that were hearing impaired or Deaf, I was reluctant but gave it a go as I was beginning to get into the swing of AUSLAN through school. I have met some of the most inspirational people through Deaf SA (now Deaf CanDo).

Identity with the Hard of Hearing Community

I'm not very ingrained with Deaf culture. I have friends that are Deaf or Hearing Impaired. We are now expected to call ourselves Hard of Hearing, in line with the World Federation of the Deaf and their 'recommendation' of what we call ourselves. I am comfortable with the title of Hearing Impaired and will continue to use it. I do not feel broken or mangled in anyway, but instead associate 'impaired' to mean that my hearing IS impaired. It is not affiliated in any way with my actual identity.

If I was making suggestions to other people in my situation, I think that I would say: Try something different every time and learn what you like/don't like from everything you try and WHY. What can be changed? Your disability cannot define YOU as a person with a unique PERSONALITY. Want to try camping – go for it! Want to do rock-climbing?! Yeah!

Want to stand in front of an audience and make fun of yourself? Go for it! The world is waiting for you to join and change it.

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