

Belonging Matters' Podcast

Transcript

Episode 5: What Does Inclusion Mean to Me?

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Welcome to Belonging Matters podcast series. Now available on Apple podcasts, Google podcasts, Spotify, and www.belongingmatters.org. You can email Belonging Matters at info@belongingmatters.org. Episode Five, "What Does Inclusion Mean to Me?" Dean Richards lives in Melbourne and is an active contributor to his workplace and local footy club. He enjoys being a part of his local community and getting around Melbourne. Dean's introduction to disability services came following an accident in 1987, which resulted in quadriplegia. Originally, Dean was supported by his parents who understood flexibility and providing supports when they suited him. However, his family became increasingly worried about the day when they will no longer be around to support him. Inevitably, Dean learnt that services were not always flexible enough to meet his needs, as more often than not, they

met the needs of the workers or the service provider. This led to Dean working with a small group of people to develop a flexible nighttime service called 'Nightlife' in 2007. 'Nightlife' enables people with disabilities to remain living in their own home and direct their own supports in a way that meets their needs. In this podcast, Dean discusses some of the assumptions he has faced, the strength of community connection and naturally occurring relationships and how paid supports can get in the way. Dean's podcast is narrated by Brett Carroll.

It's interesting that since acquiring quadriplegia, I've had to challenge many assumptions held by others. For example, I found that opportunities often offered, or encouraged, or limited to traditional options created specifically for people living with a disability. In addition, there is an assumption that paid support is always required to accompany me, or that I want to spend my time socialising in 'special' groups for people with disability regardless of my interest or ability. In many ways, I was fortunate to have acquired my disability after school, I had already established a career path. I recently heard of a mainstream school that had a career advisor for their students. Yet students with a disability were sent to a counsellor. I find this deplorable as these young people are being labelled, treated differently to other students and not given the same expectations or opportunities to pursue a career. After school, students are often referred to disability programmes without any consultation about their desires, abilities, or what support they might require to pursue typical pathways that are available to other students such as employment and university. Often, we automatically think that people with a disability

require paid support to become included in the community. Although paid supports are sometimes necessary, they can become a barrier to spontaneity, and can actually disconnect people with a disability from relationships with their colleagues and friends. I found it vital to look for ways I can continue my roles and attend functions and activities in the community independently or with my family or friends. As a result, I cannot think of the last time I had paid supports to attend a social event. When I started work in Dandenong my work colleagues spoke about the Dandenong market and the array of things available. After a while, I went over with my workmates and enjoyed the experience. I now go to the market every Tuesday and buy fresh fish and fruit. Originally, my work colleague assisted with reaching up to pick my fruit soon, soon the time came when she was not available, so I ventured out on my own. Sure enough, there were people who would assist when there was a high counter. When it came time to purchasing fruit, The shopkeepers or their assistants would help. I soon realised I was getting the best produce as they picked out the best quality. I now happily go on my own and have become well known by some of the shopkeepers. When I pay for the fruit, the people at the cash register happily pack the fruit in the bag on the back of my wheelchair. This, for me, is social inclusion. It may sound ordinary, but sometimes without a support person around it leaves spaces for others to come forward and assist. I have become known as a regular customer that just requires a bit of a hand. Initially after my accident, I was fortunate that my employer offered me a full time paid position. At this stage I had no attendant care so supports were only available through family, friends or fellow employees. Luckily my father was able

to work for flexible hours and was able to assist my mother to help me get ready and take me to work. At first, he would also pick me up after work. If it was a nice day, I could take myself home in the wheelchair. But that took 60 minutes. Through connections at my father's work, a van that was big enough for me to sit in my wheelchair became available. I had a floor and a manual ramp fitted, and it made a world of difference. It now many others could drive me. Soon I had a roster of friends who volunteered their time, they would drive or walk to my place, pick up my van and then pick me up from work. This gave me more independence, gave my father a break and created yet another opening for connection and relationship. Any support I required at work was provided by my fellow employees. I found people to be supportive, flexible, and accommodating. Interestingly, when I started my employment with the Department of Human Services, I decided to hire a paid support worker to assist me at lunchtime. What I found was that I was no longer responsive to on the spot offers from work colleagues, I'd be asked to go somewhere for lunch. And I'd have to say no as it was during the time the support worker was due. I also had problems with making arrangements if the support worker was not on time or late, people would be waiting for me and I'd be stuck waiting. Although the service provider did their best to address the problem. I felt like I was always on edge. Soon, financially, it was not sustainable. I spoke to fellow employees and they happily offered assistance. It now means I can be more impromptu, change plans if needed and not be excluded from occasions with my work colleagues. As a young person, I played football at the Bentley Football Club. Although this was no longer possible after my

accident. I wanted to start looking at social opportunities outside of home and work. People that I played football with now held various committee positions at the club. I approached them and asked if there was anything I could do. I was invited to attend meetings once a month to assist the committee. I was voted on to the committee at AGM. I also attended games on Saturdays and took some basic statistics for the coaches. Soon I was starting to get to know other people and players. At one stage I'd go to the club after work on a Thursday, and all day Saturday. Players and friends started coming to my place and driving me to away games. Soon, my van was the party bus. Anyone I approached for assistance was always willing to help. I actually overheard two of the club members' mothers comment, "You don't need to help Dean unless he asks." I was included, developed a diverse array of relationships, and most importantly, felt I belonged. I've continued my commitment with the Bentley Football Club, unbroken since 1993. I've been the secretary which entailed dealing with councils, the Football League and inquiries from any organisation's. I've won awards for Best Club Person, the President's Award and have a life membership. In 2001, I was made the eighth Hall of Fame member, a fete that only 16 people in the club's 48 years have achieved. I felt like I had many roles and was valued for my contribution. In all this time at the club, not a support worker in sight. As I'm getting older, I often ask myself what's next. Although my father doesn't provide me with personal care anymore, there are other things he assists with. If he was no longer living with me, I'd need someone to assist me. So I need to look at what I would do if I moved out on my own. The idea of congregate care is not appealing at all. Living in a house with

people that are grouped together because they have a disability is not a situation I want to consider. I've known people with a disability who have become disconnected and very vulnerable in congregate care. For example, owners who closed down private facilities, people being moved from their communities and places they're familiar with, and being moved to the other side of town, thus causing a disconnection of relationships and the risk of being isolated from family and friends. The lack of control also makes people vulnerable to being moved again and again, thus making social inclusion almost impossible. Conversely, living in my own home in the community, where I'm well known not only encourages connectedness, but support from others. For example, when my father goes away on trips throughout the year, I remain living at home through the support of my wonderful neighbours, I can call and they assist. Only yesterday I found my mobile phone was in a position I could not reach. I called my neighbour on the landline and she came over. We then spent the next 20 minutes catching up as people do. I believe it's important for people with a disability to live in their own home and remain in their local community. As my story illustrates that by adding support, some of which may require extra funding and involve a whole range of informal support, it provides a real sense of home, and the cost is far less than congregate care. People with disabilities can also maintain a more typical living standard and stay in their communities that they like and are well known. Self directing my funding also gives me control. This began many years ago when the Department of Human Services, or DHS in Victoria, first offered direct payments. This meant I had control over how my funding was spent, and

enabled me to choose my support workers and determine the time I actually required support. It provided greater accountability and transparency, and I could choose items and services other than one to one support. This then enabled me to feel empowered, stay living at home, work, volunteer and enjoy family, friends and my community. At one stage, I joined the Direct Payments initiative. This meant I took responsibility for the recruitment of my support workers, including advertising, interviewing, staff training, rostering, timesheets and salary processes. This was a technical process. However, once again, through my volunteer work in the community, a person that I knew assisted me to set up MYOB, which enabled me to administer employment and budgeting processes online. All of this invaluable assistance and ongoing advice was done at no cost. This is the power of community, connectedness and inclusion. So in conclusion, there are many dangers in labelling people with a disability and expecting that they need something different or special. In doing so we keep people apart. It's through my friends and connections that the spontaneity of life is enriched and enhanced. This is what social inclusion means to me.

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