CRUCIAL TIMES

Community Resource Unit Inc. **November 2004 Issue 31**
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Editorial

Congregation: The Wrong Answer to the Wrong Question

Jane Sherwin

This edition of CRUcial Times is dedicated to exploring two of the dominant responses to people who are devalued in our society: congregation and segregation. It seeks to understand the issues underlying congregation and to understand the impacts of these responses on people who are vulnerable.

This edition is less concerned about arrangements where people with disabilities *choose* to spend time with each other because of friendships over many years or when people join together for lobbying and activism. It is also acknowledged that in rejecting congregation there have been unintended negative consequences, such as the abandonment of people in community, and the destruction of deep relationships between people with disabilities who have been separated against their will. In itself, congregation is not inherently negative. Congregation has many positive attributes and can be a sign of people coming together to celebrate, to share ideas or to provide mutual supports.

Instead we are keen to explore those models that combine both congregation and segregation. Under these models people who have nothing in common, other than a disability, are grouped together and kept apart from broader community. While traditional congregated models are slowly disappearing, new forms of congregation are emerging. Sometimes these are hidden beneath seductive new language and new practices, such as group homes, share housing, cluster housing, 'innovative' housing, day centres, respite services, sheltered workshops, intentional community, villages and special schools. The congregation may be less overwhelming (four people instead of four hundred), and the segregation may be less obvious (behind the door instead of behind the gate), however there is still a profound impact on people who are already marginalised.

In the lives of people with disability, congregation is the wrong answer to the wrong question. Wrong questions include: What is the most economical way to support people with disabilities? How can people be with their 'own kind'? and What will be the safest environment for people with disabilities? These questions all contain faulty foundations. These questions are the wrong questions because they have a starting point of seeing people with disabilities as not only an amorphous mass, but also as 'not like other human beings'. There is also a sense of the bizarre here: we would not assume that it is either cheaper or more desirable to support all blonde people together. We would not assume that all blonde people like each other. We would not assume that the safest environment for young dependent blondes would be in the hands of paid strangers. Yet these are some of the assumptions underpinning responses to people with disabilities.

Congregated models can be very damaging not only to the people being served, but also to the paid staff who seek to serve them. If people with disabilities are served together in a group, then it is much more difficult to meet individual needs or individual routines. Staff are placed in a position of having to use group management techniques. As a result people are likely to all do the same things at the same time or to wait while others have their needs attended to; thus workers are forced to cater to the lowest common denominator. Related to this is that both the individual and the staff are unlikely to be challenged and to grow. Environments that require higher levels of control because of the number of people in the group, rather than using developmental and nurturing strategies, are more likely to be life-sapping than life-giving. It is also much more difficult for individual identities to flourish. Instead, group needs and preferences, or those people with the highest needs, or even service management requirements, take precedence. Services might hope to use individualised planning mechanisms, but experience enormous difficulties implementing them because resources are more likely to be tied to the group.

The impact of congregation combined with segregation takes people out of ordinary life and places them in service-land. As a consequence, people are less likely to experience the ordinary things in life.

CRU's MISSION STATEMENT

- To challenge ideas and practices which limit the lives of people with disabilities.
- To inspire and encourage individuals and organisations to pursue better lives for people with disabilities.

Congregated settings are more likely to give rise to harmful power dynamics. It becomes easier not to respect an individual's humanity, dignity and worth, and the group setting can normalise or hide dangerous practices. Consequently, people served in groups are more likely to experience abuse – physical, sexual, emotional or psychological – particularly when they are already vulnerable, unable to defend themselves, unable to communicate and less likely to be believed. Furthermore, the nature of congregated settings can act to deter the regular presence of family and friends, who may act as important safeguards in the lives of vulnerable people.

Ordinary citizens, when witnessing a group of people with disabilities living together or going out in a group, are more likely to have stereotypes triggered in their mind, and to treat people accordingly. So the beliefs that people belong with their own kind, are dependent, are eternal children, are menaces, and are burdens are confirmed, and people will respond accordingly. When people who have different impairments are grouped together, then the ordinary citizen also makes assumptions that they all have the same impairment. Individual strengths and gifts are overlooked in the presence of the obvious group characteristics. Those who put the people in groups are teaching ordinary citizens the wrong things about people with disabilities and where they belong.

So if these wrong questions, based on wrong assumptions, lead to the wrong answers, then what might the right questions look like? Far better questions are ones that allow person-by-person responses: Who is this person? What are their interests, gifts, talents, needs? Who or what is important to them? What are their vulnerabilities? How would ordinary citizens have their needs met?

These questions lead to better answers. People who live by themselves or with ordinary flatmates report that they are at last able to have meals cooked to their own liking, to have the decorations of the entire flat to their own taste, to be able to invite people over without having to negotiate with other dependent people. People report that their work or leisure pursuits are much more related to their own interests. People report that they have higher levels of control in their own life, and higher levels of activities. Like other humans, a person with a disability does better in an environment that has relevance to who they are as a person and that is an expression of him or herself, and his or her interests and tastes.

These questions are more difficult: they take creativity, time, energy, responsiveness, flexibility and ongoing commitment. Likewise the answers are not simple and straightforward. There is no single recipe; each answer is a creative response to the individual and their needs and resources.

We can acknowledge that isolation for people who live by themselves is a problem. We can also acknowledge that there is insufficient state funding to support all people equally. However, it does not follow that congregation is the solution to these issues. The costs are too great.

There is broad agreement that the institutions of the past were clearly flawed models through which to serve people with disabilities. Congregation and segregation were at the core of these models. It is of grave concern that these solutions have been shown to have serious limitations, yet are promoted to individuals and families. These arguments are not just ideology; this is real life and challenges us to think about the worth of individuals with disabilities, and what sort of communities we are trying to create. This edition of CRUcial Times is offered so that there is a more conscious critique of a model that is insidiously present in Queensland, and that is offered as the ideal rather than the poor cousin that it is.

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From the President

Mike Duggan

I put myself in an institution. I made this decision because I felt that my mother was not receiving adequate physical support to continue to meet my needs to a level we were both used to. At the time, an institution seemed like the only alternative.

The institution operated on a medical model, and my basic needs were broadly met. For example, I received three meals daily, but at the same time, great care was taken to ensure I didn't put on weight, to avoid me becoming too difficult for staff to physically manoeuvre. In terms of safety, I was seen to be protected from the wilds of society – I am less confident I was protected from the wilds of the institutionalised culture.

My higher order needs – my spiritual and emotional needs – were met partly by fellow residents. We were not all the best of friends; disability certainly cannot be considered the best common denominator. However we shared a desire to make our living situation work as well as possible. A lot of invaluable support also came from the staff we saw as the 'goodies'. They were the staff who were able to operate counter-culturally to the institutionalised ethos. They were the ones, in touch with their own souls, who were able to touch the souls of others with compassion, laughter, insightfulness, and reciprocity.

I eventually 'escaped' to an apartment of my own, near the city centre. So how do I really experience life at present, now that I am living in the community? At times it seems like hard work. I have some good personal care workers, but they always need managing. Overtly or covertly, consciously or unconsciously, there are times when they try to get away without doing tasks, and these are the times I find quite difficult. In any kind of relationship, power dynamics are quite tenuous. Though I employ my own workers, nevertheless my vulnerability is ever present. If they don't turn up I am in danger. I do have some safeguards however, through the diligent support of friends.

People conscious of my security and safety may ask, 'Why don't you go and live with another person with a disability, and perhaps even combine support hours?' This strikes me as fabricating an arranged marriage, based on a dominant misconception that all people with disabilities want or need to live together. When I moved into my unit, I purposely chose to go solo.

However in the same way that institutional forms of living have great potential to be destructive, other ideologically based responses can be similarly destructive. There are times when I feel quite alone, and sometimes even lonely. Maybe I have portrayed an erroneous notion to people. Because I am seen to go to work three days a week, to attend meetings and to be attended by workers at least twice daily, other people assume I do not need them. What about my need for intimacy? What about my need to feel loved and to love unconditionally? What about my need to feel that I belong?

Being out of an institution and 'in community' is not enough. Other factors are needed to ensure good outcomes for people. All of us, regardless of (dis)ability grow through our experiences. If people's access to experience is limited, their growth will undoubted be stunted. We all need exposure to different experiences and environments, the opportunities to grow and flourish and so further develop our understanding as individuals about what we would like our life to be. We all need to be supported, as well as to support others. We all need to be loved, as well as to love others. Life is still not ideal in the community, however it is still the place that everyone else gets to live their lives and experience the joys and struggles of belonging.

A version of this article was first published in the QDHC Newsletter, December 2003. Permission kindly granted by the publisher.

Community Resource Unit Inc. would like to warmly congratulate Michael Duggan for receiving the

2004 Queensland Social Justice Award.

The awards were presented at the Uniting Care Queensland Centre for Social Justice Conference on 8th October 2004. The Queensland Social Justice Award acknowledges Mike's outstanding and pioneering contribution to social justice through his role, over many years, in initiating and providing leadership in advocacy for services and human rights for people with disabilities in Queensland. Mike was recognised for his active involvement with and initiation of projects and organisations that include Independent Lifestyles Inc., Queensland Advocacy Inc., Lifestyle Options Inc., Community Resource Unit Inc., Southside Night Attendant Care Service, West End Community Centre, Australian Communication Exchange, Micah Projects Inc., Queensland Disability Housing Coalition and Queensland Spastic Welfare League projects.

**CRU is honoured to have Mike as its president and is grateful
for his many years of wisdom, insight and guidance.**

Views from Within: A Reflection on Institutionalisation

Nigel Webb

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 disabilities, 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.

Getting Off the Big White Bus: Re-imagining Congregation

Cameron Cutts

Cameron Cutts lives in the newly established community of L'Arche Brisbane. L'Arche is an international federation of faith communities of people with and without intellectual disabilities who live, work, pray and celebrate together in freely given mutual relationships. Cameron is also currently studying a Graduate Diploma in Theological Studies.

I love congregated living. I enjoy sharing life with a group of people who are very different from me. I like that there is often someone around for me to talk to when I get home. I like that the work of the house is shared between all of us and I like that we can just hang out together.

You will notice that I have not mentioned anything about big white busses or navy blue tracksuits that seem to be the norm for most people with an intellectual disability who have experiences of congregated living. The difference between where I live and where most people with an intellectual disability live is that it is our relationships that bind us together. I live with four other people in an intentional faith community. We are a diverse mob with a whole spectrum of faith traditions, ages, sexes, political views, sexualities, abilities and disabilities. There is not a navy blue track suit between us. What we do have in common is a desire to be a sign in the world that people who are very different can live, work, pray, grieve and celebrate together in relationships of mutuality. Two of the men I live with have an intellectual disability and each of them desires and needs different levels of support and accompaniment in daily life. Sharing life with these two men is what brings us all together. Our household is a place of welcome for a lot of people but particularly people with an intellectual disability. We understand that it is often people with an intellectual disability who have no place to just be and not be receiving a service.

The issue for many people with an intellectual disability is not just about congregation but about segregation and isolation from society. We have moved from a big white bus to lots of little white vans. Care has been professionalised and corporatised and removed from the sphere of freely-given relationships outside of family structures. The identity given to many people with intellectual disability is now that of consumer.

A lot of what people talk about as congregated living is more about segregation and isolation. It is not simply the number of people that makes congregational care such an issue but the societal attitude that people with an intellectual disability are people who must have something done for/to them. For many people with an intellectual disability who are living independently in the community, life does not actually look much different. It is often still highly segregated and isolated. I have seen many people chained and enslaved at the altar of independence. Folk live sad isolated lives in Department of Housing bed-sits, having only drop-in support; paid staff being the only human contact. Yet, often the support is merely functional and not particularly meaningful. Why then do we assume that the alternative to the big white bus is being abandoned in the community and to call this independent living?

The origins of the value that the western world places on independence lies in the enlightenment movement of the eighteenth century. Before this period, people were part of and accountable to, a complex web of relationships. There was no concept of 'self' outside of one's relationships and culture. It was from this sense of belonging to one's community that a person's identity flowed. People saw themselves ***as*** their community. The enlightenment movement gave birth to the notion of the 'self': as one was freed from these constraints, people saw themselves as separate from others, and both independence and individuality became the ideal.

However this ideal is highly problematic for many people. I live with a man who will never be independent. He is a man living with significant physical and intellectual disabilities. A model that provides real dignity for Jason is a model of interdependence rather than independence. By living in a group we are able to attend to the various aspects of Jason's care but we are also able to receive the gift of who Jason really is, and together with his family and friends we are able to really explore the possibilities for Jason's life that would never be possible if it was just one of us with Jason. Jason, being the man that he is, calls us to congregate around him and be imaginative about the possibilities not only for his life, but for all of our lives with him. Jason is also an integral part of a local Anglican Church community. This is an important place in Jason's life as it is a place where he is part of a congregation, not the centre of it.

An image that is used in Christian discourse for the congregation is that of the people of God being the 'Body of Christ'. All members of the congregation are called to incarnate the Christ in their daily living. At the communion table, a new community is imagined, one where all people have a place, and no one goes without. When Jason began attending this church he did not participate in communion for a variety of reasons. This was a source of discomfort though within the congregation. There was a sense that the sign of communion was incomplete without Jason's participation.

In embracing interdependence, rather than independence, the congregation began to transform itself. Physically, the old church was quite inaccessible. There is now a variety of ramps and routines developed in order to fully embrace Jason. When it came to communion it was clear that Jason was not going to be able take communion kneeling at the altar like the other members of the congregation, as Jason cannot kneel. At Jason's first communion, the entire congregation stood with Jason and received communion at his side. Now each week a different member of the congregation receives communion with Jason at his or her side. This is the heart of mutuality and interdependence. It is only through such relationships, I believe, that real change can happen for many people with an intellectual disability.

The western ideal of complete independence does not serve any of us well. All of us need to be needed, not in some token or co-dependent way, but in a way that affirms us as contributing in a meaningful way to the quality of life of others, no matter how independent we are. If we start speaking about interdependence then we can start imagining possibilities for and *with* people with an intellectual disability that are not only valuing and affirming but transforming as well.

Petition One – To the Universe

Michael Russell

Michael Russell is a young man with Autism who has been institutionalised from an early age and was introduced to facilitated communication at age 18. Ten years later he has had a play broadcast on Radio National and has written his second volume of poetry with an Arts Queensland Grant. His writing captures his experiences of autism and the unhappiness of his current living situation.

How can we get through my armour of bitterness to the love underneath? It has never been seen by anyone so it is very fragile and weak, but it is there somewhere, I know. But I can't seem to hold onto it for any length of time. It flees in the face of reality and other people's hatred.

I'm not sure if I even have any love inside me. How could it be alive after all these years of questions and no answers? It's amazing to me that I'm still alive at all. I thought people died of neglect, but I'm still here, breathing and thinking and feeling. I guess I must be very strong or very stupid to believe that I have a right to exist but I find myself waking up every morning.

Hope and joy and fear and lightness and loveliness and knowingness and gratefulness and just the bit of glow from my self that lies hidden under the weight of the struggle to survive in the mess that I inhabit on a daily basis. Getting out is my sole saviour; help is only out there. It's not possible in here. Help. Help.

That seems to be where I am stuck. I get stuck in wishing to leave and stop thinking straight. I get so weird that I forget myself. It's a tiny little self that looks like a glow-worm, flashing on and off, like "Mike," like a tune in the background – "Mike, Mike, Mike," like a refrain from a forgotten song that only a fragment remains to remind me that I exist, that I am here, that I am a person, not a thing. I am human, not an autistic thing with no mind and soul. Maybe it's my soul that keeps me alive and makes me go on, helping me to stay alive; helping me to be a better person who can give the world something that it needs. I think that's why I'm here. Maybe.

Leadership to Counter Congregation

BOB JACKSON

Bob Jackson is Adjunct Associate Professor of Education at Edith Cowan University, Chair of the Foundation for Social Inclusion Inc. and Director of Include Pty Ltd. Bob has worked in institutions in New South Wales, Victoria and Western Australia. Bob ran the largest institution in Western Australia for people with an intellectual disability for ten years. Here, Bob details why change and leadership are required in addressing congregation.

In ancient Greece and Rome the punishment for the most serious of crimes was often a choice: death or exile. In effect, the social death of exile was deemed equivalent to physical death. In our society, the worst punishment meted out is 15 to 20 years of exile from society through our prison system. In some cases we will also forcibly exile people with highly infectious diseases or for 'illegal' immigration. In all of these cases there is an element of protecting society as well as punishing the person through social exile. So how do we reconcile the forced segregation of people with a disability in institutions? What is the rationale for this incarceration without trial for the crime of having an impairment?

There is a subtler issue at play in institutionalisation – congregation. It may be possible to sustain an argument for short-term forced segregation for the safety of an individual or the protection of society while measures are taken to prepare the person and the society for their participation. However, as far as I can see there is no argument for forced congregation outside of administrative convenience. Arguments along the theme of 'they are happier with their own kind' are so patently prejudicial that they do not deserve serious rebuttal. It is as logical as rounding up all the members of the chess club and forcing them together in an institution as they will be 'happier with their own kind'. Or perhaps rounding up the Jews …

In looking at how we congregate, we see that our congregations are normally short-term. In fact our lives are a continually changing pattern of congregations around different issues and interests. Spending too long in any one grouping is likely to be viewed negatively over time.

So what is wrong with the forced congregations of institutions? Just close your eyes and think of the one thing about yourself that you would least like others to know about you. It might be a well-concealed physical characteristic, a vulnerability, or a past mistake. Now imagine that this is how you were known to the world. Moreover, you were forced to live the rest of your life with others sharing your exposed secret characteristic. This is the reality of the institution. The grouping together around this negative characteristic amplifies it to the world and ensures that it will be seen before your individuality, strengths and talents. You will become know by the characteristic rather than as ‘Joe’ or ‘Helen’. As we all copy each other, you will become more alike in behaviour, enhancing the sameness. Expectations of others are likely to fall with a vicious cycle of lowered opportunities, lowered skills and further lowered expectations. And the staff – almost all of whom will have been drawn to the work through compassion and good hearts – slowly will be absorbed into the culture of sameness and lack of hope. The soul of staff is gradually sucked out until reflection leads to a realisation that apart from a rare and precious contact at the human level, most of one’s efforts have resulted in reduced skills and further alienation of the people from the society. The road to hell is indeed paved with good intentions.

It is often stated that institutions provide a safe refuge. A reading of the regular abuse reports from institutions should put paid to any such notion.

Voluntary congregation is a somewhat different issue. All of us are able to choose our friends, associates, venues, activities and other aspects of life, even though our choices may carry some real risks physically, emotionally or in reputation. People with an impairment are in great risk of having their reputation damaged by congregating with others similarly impaired, so we would always look to avoiding such congregations where people are not able to make an informed decision.

When people make an informed decision to congregate with others similarly impaired that is of course their right as citizens, but the point cannot be avoided that even short-term congregations are still harmful. It is often stated that institutions provide a safe refuge. A reading of the regular abuse reports from institutions should put paid to any such notion. We are not made safe by having our lives controlled by systems and individuals with vested interests, often at odds with individual welfare. We are made safe by being surrounded by people who love us and will stand up for our welfare.

So the argument about institutions is not an idle academic one. It is a call to leadership. If the best that system planners and service designers can come up with is a life without hope in an institution, they should stand aside for those who can see a better way. We have decades of research showing that forced congregation of people with an impairment does considerable harm physically, emotionally, developmentally, and in reputation. What marvellous new development is now discovered that will stop this damage occurring and a positive result occurring? In searching the literature I can find no evidence of such remarkable developments.

If the best that system planners and service designers can come up with is a life without hope in an institution, they should stand aside for those who can see a better way.

What I can find however are stories of people who are trying a different way and succeeding. I read of stories of people labelled ‘untrainable’ who are employed in real jobs with a career path. I read of communities transformed by the inclusion of people with very significant impairments. Individuals find that slowing down, considering others, joining together and helping someone traditionally rejected, profoundly changes how they view life and their community. I see children growing up together in their local school with a fundamentally different view about impairment to their parents and a social awareness that speaks well for the future of the planet. I see people with impairments living in the community sharing their life and interests with friends, partners and associates.

The new way is not easy. We do not overcome millennia of rejection with a new program or even in a single generation. However the choice is stark and calls for a stand to be made. Is it to be a return to a system based on rejection and social elimination? Or do we aspire to an ordinary life for all? It is a time for leadership from individuals, families and all citizens, as well as those in formal positions of power. There is a better way.

Exposing the Disempowering Processes in Group Homes

Francis Vicary

Francis Vicary works at CRU, as a resource consultant and a project worker. She works with individuals and families to assist them to envisage an inclusive life and making this a reality. Francis has a significant disability, and lives alone in her own home. She is interested in social structures that disempower people and that create further marginalisation.

Often in casual conversation, power is viewed as something limited, 'She has more power than him', or as something that can be possessed or owned, 'He is a powerful person'. A more helpful view of power is to recognise that we all exercise some degree of power at both the personal and political level. For example, at a personal level, exercising power may mean someone making a decision about what he or she does, wears or eats, with whom a person lives and with whom time is spent and life is shared. On a political level power relates to a person's position in society and the opportunities that they have to assert personal choices. It also relates to the ways in which a person's views and preferences are respected in shaping decisions about their life and the lives of their family members, and whether their voice is heard.

There are however, factors that limit people's ability to exercise power. For many people with disabilities and their families, life is characterised by a continued erosion of power. Firstly, families and individuals interact with the medical profession to gain access to a diagnosis. This diagnosis allows them entry into the various systems that are set up to advise, prescribe, educate and assist. These interactions are necessary if one is to access funding and other forms of assistance that might help to facilitate independence and life. However, the seeking of a diagnosis from an external party also establishes a pattern for the ways in which families and people with disabilities live their lives. Interacting with these systems is the first point at which people with disabilities and their family have their empowerment challenged by systemic influences.

It is not surprising that people with disabilities and families become fatigued, feel economic pressure, exhaust limited support options, and fear the increasing age or decreasing health and resilience of parents. These circumstances, as well as concerns for the person's safety and long-term security, lead people to opt for places in group homes.

This limiting of options precipitates the step across the threshold to disempowerment. Group homes operate using dynamics where control over life decisions is largely removed from the person and their family, and placed within the sphere of the government department or organisation operating the group home.

Indicative of this disempowerment is the fact that, in most group homes, people with disabilities and their families have fewer or no choices about with whom they will live, or who enters their personal space. In most group homes, people are forced to share their resources and staff. Their personal information is also more likely to be shared with many people and recorded in documents within the group home and the institution or government department.

> *Offering group homes as the preferred and most readily available alternative to people with disabilities and their families is a further act of disempowerment towards people with disabilities, who are already personally, socially and politically disempowered.*

People are less likely to be able to choose the location of the group home in which they live. Because of the increasing costs of housing, the rising popularity of inner city suburbs and the lack of public housing stock, many group homes are located in the outer suburbs on the fringes of the city. In such locations there are few amenities, no strong sense of community and the residents of the group home are isolated within a sparse, suburban, individualistic community, where neighbours are unknown and there are no naturally occurring safeguards.

Unlike ordinary share house arrangements, the process upon which people are selected and placed in group homes is dependent upon vacancies, funding and staffing allocations to maintain the coverage of hours. People are not selected because they share interests or know each other and might be compatible.

People with disabilities and their families are more likely to have fewer or no choices about who will work with them to provide intimate, personal support. They may not have say over what those supports might entail. Many people's experience is of a daily routine based on a production-line approach to being dressed, fed, cleaned and entertained. Union conditions and penalty rates disempower people further by dictating when they can get out of bed, eat, or go out. Internal organisational policies and procedures such as Occupational Health and Safety and Duty of Care, influence what people can do with their time and what activities they can and cannot participate in, and with whom they spend their time.

Yet these activities of daily living might be seen as almost superficial compared to the deeper emotional and physical wounds that are inflicted upon the people in many group homes. These include the loss of personal possessions to the greater collective of the house and the very real threat of physical, verbal, sexual, emotional or psychological violence from other people in the group home.

The dynamics of the group home often negatively impact upon relationships. Families may feel excluded or unwelcome and friendships are discouraged from forming or continuing. Visitors are asked to book a time to fit in with a schedule, or are dissuaded from taking their loved one out because it is inconvenient, is too complicated to organise or runs the risk of 'upsetting' the individual.

Offering group homes as the preferred and most readily available alternative to people with disabilities and their families is a further act of disempowerment towards people with disabilities, who are already personally, socially and politically disempowered. In such models, there is little chance of ever being released from a disempowered position, because funding structures appear incapable of putting people and the quality of their lives before staffing arrangements, hours and bricks and mortar. Yet, people, family and friendships are the bricks and mortar of a good life. Staff, hours, and physical structures are mere symbols of personal disempowerment and the means by which society contains and excludes those that Government, organisations, policy makers and broader community continue to disempower.

Leaving Home... Letting Go

Dianne Hughes & Andrea Bearham

Dianne Hughes and Andrea Bearham work for Kyabra Community Association Inc, where they work alongside a number of families who are in the position of making decisions about accommodation for their family members who have a disability. In this article Dianne and Andrea share some of what they have learned from families about what is helpful in the decision-making process. They offer these thoughts humbly and in the spirit of seeking to walk alongside families on this very difficult journey to ensure that both parents' and their sons or daughters' wishes and choices are respected and encouraged.

We work for a community organisation which has a vision of 'local communities that are safe and fair for everyone and in which all people are free to be themselves and to achieve their goals'. There are many people and organisations who share this vision of *safety* and *fairness,* but most families find that the reality is still very different.

> People who have disabilities and their families need to be allowed the space and time to explore their definitions of what constitutes 'a good life' and to having access to as much information as possible to assist them to make informed choices about what they would like to see happen.

It is daunting and sometimes overwhelming for parents who have a son or daughter with a disability to imagine their family member living away from them. After all, in most cases, the parents have been the person's primary carers for their whole life. It is understandable that parents often think, 'Who will be able to look after her like I do?' Even for people who have less significant support needs, sometimes their parents just cannot imagine that they will be able to live independently. For example, we know a woman who would love to move out of home, but is not able to as her parents are too worried about her safety, her finances and her support. This woman has a part-time job and participates in a range of social activities, yet still finds that she is unable to broach this topic with her parents, without everyone involved becoming angry and upset.

We certainly do not presume to think that every young person who has a disability wants to move out of home. On the other hand we do not presume that all parents want their son or daughter who has a disability to stay with them forever. On the contrary, we know of parents of young children who have commenced planning now for this important transition time.

However in our work with families, the phrases we most often hear are, 'She will just always live with us', or 'There's no way he can move out: we'd have to win Lotto first!' Some families confide that they hope their son or daughter will die before them so that they don't have to think about 'What will happen when I'm gone?' Some families believe that a group home would be the best solution for their family member; others believe that somewhere that has 24 hour care is the only solution. Others search for ways that their son or daughter can have a place of their own. For some families, even contemplating their son or daughter moving out of home is just too difficult.

For most families, it is the overwhelming fear that has at times held them back from exploring their options further. This relates to fears about not knowing how things could work differently, and the limited choices available given the restraints of resources, financial supports, energy levels and extended support networks. Families also express their fear of letting go, not only of responsibility and of the person's ongoing care; but also of their own caring role. For many, the role of carer has become a major part of their identity.

Families express a desire to make decisions in their own time and to explore the reasons they are feeling anxious and fearful. They wish to be able to freely say upfront that they do not know if or how the things they would like to see happen for their son or daughter could be possible. Other families also feel they need the space to explore their feelings about the expectations they hold for their son or daughter's abilities and levels of need and the possibility of independent living.

Families are often concerned about being separated from their son or daughter with a disability and are daunted at the prospect of putting their trust in the hands of others. There is anxiety about how to find and retain support workers that are going to be suitable carers for their son or daughter and that will have the same level of commitment to their care that they, as parents, do.

Parents are concerned about personal safety for their son or daughter and the level of choice that they might have about where they live and whom they live with. Some families who want to maintain a certain level of direct involvement in their son or daughter's care are concerned about the lack of appropriate housing in areas close to their own homes. There is also concern about neighbour issues and whether their sons or daughters would be accepted and be able to participate in the local community.

Although many families are aware of some of the different options and models available, there are still some concerns about being able to pursue their ideas or goals if they do not have access to housing or if they have not received a funding package. For some families, their goals feel out of reach without the needed resources or supports in place to allow some change to happen.

So what does this mean for those of us wanting to walk alongside and support families as they grapple with these choices? Firstly, parents have shared with us the need to feel okay about not always getting it right: that they might make decisions and choices based on the information that they have at the time, which they may later need to revisit and change.

Secondly, families wish to be able to freely express their dreams and explore the possibilities without being told that what they wish for is 'not possible' or 'unrealistic'. This comes from people's past experiences of services that have been quite rigid and are not individually focused. It also reflects the perceptions of some people within the wider community about the value that is placed on people with disability and the lack of understanding about what can be achieved.

Thirdly, families express a desire to continue to hear the stories of other families who are facing or have faced similar issues and to talk with them about what can and has been achieved. For example, some people have experienced the 'letting go' of the ongoing caring role of their son or daughter and this has allowed them to spend time together as a family in different ways.

When we look at what families feel will make a difference to them when making these choices, we realise the importance of providing a space in which people are freely able to explore their fears and concerns. People who have disabilities and their families need to be allowed the space and time to explore their definitions of what constitutes 'a good life' and to having access to as much information as possible to assist them to make informed choices about what they would like to see happen.

In exploring these themes, we know that we have only touched on *some* of the areas that contribute towards decision-making for families. We look forward to continuing to work with individuals and their families who are undertaking this journey and to be able to be walk beside them as they explore opportunities, options and models that might work for them. We also look forward with hope to a community where there are many more options for people who live with disabilities – options that embrace and celebrate diversity, respect individuals' choices, and offer safety and fairness for all.

The Journey from Fear to Love

Ian Boardman

Ian Boardman became Queensland's first Public Advocate in October 2000 and took up his position in January the following year. The Public Advocate is an independent statutory officer with responsibility for systemic advocacy on behalf of adult Queenslanders who have a decision-making disability. In this article Ian explores some of the values underpinning congregated models and the role of values in seeking change in the lives of vulnerable people.

What <u>is</u> our highest value? Is it life itself? Are there values for which we are prepared to give up our lives? Would we die for our children? Would we be prepared to die in defence of our freedom? To what extent are we prepared to suffer for the sake of a cause or an ideal? These are all values-based questions that determine, to a large extent, how we live our lives.

Our values are implicit in how we experience the world. For example, the value we place on security or competition will determine whether we see the world as a frightening place in which we must be ever alert, or whether we must constantly compete to secure the good life for ourselves and those we love. Alternatively, we may place value on love and perceive it as the essential energetic force upon which it is safe to rely. Or perhaps we hold social justice as the holy grail of our humanist faith. Whether we articulate them or not, values predispose us to make assumptions. At a societal level, these assumptions determine how we structure our services and supports for vulnerable citizens.

Most of us who have found our way into advocacy for vulnerable citizens, hold the belief that certain societal and service practices, such as institutionalisation, are wrong. Our travels through intellectual, ethical and spiritual landscapes have shown us the dehumanising effects of congregated and segregated settings on vulnerable people. We know of people who have never experienced a real home, real friends and real love. Yet, abusive and exploitative treatment of people within institutional 'care' would not be tolerated if we as a community had not already denied their humanity and their right to live a full life. As a society we make judgements about the allocation of resources for the public good. We even make judgements about what constitutes the public good. Unfortunately, at the collective level, our society appears to have concluded that people with a disability have less utility and therefore less right to those resources.

We find ourselves wondering how this happens: how ordinary human beings collectively make such brutal judgements. We also wonder what room there is to create change or to influence the values base from which our community and its leaders appear to be operating.

It is tempting to try to persuade others to our point of view by declaring ownership of a higher set of values than that possessed by the ordinary citizen or policy maker. However such outbreaks of moral superiority please only those that are so afflicted, while the vulnerable people, to whom we pretend we are lending support, continue to suffer their incarceration.

> *It is here that the most important work is done: when a single individual begins the journey from fear to love, and models that journey in their action and their discourse.*

A more useful strategy in influencing change is to discover the thinking, the values, the judgements and the priorities of those we are seeking to influence, and work within these confines to achieve whatever is possible. Resorting to aggression, personal attacks, humiliation and the other unlovely weapons commonly wielded in the hurly-burly of public policy debate, is a betrayal of the very values we purport to uphold.

The national and international community appears to be sinking ever more deeply into a culture of fear, where resources are increasingly channelled to create the instruments of conflict. We can be certain that moral discourse will equally descend to simplistic and self-serving claims that ‘god is on our side’. In such fear-laden cultural environments, more sophisticated moral arguments are unlikely to prevail.

Thus the exploration of values becomes a lonely task for each of us, to be conducted in the privacy of our own hearts and in the way that we live our lives. It is here that the most important work is done: when a single individual begins the journey from fear to love, and models that journey in their action and their discourse.

Members of the general community will finally insist that institutional arrangements are ended when they can no longer bear to see their own abusive neglect reflected there. I would suggest that that time is many years away for even as I write, we are building new institutions to incarcerate refugees who have thrown themselves on our dubious mercy.

It seems to me that the task is as it has always been: to push the boundaries of what is possible, to find ordinary happiness in what we do, and to find the means of sharing that happiness with those around us. To strive for more is dangerously arrogant. To strive for less is to surrender to the fear-based consciousness that increasingly pervades our world. We can be robust, enthused, spirited, and provocative. It matters not, so long as we are also effective, and have lived our lives in a way that has made a difference, firstly in how we experience our own life, and secondly in how we have helped others to find joy and hopefulness in theirs.

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