

Belonging Matters' Podcast

Transcript

Episode 7: What does it mean to be included?

Deb Rouget

This podcast is an edited version taken from:

Rouget, D. (2013). What does it mean to be included? In [*Thinking About what it means to be included*](#). Issue 17, pp 32-37. Belonging Matters: Melbourne

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 Seven, What does it mean to be included? Deb Rouget has been involved with people with a disability and their families for over 30 years. In 2003, Deb was integral in the development of Belonging Matters, which sprung to life as a catalyst to prevent the exclusion of people with a disability from their communities, and enable individuals to enjoy a fulfilling life that is well embedded in community relationship and citizenship. Since that time, she has been the CEO of Belonging Matters. Deb has also been keen to foster advances that leave people who have a disability and their families with greater control over their

lives. The following podcast outlined some changes that can bring life to the values of equality and inclusion.

Even given Australia's ratification of the Convention on the Rights of Persons with a disability in 2008, legislation such as Australia's Disability Discrimination Act, and considerable goodwill and agreement, we still really struggle with how we authentically include people with a disability in the fabric of our lives and communities. Since 2003, our work at Belonging Matters has been aimed specifically at this question. What we have found is that people are not always clear on what it means to be included, which is really perplexing as so many people who support people with disability, are themselves included in the life of the community. This paper offers some of our reflections about what it means to be included, and why we may be not making as much progress as what is hoped for. Social Inclusion means recognising what it actually feels like to be excluded. What does it mean to be included? This is an important question for all human beings. Often in regard to people who have a disability we speak in the terms of social inclusion. In the literature, social inclusion is not well defined. It's often defined in regard to social exclusion, in which people are pushed to the margins of society and denied opportunities or prevented from full participation in mainstream society in which they live. At a recent conference, delegates were interviewed and asked, What does social inclusion mean to you? One parent said that until she had a child with a disability, she had never thought about social inclusion, and interesting response. As for most of us, we have never had to concern ourselves with being socially included. It's just a given except of

course, if you have a disability. Perhaps it's only when we feel excluded that social inclusion becomes important. If we encourage each other to reflect on our own lives, where and when we are included, or more importantly, excluded, and how that would feel, we open our hearts to the importance, deprivation and vulnerabilities that arise. We recognise the importance of inclusion and become motivated to take steps to practice inclusion rather than practice behaviours that exclude and wound our fellow human beings. Social Inclusion means having a range of opportunities that are experienced by other citizens. According to Wolff Wolfensberger, genuine social inclusion and equality occurs for those who saw society views as different when conditions are at least as good as that of the average citizen. This means having the same opportunities to employment, education, home life, relationship rights, citizenship, recreation, and health care, as do other citizens. It's often helpful to think that if this was me, or my son or daughter without a disability, what typical and valued opportunities would be available at this particular point in life. Then doing all we can to make these opportunities available to an individual with a disability with the support that might be required. This also means connecting people to ordinary places and in typical ways. For example, if a person is interested in singing, then local singing groups might be researched, where other people who love to sing come together, for example, a local choir. Then we connect the person in a typical way. For example, we don't look for special singing groups for people with a disability, announce the person has a disability, or provide support in a manner that assumes dependence. When we provide support, we do so like

a chameleon, we blend in rather than exacerbate difference. Often, it's ideal for that support to come from a person who also loves singing. However, this does not mean we abandon people. It's a delicate balance of providing the right supports to nurture belonging and connections without getting in the way. Social Inclusion means believing people with disabilities have valuable contributions to offer. Social Inclusion means that we wholeheartedly believe people with disabilities, like all people have attributes, gifts and talents to offer to our communities, many of which go unnoticed. For example, Dee has an ability to make me slow down, notice the things around me and has a wonderful gift of introducing me to people in her local community. She has this gift because she's genuinely interested in people and has a wonderful memory in which she is able to maintain details about people and their lives. She makes people feel important, welcomed and cherished. I once met a lady some years ago, who had this amazing knowledge of clocks, many saw it as an obsession, but it was actually a gift and a specific knowledge that she had to offer. Cameron has an amazing gift for knowing everything there is to know about AFL football. Once on a plane trip with him. He introduced me to Rex Hunt and Robert Walls. They shared passions, interests or gifts. I connect this and passageways into community life. Social Inclusion means abandoning segregation and congregation. Meg Sweeney often says that her daughter has never been offered ordinary experiences, and her family has had to remain vigilant to ensure Jocelyn was not excluded. Meg says as amazing as this seems, in her 22 years, Jocelyn has only ever been offered segregated, disability specific options. Unfortunately, this is the case for many individuals with a

disability, not necessarily because of their disability, or the community, but the assumptions that we make about what should be offered to people with a disability. We increasingly believe that every need of a person with a disability can or should be met by a formal service, or that people with a disability need something special or different. For example, special education, special programmes, special workplaces, special recreation, special group homes, special respite, special holidays, special outings, special music, special therapy, everything special. I heard Stella Young once say that she learnt early in life, that 'Special' often equated to nothing special at all.

Our tentative forays into community have also seen the creation of special groups, specifically designed for people with a disability in community places. For example, local neighbourhood houses often run groups specifically for people with a disability to learn to cook, to play music, or a whole host of things. Or some services create special work enclaves that support a number of people with a disability in a particular store. This is not authentic inclusion. It's a reinforcement that people with a disability need something special and separate. It's not the real deal. How are citizens ever going to meet and value each other, if we continue to keep them apart. People can get adequate support from each other if we give them the chance and support their efforts. Another reason we tend to congregate people based on their disability is that we assume that people who share the same diagnosis like the same things. This would be like saying that all people who wear glasses like the same thing, or it's more convenient or cost

effective to deliver a program to all of the glass wearing people together. If you wear glasses, you know how flawed this assumption is. All human beings are different with different likes, dislikes, passions and abilities. Even the way we approach a certain hobby or job will be completely different. Thus, authentic social connectedness is more likely to occur when people are in relationship with people, one person at a time. Social Inclusion means not seeing services as being able to meet all needs. David Swartz in 1997 discussed the counterproductive impact that the growth of formal services has on the hospitality and likelihood of ordinary citizens coming forward. Hospitality, he argues has now become a systematic industry, which devours the informal. Swartz describes the story of a woman about to jump off a bridge. The formal response was to call emergency services. However, an ordinary citizen, a bus driver, saved her life by simply stopping the bus and grabbing the woman's arm. Although formal services have a place, especially in emergencies, in this instance, mobilising the formal response would not have saved a woman's life given the time it would have taken. But the informal did. If we concentrate on the growth of formal systems, and the insatiable need to get bigger, rather than providing the support for people to experience the ordinary, we risk replacing everything that arises informally or naturally in our community with systems and services. Not that community is a panacea, but we are at risk of denying people the chance to meet and get to know each other, feel comfortable with diversity, learn new things, and share their gifts. Ultimately, our pursuit of the special reinforces the rejection and relegation of people with a disability to the margins. Social Inclusion means inviting and

welcoming ordinary citizens to come forward. Through many of the examples we have encountered, and those distraught described in countless stories, for example, in David Swartz's book, citizens will come forward if asked to do so. Often they're unsure about what role they could play, how to communicate with a person or how to support them. But this is often because they have never been given the chance to get to know a person because we keep people apart.

Dane Richards talks about his very ordinary experience with his mates at the footy club, who drove him to parties, colleagues who go shopping with him at lunchtime, and neighbours who pop over in an instant to help him out. Many families have found young people to flat with their sons and daughters go to music gigs, go away for weekends, and help out with small tasks. All because they asked, created space, and welcomed a range of people into their lives, other than services and paid support. This is social inclusion. It's not extraordinary. It's very ordinary. Of course, when you welcome people, they also have connections, associations and information that we could never have. Social Inclusion means it's not for the other. It's vital that we don't think that social inclusion is just for the other. It's actually a concern for all of us. In this regard, we also need to exemplify what it means to include and create welcome if we're going to expect it of others. Once I was asked to present a training to staff at a Disability Support Agency, loaded with my bags on my arrival, I found my first encounter was with a locked electronic security system. I could not even get in the front door. Finally, when the receptionist tore herself from her work,

she looked up and pressed the button. I then enjoyed a further uncomfortable wait while she finished her work. Then feeling like I was interrupting, I politely asked her for the person I was meant to see. She heaved a sigh of annoyance and darted off to find the person, who could not be found. Another person ushered me into a room, hardly mattering a word, and then abandoned me to set up for the day. It was not her job. Even though they had invited me, I felt lost, bewildered, and unwelcome. Hospitality and welcome begins with ourselves. If we're going to expect our communities to include people with disabilities, then not only do we need to include people with a disability in our lives, but we need to be part of our communities as well. For example, what do we ourselves give to community? Who do we know and connect with? How do we support our community? Do we know our neighbours? And what do we offer them? Do we know what's happening in our local community? Where do people meet? What associations or groups exist? Those who immerse themselves in community are great connectors, they know what's going on, who to talk to, and what's happening under the radar. David Swartz, in his book in 1992, quotes a study in Chicago that aimed to identify invisible association groups in a 24 block area. The study found that 575 hidden associational groupings existed. Thus, the need to immerse oneself in the local community and know people well is a vital strategy.

Social Inclusion means more than presence. There is often confusion between presence and access, and genuine belonging and inclusion. People can have access, for example to a shop, but it doesn't mean they're included, even if they're a

valued customer. To be included, one would need to have a deeper role or connection. For example, they would need to become an employee or perhaps become friends outside of the parameters of purchase. For example, going to watch a movie together. It is when people are part of community and take up valued roles within our society that they become accepted for who they are and their contributions. It is through becoming an employee or club member that people become more than a disability, and many of the negative assumptions about people fade away. It is also possible to expand people's valued roles to deepen their sense of belonging. For example, a person may be a Club member, but exploration of further valued roles may lead them to becoming the welcome or at the club. Or perhaps the social organiser, or equipment organiser. David Hagner in his book, 'Working Together, Workplace Culture, Supported Employment and People with Disabilities' writes extensively about assisting people to become involved in the culture of an organisation or workplace. For example, although most of the work practice at McDonald's stores will be the same, the workplace culture will differ from store to store. This may not be obvious to the outsider, for example, where do staff mate after shift, how does the workplace celebrate birthdays and the various social activities that the staff team may do together? For example, is there a bowling or football tipping competition? Examining such cultures in this way nurtures belonging and genuine inclusion. So in conclusion, like anything we do in our lives, we do much better at things if we believe in them and are passionate and enthusiastic about them. The same goes for nurturing, belonging and connection. We have also found that being unambiguous in our efforts

prevents us from being distracted from our vision and goal. For example, we cannot provide segregated programs while trying to include people. This does not mean we don't recognise the vulnerabilities of communities and put safeguards in place, like we all do. But we need to hold on to the rationality and not use the weaknesses of community as an excuse to exclude. After over 30 years of service to people with disability, I have witnessed far more wounding and damage to people when they are kept apart from community. So let's make a difference. Start with one person, and one moment of inclusion, and don't give up. It's the way of life

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