

## The Community: Heroes and Villains

*Bob Lee*

For the past ten years I have worked as the Coordinator of the Sunshine Coast Citizen Advocacy Program. When I first started doing this work, I had a set of expectations about 'community attitudes' which were largely formed by twenty years of work as a service provider, and much time spent in the company of people with disabilities and their families. I felt sure that families were always motivated to act in what they felt were the best interests of a family member with a disability. I was confident that the most effective path for people with disability to greater independence and participation in community life came through the programs offered by service providers. Strongest of all was my belief that life for people with disability would be so much better if the community were just more tolerant and accepting. I agreed with those who believed that the community needed to be educated, and if necessary, legislated into a state of acceptance.

I quickly found that my job in citizen advocacy had provided me with a rare perspective. I found myself deeply involved with those people with disability who are seldom if ever heard. Those who are unlikely ever to be present at a gathering like this. Those who are abandoned, rejected, isolated, neglected and all too often abused.

I realised also that the nature of my work meant that I had stepped outside the typical networks and relationships of service providers. As a citizen advocacy coordinator, I spend many hours talking to ordinary people about people with disability in our society who are vulnerable to abuse, neglect and exploitation. These discussions have been a revelation. I found that there is far more interest and understanding of the issues than we like to think. What concerned me most of was the overwhelming sense of confusion.

For as long as they can remember, it seems they have been told how difficult it is to be with people with disability. It's so difficult that those of us who have the training, the skills, the knowledge, the experience, the patience and the courage to work with people with disability must have a special expertise which distinguishes us from the rest of the community.

So why are they confused? Well it's because we, the 'experts', are delivering some very confusing messages. Seemingly oblivious to the irony of it all, we are telling the community that people, who they are told are difficult, dangerous and burdensome to...us, should be valued, welcomed and accepted by.....them.

We are quite rightly being challenged about what we are saying. We are being asked for an explanation. If we truly believe that people with disability should be valued and accepted by the community, why is there so much effort to talk them out of it?

So where does this 'burden' talk come from and who benefits from it?

It's surprising just how many people one meets who, while they do not have direct involvement with a person with disability, are informed by the experiences of others who do have some direct connection. I once met a woman who, after hearing about my work, told me with some enthusiasm that her son, a support worker in Sydney, had recently been in Queensland on holiday and had brought with him on his mobile phone, photos of the people he worked with to show his family and friends how difficult his job was. The images were apparently explicit and featured self-harm, public nudity, and other behaviours he thought would shock observers. How many members of the community had just this one person influenced with his bizarre actions?

A deeply disturbing issue for people with disability concerns the way in which caring, loving family members will feel that they are forced to characterise a family member with a disability in extremely negative terms by the processes used to make funding applications. I cannot guess at the harm that this does to private family relationships, but I have seen more than enough tears and heartache to know that this is often a source of pain and regret. As traumatic as this process is for those intimately involved, the impact can reach much further. When people with disability are described as burdensome, difficult or *even* dangerous by those closest to them, these labels are then far more likely to be believed by those who hear about it. Whatever the reason, whatever the benefit to be gained from describing people in this way, there is a terrible price to be paid. A reputation thus constructed will remain with a person with disability forever, and can be used as justification for poor service practice, unnecessary restrictions, neglect, or even abuse.

All of us who share a concern about the lives of people with disability need urgently to be aware of the dangers of indulging in 'burden' talk. We need to stop doing it now, and we need to appeal to others to stop. We need to examine critically who benefits from speaking about people with disability in this way. We should have a coherent position to stop the confusion that exists about this in the rest of the community. If we do indeed value people with disability; we need to talk as though we do.

Related to the 'people with disability are a burden' idea, is the notion that 'the community' does not accept, welcome, care about, or take an interest in people with disability directly, and while the community is prepared to donate money, and pay taxes to help relieve the burden imposed on caregivers and services, no-one wishes to become personally involved.

What basis is there for such a belief?

My own experience is that any expectations I had of a community which was uncaring and disinterested were quite simply unfounded. I found instead an overwhelming belief that people with disability should be "given a fair go". I found that the community wanted adequate personal and material supports to be provided to people with disability. I found that many people were *very* interested in being involved with and assisting a person with disability but believed that such activity was the exclusive province of family members and professional experts. Some *even* expressed their belief that legal restrictions such as 'duty of care' governed who could associate, *even* voluntarily, with people with disability.

Where do these notions come from?

Many people have commented to me that they believed that if they approached or expressed an interest in befriending a person with disability, they would be regarded with suspicion or even fear. They noted that while they often saw groups of people with disability with service workers, they rarely witnessed efforts to involve people with disability in ordinary community life. One memorable comment illustrates well the perspective of the typical bystander. "I see plenty of disabled people here but it's as if we are living parallel lives...in the same space but *never* crossing paths.

They are always with people who hurry them along and don't give them time to talk to anyone".

Those who wish to have some personal voluntary interaction with people with disability generally find that involvement is controlled and mediated by organisations, and is

conditional on a process of application, approval, registration, training, coordination, management, appraisal, demands for loyalty to the organisation etc. In short a comprehensive removal of any form of independent action and a drawing into the process of creeping professionalisation of *every* aspect of the lives of people with disability.

Despite overwhelming evidence to the contrary, many of those who are involved with the lives of people with disability continue to talk and act as though the community is full of exploiters, criminals and sexual predators who spend their lives waiting for an unguarded person with a disability. Great concern about 'stranger danger' is often expressed to me in the course of my work, even though there are few incidents which could be used to support this level of concern. On the other hand however, incidents of neglect, abuse and exploitation by people who are entrusted with the care of those who are vulnerable continue to occur on an all too regular basis.

It might be that because people with disability are guarded so well, only the guards have the opportunity to indulge in abuse and exploitation. It might be that the belief by some that they are unfairly shouldering the 'burden' of being with people with disability (even when they are paid to do so) justifies their abuse and neglect. Nevertheless it is the perceived threat from 'the community' which encourages measures such as congregating people with disability together in large groups behind high fences, where staff supervise rather than support, and guard rather than guide.

The portrayal of people with disability as burdens can come from unexpected places. I remember embarking on a literature review as part of post graduate study. I was interested to find the extent of research which examined the inequitable proportion of the burden of caring for elderly, sick and disabled family members undertaken by women within families. The problem here for us all is that whatever the importance of such research, it is based on an unchallenged assertion that people with disability (and other vulnerable family members) are unquestionably a burden. I cannot help but think that, when informing the development of public policy, such research carries with it a dangerous message about the perceived role of people with disabilities in harming other family members.

We have always been quick to note the barriers which isolate people with disability from the communities they live in. We spend much time devising ways to overcome the barriers with programs of 'inclusion, but we never seem to talk about the motivations of those who willingly participate in constructing the barriers in the first place. The motivation might be a misplaced concern about who poses a risk to people with disability. It could be a

financially driven exercise to increase dependence on service systems. It could be a desperate effort to avoid independent public scrutiny and accountability, or it could simply be a desire to protect personal power, authority, and control over other people's lives.

I believe that the most powerful force for effective positive change in the culture of community acceptance and support for people with disability are already in our hands. It starts with a simple recognition that those who are closely involved in the lives of people with disability are assumed to have expertise and credibility even if we do not seek, want or deserve it. We need to recognise also that 'the community' takes its cue from listening and watching what we do. Each word we say about people with disability echoes in countless ears, and each action we take is witnessed by hundreds of eyes. The 'good news' stories generated by the efforts of fundraising departments and Government bureaucrats are little competition to what the people actually see and hear in their own community.

Each time a child is described by what they cannot do or by how much aide time they need, each time a person is identified as a 'behaviour problem', each time people with disability are herded through public places in groups and are spoken to as though they are children, each time a group of adults with disability is taken to visit a tourist attraction which caters exclusively for children, each time a person with a disability is referred to as a burden to their family, each time a person with a disability is placed in an institution far from family and friends, all people with disability...all of them, are made more vulnerable. They are more vulnerable because these actions are powerful messages to the community about what experts think is appropriate for people with disability. The frequency of these messages is adding to the confusion, and is steadily eroding the still widespread belief in justice and a 'fair go' for people with disability.

Throughout this presentation I have used the lessons learned through my work to support the assertions I am making here. After twenty-eight years I have yet to see evidence to support the notion that the community is the source of problems for people with disability. I have found that the overriding issues of rejection, neglect, abuse, exploitation and isolation seem to be far more likely to be located with those who live with, care for, and work with those most vulnerable people.

Rather than feeling that people with disability needing to be protected from an uncaring 'community', we should acknowledge that the community itself has an important role in safeguarding the lives of vulnerable people. It is critical that the community be more than simply accepting and welcoming to its members who have a disability. People with disability need the community to be interested in how things happen, to ask

uncomfortable questions, to provide independent advocacy, and to demand that people with disability are treated with dignity and respect.

I want to conclude by saying, before others do, that in making this presentation, I have generalised extensively about the actions and motivations of those whose family and work relationships involve people with disability. I need no-one to remind me that many people with disability are surrounded and supported by those who are genuinely motivated to do what is in the interest of those persons. I also need no-one to remind me that there are those in the wider community whose fear, misunderstanding, and straight out selfishness, leads them to ignore, ridicule, and even harm vulnerable people with disability.

My personal experience however leads me to believe that such people are by no means representative. As I have stated, I believe that the community learns by watching, listening, and by taking its cue from those who maintain that they are the experts. It is clear to me that governments listen very carefully to the voices which are loudest in their claim to represent the views of people with disability and their families. Those loud voices are no longer the ones which clamoured successfully in the past for the closing of institutions and funding for personal independence. The loud voices now are shouting for new institutions, and more funding for supervised life wasting programs.

We might need to accept that personally doing the 'right' thing is just not enough. We might need to more actively challenge, debate and argue with those who, in a short sighted and short term pursuit of funding and career opportunities, act to promote and maintain the perception that people with disability are burdensome, because by doing so, they contribute to making all people with disability more vulnerable to being unwelcome in their own community.

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