

Nicks's Story

Nick told his story in a recorded interview. This is the transcript.

My name Nick Schumi, I'm twenty-five years old, I'm a Leo. I'm just a regular guy. I also happen to be born with Cerebral Palsy (CP). The kind of CP I have is called Cerebral Palsy Spastic Diplegia, which basically means the lower half of the body is mostly affected.

Spastic meaning spasticity or tightness of muscles, and *Diplegia* meaning lower half of my body which means I utilise a manual wheelchair, but I can also walk with the aid of two walking sticks which I use all around home. I use the manual chair for the majority of everything else, if I go out to town or I'm at work, I use my chair.

Right now I'm living with my parents in our family home that they have had way before my time, and I'm fairly comfortable there at this point in time. I get along with my parents very well. I'm very lucky for that.

My parents are still together, they've been married over 30 years. Sadly, that is somewhat of a rarity these days and I think that answers a lot of questions about me. I think this is the foundation that has made me be the person that I am today. Even their mentality towards me—the fact that I have a disability—they treated me as any other person.

Growing up with CP and not acquiring an injury of any kind, I believe, had worked well for me—you become used to something after twenty five years of having to live a certain way. I can honestly say that 99% of the time, I'm happy with my situation.

I have a lot of conversations with people about all these sorts of issues, and I believe that the more people that communicate in any way they can, the more everyone can learn from it, and that's what I've learnt in my life.

Obviously there's been circumstances where I've felt like biting somebody's head off about certain things but then I think to myself, "What good is that going to do towards them learning about something that's different than themselves?"

You can't always assume that they would understand everything about what someone with difference has to deal with because they don't understand wholeheartedly what somebody goes through if they have no experience.

But I am saying this because I'm trying to get people to be more open-minded to all forms of difference. I'm not going to be the kind of person who says, "How dare that person be that way", or, "Others owe me something because of my situation" because if I didn't have to deal with what I deal with, I might be seen to be ignorant also.

I have learned to love that things are somewhat 'different' for me. Getting up some stairs is something that is unique for me to do. Yes, it's something that's harder for me to do.

If I could just hop up those stairs like the majority of people can, it wouldn't be one of those special moments of bonding with someone who may be helping me, or the laughter of my struggle, or the sense of achievement if I do it on my own.

Also, having that experience of getting helped, I suppose it takes time to be okay with wanting somebody to help you, and I think that's one of the things that a lot of people struggle with.

A lot of people with disabilities struggle with asking for help because I sense that some people think that it shows a moment of weakness. But I don't necessarily think that it should. From my perspective, I don't like to put that sort of pressure on myself.

If somebody offers to help as me, as long as somebody asks before helping—there is sometimes nothing that's more annoying than somebody helping when you haven't exactly asked for it. It takes time and effort to get the confidence to ask and to know when not to ask.

Would I rather not ask or would my fear of asking somebody to help me with something outweigh that which I would like to achieve/experience? I've always thought—not that it's bad to miss out on something every now and then—but if all I need to do is ask somebody for a helping hand for me to experience something—what's the big deal?

I guess I'm very much the kind of person to just take every opportunity for what it is, and it's just the way that I want to be. If all I have to do is just simply ask someone to give me a hand with something—so be it. I don't see that as a failure of my abilities, I see that as making the most of life.

Until recently, I worked at Julia Farr Association (JFA). As front-of-house administration, I also dealt a lot with the events that happened there, and I also run and chair a youth committee for young people with disability to come together and speak about what issues are around for young people with disability.

I am slowly realising that this is my path/purpose in life. The way I got involved with Julia Farr was actually through initiating the committee. I initially did a lot of voluntary work for an organisation called [SHine SA](#) which does amazing work around sexuality and young people, and I was involved with the Youth Advisory Team there. That's where a lot of my learning for youth issues grew.

I actually heard about the Julia Farr Association through a friend when JFA wanted to hold a youth forum for young people with disability. So of course I jumped at the chance to be involved.

The person that told me about it and myself were the only two people to show any sort of interest in the forum. That blew my mind at that point. I thought to myself, "Well, I know plenty of people who would benefit from these sorts of opportunities to have a voice".

So, I basically said to JFA staff at the time, "Look, this is really important to me, and this is why this needs to happen, and I'd like to come along and reorganise it with you". From there, JFA was open to having these conversations which was great, and after having a couple of meetings I was asked if I would like to apply to be a member of the board.

There was no youth representation on the board at the time. So, I did an application and I was successful. It was quite the learning curve too; everyone else was roughly

twenty years my superior but I knew what my responsibilities were in knowing that not everybody gets that kind of opportunity.

When that opportunity came my way, we reorganised and held the youth forum. I remember about ten young people coming along—which is a lot better than two. And we were able to have some amazing conversations and identify some great issues.

I loved the conversations that were coming out from all those people, and that obviously showed the organisation the importance of it, and it has now grown to an initiative where the group meet every month. The group is recognised within the organisation which I am very proud of.

Once we had identified certain issues from those first conversations we wanted to tackle them head on. One of the ways we wanted to do that was formulate a peer-to-peer mentoring program, which was implemented and created by us as a committee and has been up and running for quite some time now.

I had always planned on getting full-time employment and I had always discussed this with people at the Julia Farr Association. This led to my admin role at JFA. My contract has recently ended and I needed to look at what my next options were. I have now decided to go back and study Youth Work which is starting shortly. I am still very much involved with the youth committee today.

I am also very passionate about music. I studied music all the way through school up until Year Eleven. I would have probably been in Year Nine when I heard about a lot of local bands and shows that were happening around Adelaide.

A friend said, “You should come and check it all out” and obviously, at that age, I knew that there were certain things that I needed to put in place for that to happen. I found a gig that I wanted to go to and I figured out where it was, when it was, all that sort of thing, and found out that the bands played upstairs where there were no lifts.

So I thought I’d do the right thing and ring the place up, and said, “This is my situation; I’m in a chair, I completely understand that there’s no lift or any sort of access, but how can we make this happen?” I was then told, that because of my situation, if something did happen, I would be a fire hazard to everybody else, so by law, they could not let me in the door.

So as a relatively young person at that point in time, obviously that’s a hard thing to hear. I came away and told my parents what had happened and they said, “Well, I guess you won’t be going then”. My response was, “Oh, you don’t know me very well do you!” and I rocked up anyway.

I have been going to shows there and all over ever since. It is not a rare thing to see me get carried up a few flights of stairs, chair and all. I am thankful for my friends that are willing to do that for me. I have also been known to organise a few shows myself.

Only years later do I realise the kind of worry my parents were under. I asked my mum to drive me into town for that first night and she didn’t know whether I was going to pick up the phone when she was two minutes down the road, saying “Mum, I really can’t make this work”.

My parents allowed me to experience and work things out on my own and I wouldn't have that any other way. Their mentality never seemed to be, "Can Nick do this?" Rather it was, "How can Nick do this?"

I can only imagine what it would have been like for my parents to only find out about my Cerebral Palsy when I was about nine months old when I didn't reach the milestone of being able to sit up for myself. And for them to be able to treat me as 'normal' as possible is a credit to them.

I suppose I also need to learn to give myself some credit for taking those skills and achieving what I have. I have come to know that I have a great skill to speak my mind for myself and others. That is why I have chosen the path of Youth Work and I am so proud to be able to work with the people that I have so far. Currently I am a mentor for a young 13-year-old boy living with disability.

I have huge aspirations to travel more, be a home owner, and eventually start a family. And not to mention, teach people about disability. I am on my way to a lot of those things.

Am I a leader or just a regular guy? You can be the judge of that. If this story has been able to give you something positive purely out of the way I have chosen to lead my life, then I have achieved something that I can be proud of.

Thank you for reading!

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