

Learning with Amanda

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Abstract

Currently there is a great deal of rhetoric around the issues of equal opportunity, equal rights and community engagement. There is little demonstration that this talk is being followed through with action in the field of intellectual disability.

The political and social debate associated with community engagement, when it touches on disability at all, focuses primarily on those with a physical disability. People with an intellectual disability appear to be largely forgotten or ignored.

This paper reviews the effectiveness of a variety of approaches utilised to support a vibrant and dynamic intellectually disabled young woman to lead a meaningful and inclusive life. It pleads for the right of the intellectually disabled to be fully engaged with community to the extent that their individual capacity and potential permits. It looks at the limits placed on a whole section of the society by social constructs and fixed mindsets.

The authors, one the parent of a disabled daughter and both with a background in disability and community interaction, examine the constraints placed on intellectually disabled individuals by commonly held perceptions. They argue the need for a catalytic shift in thinking that permits a new focus on the support required to develop individual potential and effective community engagement rather than on disability as a generic condition where one size fits all.

The perspective that a flexible organic systems approach to support is more appropriate in many circumstances than a standardised institutional model of care is discussed.

Keywords

Disability, relationships, systems, constructs, engagement

Introduction

The 21st century is seen as an era of equal rights and equal opportunity, yet this rhetoric has only had a minimal impact on the lives of the majority of intellectually disabled people. There are, however, approaches that can assist those that society identifies as 'different', to live a full and inclusive life and more effectively engage with the broader community. Currently a whole section of society has limits placed on it by social constructs and mindsets focussed on limitations rather than opportunities.

This paper highlights the ordinary life of Amanda, a vital and lively intellectually disabled woman who leads a meaningful and inclusive life. The fact that her life is ordinary is extraordinary for the intellectually disabled in today's society.

The authors draw on their personal experience with the intellectually disabled and examine the literature. They also utilise a qualitative evaluation undertaken in 2004 that scoped the changes in Amanda's life, and the catalysts and impediments that could continue to impact on her quality of life. A qualitative approach was deemed appropriate for the study as it could not be limited to only what was able to be measured. Qualitative research allows the researchers to familiarise themselves with the topic, and the issues and terms involved in the discussion of the topic. According to Glesne and Peshkin (1992) qualitative research provides contextualisation, interpretation and an understanding of the actors' perspectives. Amanda's story is used in this paper as a touchstone to the theory, and to give the community engagement and disability issue a personal face for it is only through our relationships with intellectually disabled people that we open the doors to effective community engagement for them.

Additionally, the paper explores the theory that our modern culture places further limitations on the disabled, over and above those of their impairment by focussing on weaknesses not strengths. It identifies the need for a catalytic shift in thinking that permits a new focus on the support required to develop individual potential and effective community engagement. Furthermore it advocates the perspective that a flexible organic systems approach to support is more appropriate in many circumstances than a standardised institutional model based on disability as a generic condition and where one size fits all.

Who is Amanda?

The enigma called Amanda is multi-faceted in ways that are often contradictory. Amanda is now 35 and has been disabled since birth. She reads brilliantly but cannot tie a bow, she has a vocabulary unmatched by many educated adults but is not safe to cross the road alone. She loves her music, from Beethoven and Bach to ABC Play School songs. She will watch Swan Lake and Cats on video, but loves Thomas the Tank Engine and Postman Pat with equal passion. Amanda can be a brilliant hostess and raconteur and has a wicked sense of humour, but often seeks her own space.

Since leaving the family home about four years ago, Amanda's world has expanded and she has rushed to fill it. She has matured as a person. Both her living and social skill levels have improved. Amanda has never seen herself as 'disabled'; now living 'independently' she sees herself as an adult, equal to other adults and demands to be treated respectfully — and to be

effectively engaged with the rest of the community. Holistic approaches to meeting Amanda's support needs have enabled this to happen.

Amanda has a great zest for life and new experiences. Empowering Amanda has lit a fire in her of great brightness for all who encounter her to see and feel. Amanda considers herself independent and an equal partner in her community. How far can Amanda, or other intellectually disabled people go? Currently, community perceptions and outdated thinking on support provision generate impacts that may be as limiting for a person, as their original 'disability'. The Hon. Kevin Minson (cited Croft 2002, p. 164), when introducing the Disability Services Bill into the Western Australian Parliament in 1993, noted:

“A person with a disability is handicapped if the Community of which he or she is part does not enable that person to develop and live at the optimum of her or his capacity and to have opportunity equal to all members of that community to achieve happiness.”

Disability: A social construct

Until the late 18th and early 19th century, people regarded physical or mental impairment as part of the human condition. Communities accepted and cared for those suffering from a disability (Trent 1994 cited Rice 2002, p. 170).

The start of the Industrial Revolution changed this. It created a demand for efficient and skilled workers, and those who could not meet these standards were declared unfit, and excluded from paid employment (Russell and Malhotra 2002). This resulted in the disabled, particularly the intellectually disabled, being viewed as a social problem. It gave justification for excluding the disabled from mainstream life and transferring care from the broader community to institutions, workhouses, asylums and prisons (Ariotti 1999, p. 216).

Taylor (2004), who herself has a physical disability, supports Russell and Malhotra in thinking that the idea that an individual's worth is intrinsically linked to their production value is a construction of capitalism. She also suggests that impairment is the physical or intellectual abnormality that a person is born with but that disability is the “political and social repression of impaired people”, reflecting that the only commonality for impaired people is their political disablement. She comments that “Disablement is a political state and not a personal one” (Taylor 2004, para. 12).

By the late 1800s, some pseudo-scientists within the medical profession became convinced that feeble-mindedness was hereditary, a biological defect. Eugenists portrayed social deviance as evidence of the disease of feeble-mindedness and placed the source of social failure directly on individuals (Carey 2003, p. 412). A sharp divide was created: a two-class system of those considered 'normal', and those that were 'not the full quid'. Families were

encouraged to hand their 'abnormal' child over to the state, which would then care for it in an institution. Disability advocate Jeremy Ward notes:

"They (the service providers) tell us that they (the intellectually disabled) should live with 'others of their own kind', in groups not of their choosing, supported only by paid workers, being 'minded' and occupied during the day with activities chosen by others, isolated from much that occurs in their local community, not supported as contributors to society but the receivers of care and the clients of services" (Ward 2002, p. 4).

Despite recent rhetoric, the divide between normal people and the disabled has been maintained. In Queensland, deinstitutionalisation became a cause celebre in 1994–95, when under the Goss Labor Government legislation, funding was made available to commence the process of closing down Challinor, one of the large, government-run disability care institutions. However, many people who ostensibly moved from institutions into the community, found themselves in 'institutionets' and, behind a one-metre fence, just as isolated from community as they were previously behind a two-metre wall. The institutional culture and industrial practices had not changed and, as before, there was no capacity to engage with the community.

Furthermore, modern medicine still identifies disability as something undesirable that has to be cured (Leipoldt 2003, p 4.) and provides diagnostic tools that classify, grade and label limitations: physical, intellectual or mental. The belief that all impairments are deficits and need fixing, arising from the medical model of disability, is disputed by many people as it fails to acknowledge that it is not merely the physical or mental impairment that imposes limitations (Wiltshire 2004, p. 6).

Snow (2004, p. 1) notes that in today's society such labels have become essential if a disabled person is to receive a service, becoming a person's 'socio-economic passport' to the treatment and support required. However she further suggests that labels are also used to separate people within service 'systems' and from the broader community, indicating that labels are used as a means of segregating children with similar disabilities, classifying adults for group homes and predetermining the occupations that people may undertake. As the mother of a child with cerebral palsy, she also holds the perception that life changing decisions about disabled people are often made based on a 'one or two word characteristic we call a disability label', where service providers identify someone by their disability rather than their personality.

Rioux (1997) also believes that the current standard approach to disability has been dominated by the medical model, emphasising disability as an individual issue. He suggests that this perspective has failed to conceptualise and develop variables to measure the wider community impacts on the lives of disabled people. He goes on to note that the way in which

disability is “perceived, diagnosed and treated, scientifically and socially, is reflected in assumptions about the social responsibility towards people with disabilities as a group ...” (Rioux 1997, p. 3), with the two current major schools of thought linking disability to either disease or personal deficit, or placing it in a social and political condition framework.

Models and systems

After almost 200 years of separation, society no longer has a collective experience of disability being part of life and community. Our current level of thinking has placed an artificial divide between the disabled and the community. It is only through social interaction and community engagement that we learn to know each other. “And knowing people leads to acceptance of responsibility for them, and acting upon this responsibility rather than merely observing them from afar” (Leipoldt 2003, p. 2). Furthermore, Taylor (2004, para. 10) suggests that the disability movement has so far been unable to convince the ordinary people that existence of ‘impaired’ people in society is valid and essential.

If we as a society are serious about ‘equality’, ‘rights’ and ‘community engagement’, we must acknowledge disabled people as a normal part of community — individuals with support needs that certainly differ and may be greater than those of the majority of people. A need is not an option or a choice. By definition, it is a necessity (Croft 2000, p. 168). The able-bodied community has the ability to address its own needs, whereas people with disabilities are more dependent on others. However, “dependency is not unique to disabled people” (Finkelstein 1980 cited Ariotti 1999, p. 217).

The support needs of the disabled, like those of the general community, need to be met in a systematic manner. The system has to be responsive and appropriate for the person with a disability — not try to fit the person within a ‘system’ of medical or educational care that would more correctly be called a model. Systems by definition (Concise Oxford Dictionary, p. 1174) are a ‘complex whole’; they are flexible and pluralistic. Systems operate effectively on situational ethics that recognise variables, interconnectedness and ambiguity.

Models by definition are ‘simplified descriptions of a system’ (Concise Oxford Dictionary, p. 701) They are one dimensional, taking a one size fits all approach; dualistic, hierarchical and ill-equipped to cope with variability and individuality. The focus tends to narrow to that which can readily be measured, and nuances that are in the abstracts are ignored. Hence there is frequently little scope within the operational frameworks of many service providers for the flexibility to care for the social and emotional needs of their clients or allow for holistic approaches that deal with people as people, not disparate sets of disabilities or problems.

Disabled children and their parents are forced to cope with consequences of this type of service delivery. The work by Croft (2000) cites numerous personal examples of people

experiencing enormous difficulties with current approaches to disability support service delivery. These included parents, Mary Louise and Ian Allen, who struggled with a situation where:

“For over six years Simon attended a special school where, for at least three years, he was the only child who was mobile or had language skills. There were no peers to act as social models” (Croft 2000, p. 72).

Another Western Australian parent, Sue Ball, also noted in frustration:

“I was involved with doctors, (Neonatologist, Neurologist, Cardiologist, Ophthalmologist, Gastroenterologists, Paediatrician, Geneticist) therapy (OT, PT, ST, Psychologist, Social Worker, and diagnostic tests (hip, gut, heart ultrasounds, barium swallow, EEG, ABR, blood tests)” (Croft 2000, p. 73).

Furthermore, many models of service provision for the disabled are developed to improve the efficiency or cost/ benefit ratio for the organisation or institute that develops them. The benefit of the disabled person with whom they work may be considered but the benefit of the institution/organisation is given primacy. Another of Croft's examples, Tony and Rosalie Sexton, parents of a Downs Syndrome child, reflected a common perspective when they noted:

“We are frequently challenged with circumstances that we believe have a negative impact due to what we see as a lack of commitment by some providers who rate accountability policies and procedures higher than the client or the support they require” (Croft 2000, p. 42).

Noted academic, disability advocate and quadriplegic Erik Leipoldt tells a personal story that also highlights this issue. He relates approaching his local Western Australian Hospital for a change in one of his usual prescriptions, as it had proved to be totally ineffective over a substantial period of time. He was advised that the hospital had already ordered six months supply of that brand for him to fit in with their new budget cycle and that they could not possible change orders just because “every Tom, Dick or Harry requests it” (Leipoldt 2004, p. 4).

Unfortunately, community experience indicates that even when the families and friends of the disabled unite to improve conditions things may go astray. When community people get together to meet a common need or goal, they are naturally part of and connected with society and therefore flexible and responsive to individual needs and differences. However, as these groups grow into organisations — because of size and complexity, and frequently influenced by funding arrangements and accountability requirements — the spontaneity and flexibility of the holistic systems approach seems to become lost. There then seems to be a natural move towards simplification; rather than innovation, code ethics rather than situational

ethics, self-righteous certitude rather than a learning environment. If this process continues the organisation will become less and less responsive to the individuals' needs, (clients and staff), and more and more output, rather than outcome-oriented. Some classic examples of this can be seen when the service provision of some of the larger disability organisations are examined. However, this paper does not want to focus attention on specific organisations rather to examine the overall effectiveness of current approaches to disability and the mindsets behind them.

A holistic and systematic approach to an inclusive life and real community engagement for the intellectually disabled requires 'different values and strategies than those embedded in the dominant paradigm of individualistic detachment' (Leipoldt 2003, p. 2). Systems must support disabled people as individuals within the community; engagement must acknowledge the importance of relational processes that give life meaning.

Will you learn with me? Love Amanda

The evolving story of Amanda provides empirical evidence of what can be achieved when community engagement and effective relationships become part of the life of an intellectually disabled person. Amanda lived in the family home well into adulthood. Amanda's parents, becoming aware of their mortality and Amanda's need to have her own space and lead her own life, sought help from Disability Services Queensland (DSQ). In 2001 Amanda was offered a small Individual Life Style Support funding package, and shortly after a place in a departmental group home. This accommodation model focuses on caring for those who cannot care for themselves. It has little capacity for skill building or community interaction.

As the other residents in this group home, were far more disabled than Amanda, her skill levels deteriorated. Behavioural problems also escalated with lack of personal space and limited community access identified as the main causes. To address these issues the department signed off on a support plan designating Amanda's funding package be used to provide her with community access and skill development. Through a non-government service provider, a self-directing support team was created to provide Amanda with about 18 hours a week of community access and appropriate skill building.

However, life in the group home placed severe limitations on the opportunities for skill building. Furthermore, Amanda's community access was driven by the need to give the other residents breathing space away from her, rather than Amanda's desire to be involved with the broader community.

A satisfactory solution to these dilemmas was reached in late 2003. Amanda was offered a 'granny flat' across a double garage from a group home with three profoundly disabled residents. The department is the main service provider and the house is run according to

departmental protocols. The small distance that separates Amanda from the main house has opened a world of opportunities for her. The community access team now has a situation where they can create a real learning environment. For the first time, Amanda has choices about food, activities, clothes, and in what room in the flat she wants to spend her time. Choices we take for granted but that Amanda was previously denied. It is through the choices each person makes s/he expresses their individuality in ways that lead them to fulfilling their potential (Croft 2000, p. 165).

Amanda is now setting the pace. Staff and friends identify huge positive changes in Amanda's confidence, independent living skills and ability to effectively engage with community. In the Paton evaluation (2004) of Amanda's progress, participants reflected on some of the key elements they saw as contributing to Amanda's development.

“Being more independent in her own home. Her support workers encourage her to interact with other people — they involve their families and friends — make it a lifestyle experience, more like a normal life — not institutional. Away from home and away from parents.

She doesn't see herself as being disabled. Boland St. (the address of Amanda's unit) equals equality for her. She behaves as an equal. She has always seen herself that way but never had the opportunity. She feels she can contribute. She is responding to respectful relationships, in the way that people normally respond” (Paton 2004, pp. 9-10).

Participants clearly indicated that it was greater interaction with community, the capacity to develop friendships and the feelings of equality and contribution that were empowering Amanda.

Necessary paradigm shifts

Leipoldt (2004, pp. 5-6) notes that there is significant research indicating that even people with major impairments report a sense of fulfilment or wellbeing equal to, or better than, that of the broader community. This challenges the popular paradigm that life with a disability is wretched and unhappy. The factor recognised as being the prime contributor to life satisfaction for the disabled is their ability to form quality relationships and therefore is no different to the experience of the general population. However, perhaps because of their inherent dependence on others for basic care, many of those with disabilities recognise the real interdependence we all have on each other. By the deliberate creation of shared and committed relationships, people are able to rise above the downside and problems of dependence and find real pleasure and enjoyment in life.

Those with physical disabilities have capacity to initiate and develop the meaningful relationships that can provide this sense of wellbeing even in trying situations. However, the intellectually disabled, those with cognitive disabilities, are dependant on their families, carers and the broader community to provide them with the opportunities to develop relationships to the best of their capacity. To do this society must acknowledge and accept the simple humanity of the intellectually disabled.

MacIntyre (cited Leipoldt 2000, p. 4) offers an enlightening perspective as he explains 'disability' to be part of the human condition. This indicates that to consider people with impairment as not human alienates us from our human nature and is illusory. There is no separateness — a popular truism captures both the common elements and differences that effect us all when it notes 'A man is like no other man, and like every other man'. The intellectually disabled do feel pain and hurt and fear. They also laugh and love. They are part of our community and do have the right to be invited to be engaged with it. The relationships in Amanda's life are both a source of great pleasure for her and a source of great pleasure for those involved with her.

The research undertaken in 2004 identified that all those closely associated with Amanda enjoyed her company, valued their interactions with her and strongly cared about her emotional growth and happiness, not just her physical wellbeing. The question about why they like being with Amanda was greeted with enthusiasm and big smiles by research participants. Amanda's sense of humour was identified as a delight by most people. "Her cheerfulness, her conversations, her honesty, her 'WOW personality', her versatility, her love of animals, her affection, and spontaneity were also seen by many as sources of joy in being with Amanda" (Paton 2004, p. 6).

This finding is challenging on several fronts. First, it clearly identifies that those without disability can get real pleasure and satisfaction from relationships with those that are intellectually impaired. Second, although Amanda herself cannot always clearly articulate concepts and emotions, her behaviour and the insights of research participants closely associated with her, indicate that Amanda herself does have a happy life, made all the richer through broad community engagement and her capacity to interact with a diversity of people and in a wide range of situations. Third, the single most important factor in creating this situation is the willingness of many of Amanda's paid support staff to step beyond the client/carer paradigm into a real relationship of mutual respect and friendship.

Operating on a traditional paradigm, many support services and government departments actively discourage the development of close personal relationships between carers and clients. First, it is seen as 'not professional' and, in line with the medical model of disability, appears aligned to the doctor/patient model of relationships and in many instances is

focussed solely on maintaining the physical integrity of the person. Second, relationships between staff and clients are frequently presented as placing the staff member in the position of 'conflict of interest'. We must ask ourselves: 'How can this be?', if the institution, agency or service provider is truly focussed on working in the client's best interests and providing quality of life as well as physical care. The traditional paradigm assumes that the intellectually disabled either do not require love or friendship or that they are able to meet these needs outside the care network. The perception from the medical community that 'children like that don't need love' (Smith 1997 cited Croft 2000, p. 170) was, in the past, also used as justification for institutionalising them.

The work done with Amanda supports the Schalock study (cited McConkey et al. n.d., p. 3), which notes that the two most important aspects of quality of life for intellectually disabled people in residential care are: "the quality and breadth of interpersonal relationships with family and relatives, and the extent of residents' involvement with their local community and their social inclusion in it."

O'Brien (1999, p. 2) notes that for many intellectually disabled, 'friends' include individual care workers who have a strong personal commitment to the wellbeing of their client, and are identified by that person as a friend. He further suggests that excluding people from the possibility of friendship on the basis of their role alone runs contrary to the personal experience of many disabled people and their families, noting: "Such exclusion by definition denies the fact that some service workers do transcend their roles."

The reality for many cognitively disabled people is that they do not have the consciousness, capacity or opportunity to initiate meaningful relationships for themselves. Yet, as previously noted, it is the quality of our human interactions and the depth of our relationships, which add real value to our lives. However, the development of equal and respectful relationships does not just 'occur'. Relationships require an initial and continuing commitment of energy from both parties. Paton (2002, p. 8) notes that effective relationships are not warm, fuzzy options but require work to keep functioning efficiently. The level of the input into each relationship is, of course, inherently linked to the capacity of the people involved. Yet paradoxically while people with intellectual disabilities may be limited in the conscious contribution they make, many like Amanda, when provided with the opportunity to form relationships, give everything they have to give in love, loyalty and commitment. A comment by one of Amanda's friends highlights the value she finds in this relationship:

"She teaches me things, and I also learn from other peoples' interaction with Amanda, she sees and feels everything and she can communicate this. Feelings come to life — she makes you take notice of the ordinary. She has her view; she is childlike but not childish" (Paton 2004, p. 15).

Croft (2000) again presents us with many examples, this time, of those who do find enjoyment in the company of the cognitively impaired, including Sue Ball, the mother of an intellectually disabled six year old who notes: "My daughter Emma is a delightful child, appealing and affectionate" (Croft 2000, p. 73).

Furthermore, whilst acknowledging that the capacity of intellectually disabled people to develop and maintain complex relationships varies, we must also understand that this is no different for individuals in the general population. Even though we recognise the difficulty for intellectually disabled in initiating relationships and consciously working to maintain them, we cannot deny that the relationships developed and maintained by others enrich the lives of all concerned and give meaning to the life of the disabled person. Leipoldt (2004, p. 6) comments: "Improving the experience of disability depends on a social model that recognises that first and foremost our wellbeing lies in good social relations".

Dowrick (2000, p. 436) relates the story of a profoundly intellectually and physical disabled person and his relationship with a volunteer carer who visits daily. Although deaf, blind, non-verbal and severely limited in movement, the disabled person indicates by his behaviour, (smiling, moving and noises) his awareness and pleasure as soon as his visitor enters his residence, even though he may be many rooms away. She notes that although 'Geoff' is someone who appears to have minimal powers of comprehension, his ability to sense his visitor's presence and to draw consolation and pleasure from it is acutely evident. This tale serves as a reminder that we should continue to challenge our own paradigms about the capacity of others to draw satisfaction and comfort from relationships.

Additionally, in an environment of an ageing population, there is the issue of ensuring on going love for the intellectually disabled, not just their physical care, as parents become incapacitated or die. One approach, that has achieved international credibility, is the establishment of a 'Support Circle' or a 'Circle of Friends' to have oversight of the care and support of the intellectually disabled person, in the long term. However, although this approach may ensure ongoing attention to the operational issues related to dependence, to provide the real value of friends to the emotional life of the person concerned, those involved in the 'Circle of Friends' must have an actual relationship and meaningful interaction with them, not just be associates of parents, siblings or 'people doing their job.' Ward (2002, p. 3) asks why, if we as a general community want our children to love and be loved, to have strong friendships and cherished relationships, to live independently, to contribute to society, to take pleasure in activities of their own choosing, to have full, enjoyable and inclusive lives and to be able to continue to learn and grow, we expect parents of an intellectually disabled to accept anything less for their child?

Therefore, holistic and real systems approaches to providing support for the intellectually disabled to become an integral and not peripheral part of our communities must provide the maximum possible opportunities for social relationships, community interaction and engagement. Yet to maintain the integrity of always working in a respectful relationship with others, this interaction must be aligned to the cognitive ability of the disabled and must never be tokenistic.

Another paradigm, utilised by some support agencies, is the concept of assisted decision-making. Generally this equates to the need for clients to be present at all discussions related to their welfare. Anecdotal evidence in the disability community shows that there is deep-seated apprehension and distrust for this approach, with many identifying it as a 'bureaucratic band-aid', both patronising and tokenistic. This paradigm cannot be considered actual community engagement if the client has no interest or understanding of matters under discussion.

For the service providers it appears that it is the formality of the process that gives it legitimacy, i.e. the client being involved in a formal meeting can be ticked off as 'client consulted' or 'client involved'. In reality, assisted decision-making is an intrinsic part of life, community and living. As part of the general community, we accept the input of others into everyday decisions affecting us. We receive this advice both formally and informally, limited only by our capacity and desire to be involved. We accept this as a right. For instance, when a doctor or mechanic provides options and then offers us advice and guidance so that we may make an informed decision, this is a form of assisted decision-making. We are not told what to do; we are assisted in making a decision for which we accept responsibility, and which we own: a decision that we otherwise would not have been able to make.

The advice and support provided is no less meaningful because it is given in a workshop or classroom and not in a formal meeting. Frequently too, a relaxed and informal situation, allows us to be relaxed in receiving information and having input. Strongly formal situations may be very stressful to those not used to dealing with them or feeling that they have little control over the end result. O'Brien (1999 p. 12) indicates that when it comes to the decision-making aspect of community engagement, informal situations such as 'kitchen table conversations' that involve the disabled person and their family/friends communicating in an atmosphere of trust, allowing fundamental questions to be discussed and enabling the disabled person to have appropriate input, present maximum opportunity for success.

To achieve the optimal level of community engagement and the best possible end result for the disabled person, the focus must be outcomes not outputs. Not 'was the person engaged in a meeting', but 'was the person appropriately advised of the issue, did they have the opportunity to voice their feelings about the matter (either directly or indirectly), were their

views taken seriously and most importantly are they comfortable with the outcome and is it in their best interest'. The appropriateness of the involvement in decision-making is crucial. For example, past experiences indicate that Amanda does not identify herself as disabled, and hence expects to be treated with respect as an equal. This has taught her family, friends and carers that unless she has equity in the decision she will not take responsibility. Her response and body language make it clear that she dislikes being patronised.

Just as physical access is an issue for the physically disabled, access to the opportunities for love, friendship, emotional growth and appropriate and worthwhile input into decision-making is an issue for the intellectually disabled and those who love for them. This is community engagement in its actual and most fundamental sense — to be recognised and accepted as an integral and contributing part of the broader community.

Opening the door

If the general population has a genuine intent to engage the intellectually disabled as part of community and break down the barriers imposed by the social constructs that surround disability and in particular cognitive disability, then there must be a radical shift in thinking by support agencies, government services and the community itself. People with disabilities must first and foremost be recognised and accepted as just that: people with personalities, strengths and weaknesses, who happen to have a physical or intellectual impairment.

Many of the current models of support provided for the intellectually disabled are focussed primarily around the disability with little flexibility or capacity to deal with personality, emotional needs and the luxury of providing clients with opportunities for friendship and community engagement. Furthermore, if paradigm shifts are to occur, the service providers themselves must focus conscious attention on eliminating the barriers imposed by social constructs. This is best achieved by actions not rhetoric.

The catch-22 is that those with physical or intellectual impairment will only be accepted as part of the community when they are able to interact with the broader community in ways that support the maximum opportunities for community engagement and relationship building. Yet there are still many social constructs and traditional paradigms that prevent the intellectual disabled from engaging with community, even where physical access is available.

O'Brien (1999, p. 9) suggests that the only way to move forward towards real community engagement for those with impairment, is a two-pronged proactive approach that needs to be driven not only by those with a disability and/or their families but also by those who work with the disabled.

He identifies the two essential elements as:

1. A much greater interaction between the broader community (people and organisations) and the disabled and their families
2. A more organised and systematic approach to influencing decision-making, by the disabled and their families and friends.

This culture change can only be precipitated through creating circumstances that allow the development of personal relationships and alliances; providing opportunities for people to make real contributions to their communities and by allowing the development of supportive alliances that can influence policy and decision-making associated with disability support.

Conclusion

Dualistic and hierarchical models of care do little more than maintain a status quo in health and wellbeing of those with disabilities. A flexible systems approach that empowers staff and supports clients as people, not disabilities, is pivotal to the relationships of mutual respect essential to community engagement. O'Brien (1999, p. 9) clearly states that to achieve more effective community engagement we will require the compassionate cooperation of employers and the growth of new and more receptive forms of personal support.

Amanda's experience has shown that a holistic focus on 'what is best for the person' can provide amazing results. By empowering Amanda through giving her options and choices, authority and responsibility and real opportunities for community engagement, she is constantly evolving and moving towards her potential of living a meaningful and inclusive life.

If intellectually disabled people are to effectively engage with their community then this has to happen through adaptive systems that sustain and empower the disabled person, enabling them to develop credibility and respect in the community. And again the Hon. Kevin Minson (cited Croft 2000, p. 166) reminds us of something we as a community cannot afford to forget when he suggests:

"The extent to which disability, becomes a handicap, ... is a matter over which we, as a community have some control. By providing choices and opportunities for people with disabilities we can all take part enabling them to play their roles as equal and valued members of society."

However, when it comes to summarising the key element of community engagement for the intellectually disabled, perhaps a traditional aphorism expresses the necessary process most simply, when it says:

Don't walk in front of me, I may not follow.

Don't walk behind me, I may not lead.

Walk beside me and just be my friend.

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