

Views from Within: A Reflection on Institutionalisation

Nigel Webb is a disability activist with many years' experience in disability organisations in Queensland. He was a committee member of Queensland Advocacy Inc for nine years and has been appointed as a community representative on a number of Queensland Ministerial Disability Committees. Nigel is also one of three Queensland representatives of the National Disability Advisory Council. Here Nigel contrasts his experiences living in an institution with his current life in community.

The issues of congregated and segregated living are highly relevant to me: I have spent fifteen years of my youth in a variety of institutional settings and the last fifteen years of my adult life living within my community. These experiences leave me very clear about what constitutes a real life. I want my life to be rich with experiences. Being isolated, congregated and segregated did not afford me ordinary experiences like being loved, making a meaningful contribution to my community, working and seeing different places; I missed out on many things that help a person grow.

Many families face difficult decisions in providing the best possible care for sons and daughters with disability, as well as trying to meet the needs of their other children or siblings. My family's decision to send me to an institution was based on my need to be educated and to have access to therapy services. This meant I was separated from my family for the school year. In turn, it limited my ability to contribute to both my family and my community.

Often when we think of institutions we think of large buildings, built on the edge of town, filled with hundreds of residents. We assume that the absence of these monoliths means an absence of institutionalised practices. Yet many of our current support models, including group homes, innovative housing, and the Alternative Living Service (ALS) are simply smaller institutional systems. It is not so much the dwelling type but the systems we choose to use within them which can inhibit the residents' lifestyle opportunities.

Regardless of their size, institution-like settings are lonely places. The physical design can be clinical and sterile in nature. The workers are often unfamiliar to the residents and are often seen as rented strangers by the residents or tenants. There is little private or personal space. The environment in these instances is simply not welcoming and conducive to social interaction and meaningful relationships with people of our choosing.

Many institutional settings are not located well in relationship to other community facilities and services. This means it can be harder to pop out for a loaf of bread or to meet people down the street. These services tend to dominate people's lives. They can act as a one-stop shop encompassing most or all life domains. Institutions are extremely regimented by design and will often meet industrial requirements before meeting the needs of the people they claim to serve. It is therefore not surprising that people in these circumstances might begin to exhibit so-called 'challenging behaviours'.

As individuals, we like to believe that we have a certain amount of autonomy to decide the functions, activities and stimulus that occur in our lives from day to day. People who are congregated and segregated are often withdrawn from such liberty and instead receive case managers and programs. The types or even the quantity of activities offered may be shaped not by a person's preferences, but by how rosters are developed and implemented. Every detail of activity is documented, scheduled and prescribed, usually by other decision-makers.

Congregated and segregated settings also deny people opportunities for social interactions. In the institution, I was not allowed away from the premises unless I was in the company of an adult, nor was I able to bring friends to the premises. Other than school holidays we had three outings a year to various tourist destinations. By contrast I now have the independence to decide with whom I interact, how often and for what purpose. This is what I call autonomy.

Another common experience in institutional settings is long periods of time of inactivity, or time wasting. The routines are so focused on meeting functional needs such as eating, toileting, or showering, that little attention is paid to developmental needs like having fun, learning or developing social skills. The contrast for me now in the community is that I am constantly finding new ways to have fun, readily learn through education and employment opportunities, and socially I am able to do the same as my peers.

My experiences in institutionalised settings have led to my fundamental belief that everybody has the right to participate within his or her communities, including both social and economic participation. Where we live, how we live, and with whom we live are individual choices. We survive with a disability or disadvantage; these should not be the predominant drivers that determine a decent life.