

It is so close that you can touch it and smell it so why aren't people with disability able to pierce the membrane into community?

Ann Greer is the Manager of Community Connection in Townsville, an organisation she helped to establish in the early 1990s. Community Connection was established to provide individual customised support for people with disability to build a good life based on full and valued participation in community.

Ann has particular skills in the areas of behavioural strategies, communication and lifestyle planning and she is also the mother of 3 adults, two of whom live with disability. She has a long history of working to promote community inclusion as both a family member and worker, including with people at particular risk of community exclusion.

When we are working on achieving the inclusion of people with disabilities into the community, it appears that we have a very narrow idea of what needs to happen to make this a possibility. In the past 25 years, we have moved from an isolating, institutionalising model of support into one that maximises presence in community but we have not been as successful in achieving full participation. There are many reasons why this is so, but a lack of understanding by all key stakeholders on how community works is a major reason.

True inclusion is to belong and to belong is more than presence. It involves relationships, contribution, purpose and identity in a person's community. To maximise this and to form a fertile bed for friendships to grow between people with disabilities and other community members we will need to understand the world we live in. We need to consider the quality of the support provided and the barriers that are created by people with disabilities and their families. We need to acknowledge and challenge the overt and covert barriers created by a community that de-values people with disabilities. We also need to understand how the systemic segregation that starts when children are young further ostracises people with disability, leaving the community socially inept when confronted by any difference.

Services have largely been created to support the deficits of people with disabilities – to do for the person what he or she can't do for themselves. This deficit based model does not expect or create the necessary skills in its workforce to truly support people to a life in community. Many services are risk averse and rarely 'colour outside the lines'. This leaves the people they support isolated in a world of paid companionship with few opportunities to meet people outside of this world. It also denies the community the opportunity to see people with disabilities as gifted, talented and attractive human beings, rather than someone who is inherently needy and deficient.

Families, people with disabilities and service providers need to be aware how seriously this style of service negatively affects the quality of life and opportunities of the individual supported.

Some families will have to re-think their approach to rearing a child with a disability. By parenting in such a way that the child never grows into an adult they miss the opportunity to take risks or make mistakes in the way that brothers and sisters do. Ironically this protection for a perceived vulnerability, has left many people with disabilities profoundly vulnerable. A life lived on the periphery of community, not going to church with the rest of the family, not going to school with your brothers and sisters, not getting the chance to experiment sexually or spiritually, not having work or other valued roles is not a template for a full, happy, well connected life.

This is not a judgement on these families, many of whom have shown incredible depths of commitment to their children with disabilities. This is an observation of the profoundly negative fall-out that results when people are

seen not as fully human, but as different and 'other'. In other words, when 'the good life' in community for a person with disabilities does not mean the same thing as for other community members.

After living life on the sidelines, held to ransom by practices that keep people congregated, some people with disabilities will also need to rethink their expectations about their lives and be prepared to show courage by stepping out into community. Many people with disabilities talk about the isolation they feel but will opt for what is known rather than what is not known. The disability community for all its imperfections is a known factor. Opting for a life where you have to 'put yourself out there' is decidedly unknown and therefore frightening and off-putting for some individuals and their families. Many people will need to learn about what is expected of community members. A life of segregation does not prepare people for this but it does not mean that people with disabilities cannot learn these skills - the question is more about who will teach, model and mentor?

Local Quality Assurance auditors HDAA are from New Zealand and they use a wonderful Maori saying as the banner for their business. It states:-

When we ask 'what is important?' Proclaim it to the land; proclaim it to the sea..... it is people, it is people, it is people.

Activities performed in a bubble, where any contact with community members is superficial, rarely – if ever – leads to a deeper relationship. The transition from this 'client' mentality to a more holistic support to the individual – one that supports the whole person – will be complex for services that maintain a pool of workers and who do not invest in the necessary time and space required for meaningful relationships to develop between the worker and individual who requires assistance.

Human Services can also do a lot to foster the inclusion of people with disability in community. This can be done by:

- **Building a true appreciation and understanding of what a genuinely inclusive educational experience can do for the student with a disability AND the school community.** This is a major step for ensuring an inclusive society in the future and if we don't get this right, we will be doomed to puzzling about how to get people included for generations to come.
- **Starting from the point of the person's strengths and passions.** This will make it easier to understand where we should put our attention when we are trying to find a place or space for the person supported.
- **Building a deep belief in the rightness of people with disability living and playing in our shared spaces.** This will assist us to continue working on this, even when the going gets tough.
- **Understanding that community is not a perfect place.** We must pay attention to what makes the person with a disability vulnerable and to build supports around him or her to minimise that vulnerability.
- **Employing competent and attractive people with good judgement and social skills and who understand their role.** This will go a long way to building a network around the person.
- **Understanding that a positive image for the person with disability is paramount.** As well as helping an individual to build a positive self-image, it is vital others see them in a positive way. Key to this is being mindful about how that individual is dressed, what he or she is doing, how supporters are relating to him or her and to the general community. When these concepts are attended to, it becomes much easier to find a place for the person with a disability in the community. Social Role Valorization (SRV) offers a framework that shows how this is done.

- **It is crucial that we let go of the heavy investment in congregation for people with disabilities.** These settings are a barrier to inclusion and are counterproductive to the concept of positive image, growth and development and valued social roles. Families are often drawn to them because they have concerns about community and it is fair to say that we have not been as successful as we need to be in achieving a full and connected life for many people with disabilities. It is concerning to hear many families of younger children talk about the lack of welcome and the level of judgement that they feel when in community and that many families of young children are opting for the 'safety' of congregation. This is a false sense of safety which uses resources that would be better invested in community to help find a space for people with disabilities.
- **Thinking and working creatively and opportunistically is a major aspect of this new world.** It will require all stakeholders to think outside the box when it comes to what the individual will be doing with his or her time from day to day. Neil Barringham¹ talks about finding the 'sweet spot'. The sweet spot is that moment when you identify that a real connection has been made between two people. In the case of people with disability, it will often rely on what happens next – what those supporting the individual do - if the embryonic opportunity is to grow into a relationship.

It is also true that community has been inept in its approach to people with disability. There has been a profound change in the way that people with disabilities are seen by the general community. Most people are very happy to see people with disability present but they are not proactive in being welcoming towards them. The major reason for this is that society is generally very puzzled about how to welcome people in. For some it is due to the belief that people with disabilities are happier 'with their own' while others are nervous and unsure how to communicate or relate to people perceived to be 'different'. This is a major outcome of a segregated school system that gives very clear messages about the proper place for devalued people. The education provided by schooling needs to be seen as a much wider concept than just an academic one for society. A truly inclusive educational environment can be a hotbed for personal growth and a solid foundation for the development of healthy communities.

There are no recipes to ensure that people with disabilities can take their rightful place in community – no method that says 'first do this, then do that'. Friendships for people with disabilities cannot be created by others – not parents, not siblings and not support workers and their employers. However, because friendship sparks from chemistry, there is still much we can do to create opportunities for people to truly get to know each other and thus it is our role to create a fertile bed for relationships to grow.

When I think of the people I know for whom inclusion has been a living reality it is clear that the criteria for success is not obvious competence. These opportunities happened because an individual saw an opportunity and did what is called 'not waiting - creating'². They looked at the person's strengths, passions and interests and used those as the platform to ask on behalf of the person with disability. This does not rely on funding. The person who asked, believed in the attractiveness and competence of the person they were asking on behalf of and they took the action necessary to move an opportunity into reality. This is the kind of platform of support that is necessary to move people with disability from a life of isolation and 'activities' to a life that ensures that he or she is a valued, loved and recognised member of our community.

¹ Neil Barringham is the manager of 'A Place to Belong' in Brisbane and is the author of "Finding People to Be There: Rebuilding a sense of belonging".

² Margaret Rodgers. "Not waiting – Creating". CRUCIAL Times 29, March 2004.