

# Social Inclusion

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A Queenslanders with Disability Network paper



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## **Introduction**

Social inclusion means different things for different people and changes according to stages of life, cultural heritage, living environment and social status. For many people with disability their social status – how they are perceived by the community and society in which they live – is a determining factor in the degree to which they are socially included. The supports people with disability receive, and the mode or modes in which they are delivered, impacts upon the type, form and level of social inclusion they experience.

This paper takes a historic perspective and looks briefly at the origins of de-institutionalisation which included a major push for social inclusion. Prior to de-institutionalisation people with disability were hidden from society, being virtual captives of the bricks and mortar of a ‘containment model’ for keeping people with disability housed, fed and away from the rest of society.

## **Body**

To discuss social inclusion there needs to be some common understanding of what it is. One way of arriving at a working definition of social inclusion is to look at what it is not then to suggest some possibilities of what it might be.

This table has examples of social exclusion and suggests some ways to reverse this and work towards social inclusion.

<b>Social Exclusion</b>	<b>What Social Inclusion Might Look Like</b>
Living in an institution or arrangement where every aspect of life is decided by others. Getting up when staff choose. Eating predetermined meals at predetermined times. Sitting around waiting for the next meal or toileting. Having all of the activities of daily living set in a schedule that is predetermined by others.	Living in a home of your own and doing the things you enjoy. Having meaningful interactions with other people.  Being respected as an individual and having your rights respected.
Not being known in the community.	Having a network of neighbours or interested people who know you and recognise you in your community.
Not having any close relations or friends.	Having family or friends, with whom you have long-term and enduring relationships.
Having no sense of belonging and participating in society.	Being an active, recognised member of the community.
Having a constant parade of strangers determining life direction, including: where you live, with whom you live and when, and if, you can go out.	Life decisions being made by you and those close to you (with whom you have unpaid, long-term relationships).  Life decisions reflecting your best interests and meeting your personal needs and desires.
Having no personal or private space in which to feel safe or store belongings.	Being safe from abuse and having your rights to privacy protected no matter where or with whom you live.
Experiencing ill health and not having support to access health services.  Even when accessing health services, being treated less than effectively because you have a disability.	Being able to access health services.  Having access to all that modern medicine offers.  Having family and friends who advocate on your behalf, if you can not.

A further understanding of ‘inclusion’ can be gained from looking at research into groups who do not experience it and are isolated. Twenge (2005) conducted research into decision making by people experiencing different levels of social exclusion. She found that:

Health, happiness, and well-being are strongly tied to whether one is accepted or rejected, such that people deprived of close social ties suffer more negative physical and psychological consequences than those with strong social networks. Ostracized individuals exhibit a broad range of distress and pathology.  
(Jean M. Twenge, 2005)

This research supports the contention that social inclusion is a necessary prerequisite for a healthy, happy life and suggests that without it individuals are more susceptible to experiencing personal stress and ill health. Taking this research and applying it to people with disability, who experience social exclusion everyday of their lives, it can be argued that there is a strong social, economic and moral imperative to work towards getting social inclusion right and ensuring that all people experience it.

When social inclusion is meaningful and real, it occurs on a continuum which is related to life stage and social status. As a child it means going to each others' houses after school, or meeting up on weekends and doing things together. Smaller family sizes have led to changes in how people spend their time. This, in turn, means that interactions with friends, rather than relatives, are often integral in gaining an understanding of what it means to be part of an inclusive community. It is in childhood that we learn to make friends and relate to those around us.

Unfortunately for some children with disability, their experience of childhood is one of isolation. Their time is consumed by medical and therapy appointments; their schooling takes place within the segregated setting of Special Schools. Here, they **only** have an opportunity to mix with other children with disability. Later; their parents are forced to portray them as a 'burden' at risk of being abandoned just to gain minimal support. In these circumstances, children with disability find it difficult to develop a sense of self. This kind of 'busy-ness' with services and "interventions" acts a barrier to any community seeking to include children with disability.

This description of life for children and, later, adults with disability clearly illustrates that there is work to be done around changing current practice and making it more conducive to building, maintaining and sustaining social inclusion.

For many people with disability, this experience of a lack of social inclusion, that starts in childhood, is one that continues for their entire lives. The congregation that starts with special schools continues into the post-school experiences and is evidenced through limited post-school options, restricted access to higher education, and placement in 'business services' or adult day centres. It is often argued the intent is honourable yet the delivery smacks of social exclusion where marginalised people are grouped together for social and economic expediency.

This practice of grouping people with disability (or any people who differed from socially-accepted norms) together and excluding them from mainstream society can be traced back to ancient Greek and Roman times, through to the establishment of the institution known as "Bedlam", which operated from 1247 to 1948, when it was taken over by the National Health Service of England. Bedlam maintained the name and continued treating people with mental health disability until 1997 (Museum of London: 1998; BBC/H2G2: 2004).

Shamefully, the practice of isolating and containing people with disability continues today. Here, in Queensland, there are people with disability living in institutions. QDN remembers them and is ever-aware of how trapped they are and of the wasting of their lives.

The dismantlement of some institutions, and associated socially exclusionary practices, started in the 1970s and became known as de-institutionalisation. It started when people who experience mental health disability were moved out of locked wards into the community. The planning for people's re-integration into society was not well planned and many ended up living in hostels and boarding houses. In these settings, they were socially isolated and did not have adequate support to manage their medications or activities of daily living.

Also in the late 1970s, children, who had been grouped in residential care settings, were gradually placed back with their families and, where possible, supported to access mainstream schooling.

As a result of this move away from residential care for children with disability, it became common for families to take on the role of primary care-givers and this led to savings by governments in power at the time. Whilst this was a great thing at the time, and QDN believes every child should live in a supportive and supported family unit, there seem to have been very little budgetary or economic planning done to acknowledge that one day the children of the 1980s, 1990s would become the unfunded adults with disability, living with aging parents, in the 21<sup>st</sup> century.

For people with disability, many of whom had lived most of their lives in prison-like institutions, hidden from society, the 1980s and 1990s were the halcyon days of de-institutionalisation. People with complex needs were one-by-one moved out of large institutions and fully supported to live in the community. This process involved careful planning and the people with disability their families, friends and advocates were consulted throughout every step of the way.

A defining characteristic of the responses in 1980s and early 1990s was the fact that they were developed around responding to the needs of people with disability and developing individualised responses to meet their needs.

For the first time, people with complex needs were living in communities of their choosing and experiencing social inclusion because they were supported in ways that meant they were respected and valued citizens. Unfortunately, this movement got side-tracked and became perverted by models of support that began to resemble institutional practices.

In any exploration of social inclusion it is relevant to ask:

- What makes communities inclusive? and
- Are there any prerequisites that need to be present for social inclusion to occur?

These questions can be examined by looking at the social inclusion of people with disability in a number of communities and the varying levels of social inclusion they experience. In doing this, it is found that some communities in which people with disability live and wish to be included are more responsive than others.

When expecting communities to be responsive, supportive and accepting, it is logical to associate these qualities with communities that have both material and social resources as well as social time and energy. In a study examining inclusive communities and balanced social mix, Kathy Arthurson, found that the:

presence of middle-income employed residents provides conventional role models that act to alleviate the social constraints posed by neighbourhoods where large numbers of residents are disadvantaged.  
(Arthurson, 2002: 246)

In this case, it can be argued that, in the communities Arthurson sees as supportive, the “middle-income employed residents” have financial and economic resources, in terms of being “employed”, and are not under stress. People in these circumstances, also have a less quantifiable resource that could be termed ‘social time and energy’. This is present only when people have their needs met and are not struggling to survive.

Communities with ‘social time and energy’ have more capacity to respond to requests for assistance and are more likely to know and include their neighbours. This is evidenced by the experiences of one QDN member who lives on the Sunshine Coast. She has a physical disability and a young child and is well known in her community. The community welcome her and she is included in the life of the community as a woman and a mother. When she goes out in the community, she communicates with people using a hand-held electronic note writer and easily converses with people because she is known and accepted.

A characteristic of her community is that of being relaxed, accepting and diverse. It has residents who have ‘social time and energy’. Another factor positively influencing, her life is the formal support she receives, that is delivered in a flexible way meeting her changing life stages and needs.

Another QDN member who lives in Brisbane experiences social and community inclusion in different ways, with the key characteristics being similar.

If you ever happen to be having coffee at a certain coffee shop in a certain part of town, you might meet him. He is friendly, eager to start a conversation, lives with his family and has an intellectual disability.

For many years now, he has been involved with advocacy groups and has maintained enduring relationships with people he has met through these connections. These people value him and have established long-term

relationships with him. He accompanies them to social and sporting events. He has season tickets for most things held at Suncorp Stadium and is often seen travelling to games in full team colours.

One of the first things you notice about this man is how he relates to other people. His family and friends have modelled respectful, acceptable public behaviours and he has adopted these mannerisms.

A characteristic of his community is that he is included by and with a group, similar to those identified by Arthurson: people who are employed and have valued roles in the community. This person is often seen with friends or family and less often with other people with disability and their collective carers. He is socially included because he is known and accepted in the community.

These personal stories provide a snapshot of what is possible, given the right circumstances and supports. Sadly, for many people with disability this is not the case and they are isolated and vulnerable.

Although the 1970s, 1980s and early 1990s appeared to be times of hope and change, and it seemed, just for a brief moment in time, that the dark days of institutionalisation were ending, the models for supporting people in socially inclusive ways have not been extended to include all people with disability. The tide turned and the people with more complex needs or with limited networks and no supporters were left to languish in the large, lonely wards of institutions. In some cases, these large institutions were closed, sold-off and people moved to houses in suburbia.

A new term emerged and this was “Group Homes”. Whilst they were meant to replace institutions, and provide a new model of support for people with more complex needs, they became *Institutions writ small*. This is because ‘group homes’ perpetuate the worst practices of institutionalisation. They are the anti-thesis of community and social inclusion. They group people with disability, who already experience social isolation because their disability means they differ from the ‘*norm*’, together. This increases their isolation by the mere fact that people avoid groups who are perceived to ‘*belong*’ together.

A non-disability related example of group exclusion and rejection are the class of motorcyclists commonly referred to as ‘bikies’, illustrates this point further. Particularly after recent events in Sydney, but even before that, one bikie might be tolerated and gradually welcomed into a community. However, if an entire gang, who ‘hang’ together as a group, moved in next door they would be treated with suspicion and mistrust. The rest of the community would not welcome them and they would be socially excluded and isolated.

The same analysis of social grouping applies to people with disability. They are more likely to be socially included when they are housed and supported as individuals in the community.

## Conclusion

One of themes that occurs repeatedly in this presentation is 'space, base, and place'.

Community building has to include a sense of belonging – that is, an awareness of being grounded in space, place and base. Without this awareness, no matter how inspired the vision of universal justice and equity may be, people end up floating yet another package of solutions – only to find that no one solution in whatever attractive packaging can ever fit all situations. Grasping after fix-it solutions will not work: the many different, changing realities of space, place and base simply rearrange themselves out of the neat patterns we try to devise.

(Kelly & Sewell 1988: 51-52)

This concept comes from community development and is suggested as a guiding principle for sustainable, inclusive communities. It would be useful as a guiding principal driving community and social inclusion for people with disability because it takes the approach that no one solution will be suitable for all people, communities or situations. Following this space-place-base principle would entail working individually with each person with disability to assist them to find their space, place and base in a community of their choosing.

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