

## Inclusion and quality of life: Are we there yet?

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### Abstract

This paper discusses various barriers people with intellectual and developmental disabilities are facing in achieving social inclusion and a good quality of life. It is proposed that a key aspect for a person to perceive their having a good life quality is their self-identity or self-image. It is argued that there is a critical link between the concepts of quality of life and genuine community inclusion for people with intellectual disability. Inclusion and quality of life are examined within the context of philosophical, economic and political forces. The building of social capital, community capacity and the development of interdependence as an antidote to rampant individualism will be explored. The development of an ethical community could provide a framework in which to meet the broader societal challenges that not only face disadvantaged groups, but the community generally.

**Keywords:** Quality of life, inclusion, intellectual disability

*No man is an island, entire of itself;  
Every man is a piece of the continent,  
A part of the main.*

John Donne, Meditation XV11

### Introduction

Quality of life has become a ubiquitous phenomenon in the field of intellectual and developmental disabilities (hereafter intellectual disabilities) since the groundbreaking work of scholars such as Roy Brown, David Goode and Bob Schalock who first wrote on the concept in the late 1980s. It is extremely useful to understand the history of the concept, which probably had its origins in the Aristotelian expression eudaimonia that Aristotle referred to as an objective degree of satisfaction of your needs and living a life of virtue. Early Greek philosophers rigorously debated the relative merits of objective and subjective

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aspects of the good life. In more modern times, Thorndike (1) was one of the first scientists to study the quality of life on American cities in the 1930s, specifically in terms of objective characteristics. However, most contemporary writers agree quality of life consists of both objective and subjective dimensions. The concept of “well-being” is suggested by some as a preferred concept to “quality of life” (2).

Various approaches to the concept, including the measurement of health outcomes, have been adopted in the health field; including intensive work by the World Health Organization (3). To some extent, researchers in the field of intellectual and developmental disabilities have not entered into the broader debates on the usefulness of the phenomenon (4,5).

Again, we need to embrace wider world contexts in our debates concerning issues which appear highly pertinent to our field of inquiry. It is suggested that we need to explore concepts in our field through the prism of the broader historical, philosophical, moral, economic, social and political contexts within which all people exist. We are in danger at times of being too introspective in our consideration of research, policy and service issues relating to people with disabilities. Hence, this paper explores issues related to social inclusion and quality of life for people with intellectual disabilities in the context of forces in the wider community. Without this broader perspective I am afraid these concepts run the danger of becoming mere rhetoric, largely ignored outside of the disability environment.

## Self-image and quality of life

I recount a worrying phenomenon in the context of the London Paralympic Games held in 2012. There were glowing reports in the world media on the remarkable achievements of athletes with disabilities and corporate sponsors were anxious to bask in the glow of those achievements. However, when questioned as to whether they would invite these athletes to become involved in sponsoring their products, as is the case with famous sportspeople without disabilities, there was an ominous silence. Apparently, they were not prepared to risk the possibility of the negative attitudes the general

population still holds towards people with disabilities affecting their product image.

It is the image people with intellectual disabilities may have of themselves, however, that I want to address. My proposition is that without a sound image of themselves, this population would find it difficult to experience the feelings of well-being or quality of life. Despite having suggested that we need to address issues in the disability field in wider contexts, there is a case for analyzing the concept of quality of life through the lens of the epistemology of disability (6); in particular from a symbolic-interactionist viewpoint (symbolic interactionism, a sociological theory, that suggests the way we learn to interpret and give meaning to the world is through our interactions with others).

The negative stereotypes and attitudes toward people with intellectual disabilities are pervasive (7,8) and impact upon the development of their self-image. In his discussion of the phenomenon of labeling, Burbach (9) suggested that people with a disability are in a double-bind situation. In coming to terms with what it meant to be disabled, they are confronted by two, at times conflicting, messages. One comes from outside and is influenced by the social order. The other comes from within and relates to what they know they can or cannot do. So, on the one hand they have to come to grips with the negative aspects of their personal condition, and on the other, cope with the negative effects of stigmatization and stereotyping. I have earlier suggested (10) that, “from a philosophical position there is a conflict between the existential nature of the person and the social nature of human experiences” (p. 267).

One of the factors that impacts upon both the internal and external image-influencing process is the traditional assessment and classification system that surrounds the diagnosis of intellectual disabilities. The person is continually assessed on their perceived deficits and weaknesses, rather than upon what they can do. The move to a classification system which looks at the competencies, needs and plans a person with intellectual disabilities has, and the supports s/he may need to perform them, has been a welcome initiative (11). Elisabeth Dykens’ (12) call for an emphasis upon positive psychology in the context of intellectual disabilities is apposite:

“While mental retardation (sic) is indeed defined by negatives, and the field caught up with the external, I propose a future research and practice agenda based on *positive internal* states, including happiness, contentment, hope, engagement, and strengths. In making these conceptual shifts, I turn to recent breakthroughs in mainstream psychology, and show how aspects of positive psychology apply to those with mental retardation (sic). ... Positive psychology benefits those with mental retardation (sic) and this population can uniquely inform positive psychology” (p.185)

The “capabilities” approach of Amartya Sen (13) and Martha Nussbaum (14) also focuses on positives rather than negatives. For instance, Nussbaum has proposed ten central human capabilities, which are embedded in a social justice framework and resonate with many of the theories of quality of life. Nussbaum’s central human capabilities are: Life; bodily health; bodily integrity; senses, imagination and thought; emotions; practical reason; affiliation; contact with other species (e.g. pets); play; and control over one’s environment. Dixon and Nussbaum (15) commented that, “Nussbaum has argued that, as bearers of equal human dignity, adults with cognitive disabilities are entitled to all the capabilities on the list, up to the threshold level set for all (p. 549)”. This approach is also an antidote to utilitarianism, which will be addressed later.

People with intellectual disabilities are faced with conflicting messages when trying to establish a coherent meaning for life, as well as creating and maintaining self-esteem. They can either exist in an isolated and over-protective environment which leads to socially un-validated meanings, or they can conform to the patterns of behavior expected of them by society generally. Neither of these approaches leads to a satisfactory resolution to the question of how these people define their own meanings. This brings us to the nub of the quality of life issue. In this context I have suggested that, “quality of life represents the degree to which individuals have met their needs to create their own meanings, so they can establish and sustain a viable self in the social world” (10, p.267). The principles of symbolic interactionism suggest that there is a need for co-sensuality whereby humans help each other unfold and establish contact and unity in their social existence.

It is interesting that the special education curriculum for students with intellectual disabilities used to place strong emphasis upon the notion of “social competence” (16). Early research into the preparation for employment for this population also emphasized the importance of building of social skills and relationships (17,18). The building of social relationships for people with intellectual disabilities provides a mechanism for reciprocity and the development of a positive self-image.

Within a symbolic-interactionist/ecological theoretical perspective I developed a quality of life model (10) which included three interactive components: the person’s conceptualization of self; the person’s functional behaviors within the environment; and societal responses the settings might make to the individual. The *self* component included both cognitive and affective domains; the *functional* included areas such as social interactions, occupational/material wellbeing and community living; and *societal responses* included attitudes, value systems, economic and political circumstances and access to support services. It is proposed that the strength of the model lies in its emphasis upon how well the person with an intellectual disability perceives him/her self within a community. What is paramount is the level to which the person grows and develops as an autonomous individual within an interdependent societal context, with an opportunity to achieve his/her hopes and aspirations, a key feature of the contemporary person-centered approach to life long planning (19).

This argument would also resonate with the challenges families with a child with a disability may face. In many cases, parents and siblings tend to isolate themselves from friends and the wider community, fearing stigmatization and rejection. In one of my research studies the father of twins, both with disabilities, purposefully committed an offence which led to a jail term, because he was unable to cope with the pressures of having two children with disabilities. This is not an isolated case of family breakdown as a result of the psychological pressures brought about by the birth of a child with a severe disability.

As principal of a special school for students with intellectual disabilities one of my tasks was to assist them to develop resilience to counter the

stigmatization they received from students from mainstream schools who used the same public transport. In fact, one of the major reasons for their enrolment was that the regular school system had rejected them. My staff and I worked with the families who experienced a similar degree of rejection, to help them build pride in their children's talents rather than concentrating solely upon their weaknesses.

On another positive note, research has demonstrated that families, and mothers in particular, valued the opportunities that early intervention programs and playgroups afforded them to develop friendships with other families with or without children with disabilities (20,21).

## Moral status of people with intellectual disabilities

Historically, society's continued denial of the humanity of a person with intellectual disabilities, as well as its seeing such persons as a disposable commodity, challenges us. The question of the personhood of people with intellectual disability has been an issue since antiquity; from Plato and Aristotle through to Luther and Locke. Each of these writers proposed that an intact intellect was the *sine qua non* for humanness. For Plato, low intelligence was something to do with the nature of slave mentality (22). Aristotle (23) maintained that:

“...the deliberative faculty is not present at all in a slave; in a female it is present but ineffectual, in a child present but underdeveloped”

Martin Luther saw demonic forces underlying mental disorders:

“Idiots are men in whom devils have established themselves, and all the physicians who heal these infirmities as though they proceeded from natural causes are ignorant blockheads, who know nothing about the power of the demon” (24)

Despite ushering in the “Age of Enlightenment”, John Locke (1623-1704) maintained that the defining characteristics of personhood were rationality and

consciousness, including self-consciousness. Locke's writings reflected the widely held view that persons with intellectual disabilities do not attain the same level of personhood as those of higher intellect. He drew a comparison between animal and “idiot” intellect (25).

In more modern times, the concept of *otherness* of persons with intellectual disabilities was developed by people such as the epidemiologist Dr FG Crookshank, who in 1924 asserted that Down syndrome represented a regression to non-human species (22). Likewise in 1968, Boyd and Fletcher [cited in Parmenter (26)] proposed that someone with a disability such as Down syndrome is not even a person. Goodey (22) in this context commented,

“It would hardly be surprising, given how all the historical evidence shows that the psychological characteristics of modern intellectual disability are a distillation of former social, racial and class stereotypes”. (p. 245)

In answering the question as to what lies at the heart of this *otherness* and its consistent and potent source of oppression for this population, Stainton (21) suggested that, “...intellectual disability strikes at the very heart of classical and modern ideas of value and humanness” (p. 115). Clapton (27) argued that, “...Judeo-Christian beliefs and practices have intersected with philosophical notions of the superiority of the mind, the orthodoxy of reason, the primacy of rationality, and the control of the body” (p.36). In 1985 the Australian bioethicists Helga Kuhse and Peter Singer (28) wrote:

“Decisions about severely handicapped infants should not be based on the idea that all human life is of equal value, nor any other version of the principle of the sanctity of human life. ... There is, therefore, no obligation to do everything possible to keep (them) alive in all circumstances. Instead, decisions to keep them alive - or not to do so - should take into account the interests of the infant, the family, the next child, and the community as a whole”. (p.172)

More recently Singer (29), suggested:

“To have a child with Down syndrome is to have a very different experience from having a normal child. It

can still be a warm and loving experience, but we must have lowered expectations of our child's ability. We cannot expect a child with Down syndrome to play the guitar, to develop an appreciation of science fiction, to learn a foreign language, to chat with us about the latest Woody Allen movie, or to be a respectable athlete, basketballer or tennis player". (p.213)

It is illuminating that research portrays a dramatically alternative view of the capabilities of people with Down syndrome and people with intellectual disabilities more generally.

Commentators, including Carlson (30), Kittay, (31), Nussbaum (14), Reinders (32), and Sen (13), have questioned the utilitarian bioethics approach to the issue of the personhood and the moral status of people with intellectual disabilities. They have essentially asserted that all human beings have the same moral status, irrespective of their cognitive capacity. On the other hand, bioethicists such as Singer (33) and McMahan (34), who ascribe to the utilitarian reductionist approach to ethics, based on the principle of the greatest good for the majority, argue that moral status does depend upon some aspects of cognitive ability, a view that can be applied to humans and nonhumans. Their position is that as some animals have a higher cognitive capacity than people with severe or profound intellectual disabilities, it should follow that animals can be elevated to the moral status of humans.

Philosopher and mother of a daughter with severe intellectual disability, Eva Kittay (31), suggested that philosophers need(ed) to uphold two fundamental ethical precepts in their philosophizing. This injunction is extremely apposite in the context of the utilitarian view. The first is *epistemic responsibility*, which means knowing the subject that you are using to make a philosophical point; and the second is *epistemic modesty* which means knowing what you do not know. Kittay has argued that writers such as Singer and McMahan simply do not have sufficient personal experiences of living with and knowing people with severe intellectual disability, hence her emphasis upon the two ethical principles. To support her argument, Kittay related her witnessing a resident with a severe to profound intellectual disability living in a group home with her daughter, mourning the death of his father. Here her argument was that this is evidence of the humanity of this person. Singer and

McMahan, however, might respond that elephants also demonstrate the capacity to mourn the death of one of their herd.

It is interesting that as Singer over the years has come to recognize the capacities of people in the mild to moderate range of intellectual disabilities (for example those with Down syndrome); his case now rests more on those with severe to profound levels of intellectual disabilities (31).

There are those, however, who question whether reliance upon the moral status of people with intellectual disabilities provides sufficient protection from harm. In his philosophical reflection on the notion of moral status, Silvers (35) has argued that,

"Appeals to moral status do not settle debates about whether there are obligations to provide protection and support for individuals with disabilities, because the idea of moral status is as contentious as the disagreements it is invoked to resolve". (p.1014)

Silver proffered an alternative approach, guided by the values and procedures contained in inclusive theories of justice.

In his book, *The future of the disabled in liberal society: An ethical analysis*, Reinders (32) suggested an approach beyond what he termed "the narrow conception of morality". In essence, Reinders argued that each of us has a moral responsibility for dependent people that has a different basis than a conception of the person in the liberal sense. For instance, he suggested that:

"...dependent others are accepted because their lives are placed in our hands. We can reject their existence and consider their lives are not worth living. We can leave them to be taken care of by their families and grant them the right to be sovereign of their own lives. But we can also accept responsibility for the fact they are part of the web of social relationships that constitute our moral world". (p. 153)

I find Reinders' approach to the moral status of people with intellectual disabilities compelling, for it brings us back to the identity issue - not so much the identity of the person with the disability, but to our own moral identity in relationship to how we react and respond to them - giving, but not necessarily expecting anything in return. Reinders' position is

also very pertinent to the nature of family quality of life in the context of having a child with a disability.

## The notion of inclusion

In her *A transformatory ethic of inclusion*, Jane Clapton's (27) concept of a "metaphorical quilt" provides a useful framework within which to examine various perspectives of inclusion/exclusion. Her "quilt" provides a meta-discourse on the meaning of disability; four pieces of which are: profound exclusion, technical inclusion, legislative inclusion and ethical inclusion.

- **Profound exclusion** describes a view that embraces the undesirability of people with intellectual disability and their being a threat to society. The intention is to exclude them from society in institutional settings. Intellectual disability is perceived as a tragedy and associated with burden and uselessness. Thus, debates about sterilization and eugenics, prevalent in the institutional era, consider that the sacrifice of people with disabilities is for the greater good.
- **Technical inclusion** focuses on needs and the provision of supports in the least restrictive alternative in the community. Philosophies of Normalization and Social Role Valorization are embedded in this perspective (36). The focus is on technologies to facilitate community living, based upon a negative deficits-based ideology. This perspective results in human service workers being needed in all facets of the lives of people with lifelong disabilities. The underlying theme is that their care needs to be "managed" by bureaucratic, administrative and professional procedures, including professional assessment processes to determine eligibility for care and support. While people with intellectual disabilities may be physically present in the community, they remain socially segregated. In other words they are IN, but not OF a community.
- **Legislative inclusion** adopts the discourse of human rights and citizenship. Independence

and autonomy are prized over dependence; and support over care. This is a movement to address social oppression and instill socio-political change. Claiming to have the same rights as others, people with intellectual disabilities find themselves in the paradoxical situation of seeking equality by highlighting difference. Legislative inclusion assumes moral agency, rationality and autonomy; whereas people with intellectual disability may require or prefer inter-dependent relationships. Because of this, people with intellectual disabilities are potentially disqualified from legislative inclusion. The emphasis here is on the *public* domain.

- **Ethical inclusion** refers to an ideal. It is readily observed in the *private* arena of relationships of acceptance. The emphasis here is not on independence, but inter-dependence, mutuality, flexibility and possibly chaos as diversity and complexity are privileged over "normal". This view accommodates difference and redefines moral personhood.

The deinstitutionalization movement which commenced in the late 1960s in Scandinavia was a reaction to the wrongs of the period of profound exclusion which not only enveloped those with intellectual disabilities, but also many others on the margins of society. The simplistic response to institutional living was to relocate former residents into small group homes in regular community residential settings in the belief that physical presence alone would lead to community acceptance and inclusion.

Research has shown that in many cases the characteristics of institutional living remain, irrespective of the size of the residence (37). For instance, basic choices, such as with whom the residents would like to live, were in most cases arbitrarily ignored, and the situation today has not much changed in this respect.

### *Technical inclusion*

The move to what Clapton described as "technical inclusion" was based on the political realities at the

time, that paid “care” was still required, but little thought was given to the underlying rationale as to why these people were segregated in the first place. The prevailing philosophy at the time was the need for training to promote “independence”. This stemmed in part from researchers, whilst working in the institutional settings, who were able to demonstrate the learning potential of this population (38,39). Their research findings and subsequent advocacy contributed significantly to the groundswell of agitation which led to the closure of the large segregated settings. The logical positivist movement, based on the early work of psychologists Watson and Skinner, certainly made significant contributions to improving the functional behaviors of people with intellectual disability (40), but little attention was given to the development of relationship skills and friendship network building.

Schwartz (41) has provided an eloquent description of the concept of “technical inclusion” which illustrates the underlying neo-liberal/classical approach most western countries have embraced in providing human services to disadvantaged populations. He described this as the “professional/bureaucratic” paradigm, which suggests that human needs can be met through structures and methods that are no different from those used to build automobiles or to run a ship. Providing there is sufficient technology and adequate human resources available, this approach assumes that most personal and social problems are able to be “fixed”.

Cocks and Cockram (42) argued that formal human services now represent powerful social institutions whose power,

“...has been enhanced through the adoption of bureaucratic professional and technological means, and a union with judicial sources of legitimacy. These purposes are a far cry from a conception of human services looking after the wellbeing of vulnerable people and facilitating their empowerment and self-determination”. (p. 224)

Mansell and Ericsson (43) in their comparative review of “community living” practices across the United Kingdom, the United States and Scandinavia, suggested that despite commitments to deinstitutionalization, the spirit of that era remained pervasive, because the beliefs that led to segregation

live on in public policy; in the ways support services are provided and in the denial of citizenship for people with intellectual disabilities.

A more recent review of the empirical literature on the level of active participation of people with intellectual disabilities in the community (44) revealed some disturbing results:

- The average number of persons in their social network was 3.1; one of which was a paid support worker;
- They are 3-4 times less employed than non-disabled peers;
- They were less likely to be employed competitively and were more likely to work in sheltered workshops or segregated settings than those with other disabilities;
- They were less likely to be involved in community groups;
- Leisure activities were mostly solitary and passive in nature; and
- They were generally accompanied to an activity by support staff.

The review concluded that people with intellectual disability living in the community certainly participated more than those living in segregated settings, but their level of participation was still much lower than non-disabled people and other disability groups.

Inclusion is not a static concept, but a process most of us work on throughout our life span. Clapton (27) commented that “...inclusion as a concept, implies a process of transition and transformation – a process of spatial movement and change” (p.23). In the field of disability the concept has been seen as an antonym to segregation, but have we sufficiently addressed the underlying factors that have led to the removal of people from the general society deemed to be a threat to the common good or a threat to themselves?

Attitude studies concerning people with intellectual disabilities have indicated that the closer the respondents are to the person’s life, the more positive are the attitudes. On the negative side there remain vestiges of the eugenics approach on the part of those who are more distant from shared personal experiences (7). It would seem we have based

emerging policies as a reaction to past practices such as institutionalization, rather than taking a more proactive approach which asks the question “what type of life would I want to live if I had a disability?” The obvious answer would be a range of responses little different from those of people in the general population.

It is the lived experiences of people with intellectual disabilities, however, which is the true test of their acceptance as an integral part of the community. It would appear that this acceptance and the opportunity to forge meaningful relationships with friends of their choosing is an essential contributor to their sense of well-being and a life of quality. Inclusion implies a sense of reciprocity and interdependence, rather than simply a physical community presence, which appears at times to be an index of inclusion in public data banks (45).

### *The rights approach*

Clapton’s third piece of the quilt concerns the discourse on human rights and citizenship. Inclusion of people with disability in general society is a benchmark of the United Nations *Convention on the rights of persons with a disability* (46) and represents the “Rights Approach” to the support of this population. While countries may sign and ratify such conventions, it is argued that this is a necessary, but not sufficient mechanism to ensure that the rights are exercised in practice. Owing to the nature of the United Nations’ structures, it is national governments which are called upon to report upon the level of compliance to the Convention, rather than people with disabilities themselves.

Both Reinders (47) and Nirje (46) have commented upon the limitations inherent in a rights approach. Reinders draws us back to his basic thesis of the importance of caring relationships. He agreed that the rights language has been most effective in opening up “... spaces that remained closed for ‘displaced’ persons, such as persons with disabilities” (p. 42). However, he has argued that the rights claims are necessary, but not sufficient to counteract exclusion, because they are limited to spaces in the public domain. It is the private sphere where the rights approach has little or no impact. For instance,

friendship, the development of relationships, and sharing one’s lives are possibly the most fundamental issues, not only for people with disabilities, but for all people. None of these issues can be directly influenced by injunctions from the public domain. Earlier, Reinders (49) commented that, “People can be forced to comply, but they cannot be forced to care” (p. 23).

Nirje (48), often referred to as the “father of the normalization principle”, pointed out that,

“Laws and legislative work cannot provide total answers to problem solving and proper actions with regards to realization of human rights. These can only come into existence in the full cultural and human context. Such problems are not only practical, but also ethical”. (p. 65)

One of the problems faced when approaching the international arena of human rights is the differences in cultural heritages among countries of the world. In western cultures, individualism is a predominant force, sometimes for good or bad, whereas many non-western nations emphasize the notion of a person’s obligations to the community or tribe more strongly than the individual’s rights.

Clapton (50) suggested that the disability rights movement has shifted the socio-political identities of people with disabilities from being seen as “... *objects* of the medical discourse, to *subjects* of the political discourse. ... Within the liberal state, there is movement of liberation from welfare recipients to a citizen; and hence is also indicative of the shift from exclusion to belonging”. (p.76). In this context, Clapton (25) indicated that inclusion, as a condition for citizenship in a society, is a moral imperative of the disability rights movement.

But Cumella (51) has noted that the concept of citizenship is fraught with difficulties for people with intellectual disability, particularly the question of whether those deemed to have impaired rationality can be considered citizens. He suggested that there was a wide belief in the community that such a stigmatized group was not worthy of determining their own way of life. As a result public policies for this population “... have been shaped by the dominant political ideologies of the day”. (p 178)

The Rights discourse has been to a large extent dominated by the voices of people with a physical or

sensory disability and it is a moot point whether this approach has contributed significantly to the emancipation of people with intellectual disabilities. Their voices have certainly been muted, although Self Advocacy groups have had some impact and the movement towards inclusive research is gaining strength (52).

### *Ethical inclusion*

The discussion above concerning the moral status of a person with an intellectual disability provides a context for Clapton's concept of ethical inclusion. The acceptance of their personhood is surely a criterion for accepting them into our lives. Reinders (53) noted that the real challenge people with intellectual disabilities pose for us is: "... not so much about what we can do for them, but whether or not we want to be with them...it is not citizenship, but friendship that matters" (p. 5). Nirje (48) possibly encapsulated the essential meaning of ethical inclusion and the genuine acceptance of people with intellectual disabilities in his profound definition of integration (inclusion) as being based on the recognition of a person's integrity, meaning "to be yourself among others -- to be allowed to be yourself among others" (p. 67). The essential message here is acceptance of diversity in the human condition.

Clapton (50) contended that it is not the notion of impaired bodies that presents barriers to ethical inclusion, but it is impaired ethical theorizing, exemplified in the traditional approaches to applied ethics which have implicitly excluded people with intellectual disabilities. This argument resonates with that of Carlson (30) who has indicted philosophers for their lack of interest in the specific nature of a person with intellectual disabilities and ignorance of their lived realities. In fact, she pointed out philosophical discourses have perpetuated certain forms of oppression.

Whilst ethical and philosophical discourses concerning the issue of inclusion are important for this discussion, the quality of the lives of people with intellectual disabilities is also impacted upon by broader economic and political forces, which are seldom commented upon in the disability literature. In studying the processes and outcomes of community

inclusion, we have not addressed the situation of people with intellectual disabilities in relation to the wider society in which they live. For instance, many of the issues addressed that relate to prejudice, discrimination and the commodification (i.e., treating people as a commodity) are a part of ordinary psychosocial reality and of everyday life of all people.

## **Economic and political barriers to inclusion and quality of life**

### *The dominance of market ideology*

Neoliberal economic policies of the major industrialized nations (e.g. the G 20), accelerating during the Regan and Thatcher years, have had an impact upon the provision of services for disadvantaged groups. A classic demonstration in the Australian context is the publication of two recent reports by the National Productivity Commission on Ageing and Carers (54) (*Caring for older Australians*) and Disability (55) (*Disability care and support*). The Commission is the Australian Government's independent research and advisory body on a range of economic, social and environmental issues, but with a heavy emphasis upon economic factors. It appears that all social initiatives must be judged primarily upon their economic impact.

Economic rationalist policies are predicated on the principle of "utility maximization", with individuals using their resources to achieve the highest level of satisfaction possible. The essential element is that people must be free to choose how they use their resources - in essence economic reform means reducing interference by governments (e.g. The US Tea Party phenomenon). In this process, strong countries can exploit the weak, while wealthy companies increase their wealth by shopping around the world for the cheapest labor.

One can sympathize with people in developing world countries who are feeling the effects of globalization. McKibben (56) related the case of farmers in Mexico, who were unable, because of so called primitive farming practices, to produce perfectly rounded tomatoes that the newly arrived international shopping chains demanded. They were eventually forced out of farming to join the ranks of

the unemployed and the result was the killing of a local industry. The materialization mantra is sapping the lifeblood of those elements which build social cohesion and a sense of mutual obligation towards one's fellow citizens, especially those who are marginalized and relatively powerless. Amartya Sen (13) suggested that the powers of the market economy need to be augmented by the provision of basic social opportunities in a context of social equity and justice.

Brendan Gleeson, director of an urban research program (57), observed that while care goes to the heart of the human experience,

“The act of care is now an exchange framed around individual consumption power, not social obligation. The power and the autonomy of the cared-for consumer are thus strictly circumscribed by imperatives of exchange: money and realization of profit. In short, deinstitutionalization rendered the socially dependent subjects without agency. This may be emblematic of the wider resubjectification of citizens as consumers under neoliberalism”. (p 14)

In countries where neo-liberal policies are struggling under the pressure of reduced welfare budgets, resulting in fewer and less experienced support staff to service a growing number of people in need, there will be an urgent need to consider a re-conceptualization of what care means. The picture is no less bleak in developing countries which are generally copying the failures of the western economic system.

### *Emphasis upon individualism*

The emphasis upon individualism and the associated economic environment have led to society judging the worth of an individual according to the amount one contributes to the economy. It has led to a commoditization of the human condition and is one of the most serious challenges facing those of us who work with people at the margins of society. One might ask whether the tremendous growth in western economies has liberated its citizens?

The rhetorical forces driving the free-market economy present a tantalizingly seductive similarity in their goals and processes to many of the contemporary goals for people with a disability, their

caregivers and families. The concepts of freedom of choice, more control over one's life, release from government regulation, self-determination, and empowerment all appear to sit comfortably in both areas. The emphasis upon individualism, however, presents quite a threat to a vulnerable population, such as those with intellectual disability. In our goal to encourage their independence, we have overlooked the essential fact that the vast majority of this population will, in many aspects of their daily lives, remain dependent on supports. Edwards (58) argued that the normative component of individualism compromises the integrity of intellectually disabled individuals and contributes further to their being ascribed a lower moral status than other humans. The individualistic view of the self, militates against people with disabilities as dependence is viewed negatively. However, Reinders (47) pointed out that dependency for people with intellectual disabilities is the *conditio sine quo non* for their physical, mental and spiritual well-being.

The challenge, then, is how do we create environments where the interdependence of individuals is a central feature and where individuals perceive their identity and conceptualization of self in the context of a mutually dependent society?

### *Quality outcomes*

Schalock (59) argued that human services organizations are being increasingly challenged to provide quality services within the context of two powerful, potentially conflicting forces; person-centred values and economic re-structured services. To justify expenditures that are measured objectively, one must demonstrate consumer outcomes. Rather than being collaboratively developed, value systems are imposed by authoritarian administrations.

In much of the administratively dominated delivery systems, we are still witnessing what Burton Blatt (60) so eloquently exposed in his essay on the “bureaucratization of values” in which terms become “mere shibboleths, devoid of their original meanings.” (p. 330) Human services are now operated as businesses, replete with a panoply of “business speak” managerialistic jargon that tends to create a veneer of

efficiency, but is devoid of the warmth of sound human relationships.

This is not to deny that scarce resources must be applied efficiently to achieve quality outcomes for the people in need. However, who is to determine the nature of the appropriate outcomes and the method of measurement? Have we reached the “tyranny of quality” predicted in 1991 by David Goode (61)?

Despite policy statements concerning quality of life outcomes for people with disabilities, I remain of the opinion that governments continue to apply traditional Quality Assurance models when measuring the standard of service delivery. For instance, in Australia the Commonwealth and several State and Territory governments continue to audit disability services against a set of service standards promulgated to accompany the Commonwealth *Disability Services Act* of 1986 (62). None of these standards addresses quality of life issues. Rather, they are essentially process issues that may be necessary, but not sufficient to ensure quality of life outcomes. Interestingly, the same Act aimed to “enhance the quality of life experienced by people with a disability by assisting them to live as valued and participating members of the community”. Government audits do not appear to address either quality of life or the level of meaningful inclusion.

As Guus van Beek (63) from the European Quality in Social Services, has pointed out, there are essential differences between products and services. He suggested that we have adopted a universal paradigm of quality management approaches to social services which are applied in a production and manufacturing environment where there is a tangible product. Here the emphasis is upon clarity in role and responsibilities, process control, efficient use of resources and meeting fixed measurable standardized outcomes based on the demands of the customer. The European Commission defines social services as “essential services directly delivered to a person”. Van Beek argued that, unlike a product, a service is intangible. Products are also more likely to be standardized whereas services are tailor-made to individual needs and choices. But as the welfare reform analyst, Jo Anne Schneider (64), commented “...people are not widgets” (p.2).

Jon Pierre and Bo Rothstein (65) of the Quality of Government Institute at the University of Gothenburg

concur, arguing that the New Public Management (NPM) is now the preferred model of public administration in most western industrialized countries. They suggested that the basic tenets of NPM, which are directly derived from neo-classical economic theory, encourage not-for-profit social services to emulate the modus operandi of the for-profit sector.

Here citizens become “customers”, who if dissatisfied with a service, can vote with their feet and turn to another service provider. This has an interesting parallel with a shift by governments in the UK, Canada and Australia to a system of individualized financial packages directly to a person with a disability, rather than to a service agency. It is argued that competition will encourage a stronger support services system and lead to better outcomes for the person. Again, we see the emphasis upon the individual, rather than to a broader conceptualization of a better society.

## The way forward

### *Conceptualizing social inclusion*

Whilst there have been a plethora of attempts to define just what is meant by community, we do not seem to have progressed the analysis in the context of social inclusion. In its early formulation in the generic literature, the concept has been discussed in relation to its opposite – social exclusion. But is this not the very issue Article 19 of the 2006 UN *Convention on the Rights of Persons with Disabilities* (46) addresses? Clause (b) of Article 19 states:

“Persons with disabilities have access to a range of in-home, residential and other community support services, including personal assistance necessary to support living and inclusion in the community, and to prevent isolation or segregation from the community;”

Whilst this is a clear statement that segregation is not an option, its import does not go beyond the concept of *technical inclusion* alluded to above.

In the eyes of many, including disability support workers, community presence is seen as a physical entity. This has led to quality assurance approaches

which measure the notion of inclusion in terms of the number of times a person has actively participated in a community outing. Little regard is given to the subjective elements which may be involved. We have also retained the notion that communities have historically been defined geographically. Modern urban communities reflect a far different scenario, wherein relationships play a more integral role in defining one's community.

In order to progress our thinking and to counter what is perceived as a diminished emphasis upon social inclusion as an outcome, we need to address theoretical and conceptual frameworks which will advance our thinking. For example, the social commentator and member of the Australian Social Inclusion Board, Tony Vinson (66) suggested that the power of social inclusion has stemmed from its flexible interpretation rather than its "analytical clarity". Bigby and Wiesel (67) proposed that we should look to concepts developed by urban researchers to assist the understanding of relationships between place and social interaction in modern cities.

### *Measurement of well-being*

Historically countries have measured the state of their economies by reference to indices such as Gross National Product (GNP) or Gross Domestic Product (GDP), but this does not indicate a population's well-being or happiness, which logically should be the result of economic policy. As early as 1972 the small Himalayan Buddhist Kingdom of Bhutan established a Gross National Happiness Commission to monitor changes in the nation's happiness (68). More recently, Amartya Sen's (13) work on capabilities influenced the development of the Human Development Index by the United Nations. This Index captures capabilities in health, education and income. The combination of economic indicators with social indicators gives a more rounded picture of well-being.

Increasingly, international economic commentators are recognizing the need to focus on a new direction. For example, *Relationships Global*, founded by Michael Schluter (69), is a network of people and organizations which recognize the importance of relationships to human wellbeing, and which seek to combat the causes of relational poverty

and build a better world. *Relationships Global* cited Lindsay Tanner (70), former Australian Government Minister of Finance, who commented that relationships are the missing piece of the political puzzle as we try to adapt to the domination of the bottom line and to the constant economic, social and technological changes. In a similar vein, the commentary of Charles Leadbeater, author and Associate of Demos, Britain's leading cross-party think-tank, was also referenced. Leadbeater highlighted the importance of a sense of identity which depends very much upon relationships, a position I noted earlier in this chapter. He suggested that, "Our sense of identity does not simply come from within – what we want to be – but from our interconnectedness and interdependence" (<http://www.relationshipsglobal.net/Web/>).

Another indication that there is an expanding world-wide movement to measure happiness and quality of life is the launch by the OECD in 2004 of a Global Project on Measuring the Progress of Societies and its recent launch of Better Life Initiatives in 2011 (71).

The European Union is also establishing its own set of indicators. The French Government recently convened a commission headed by Joseph Stiglitz and Amartya Sen to propose a new set of indicators. In 2010, the UK Government announced it would monitor subjective well-being in annual surveys. In 2001, Robert Cummins (72) developed the Australian Unity Wellbeing as a barometer of Australians' satisfaction with their lives and life.

Regular surveys are made and results published. Even newspapers have seen the usefulness of these types of data, evidenced by the Australian-based *Herald/Age* -Lateral Economics Well-being Index (73) which aggregates individual economic circumstances and happiness into a measure of national social progress.

### *Building an ethical community*

In 1992 John Ralston Saul (74), in his book *Voltaire's Bastards*, argued that Western civilization is without belief for the first time since the decline of the Roman Empire. More recently, Jeffrey Sachs (68) in *The price of civilization, economics and ethics after the*

*fall*, echoed the same sentiment. He suggested that there is a moral crisis, a loss of the ethos of social responsibility, and a decline in civic virtue; exemplified by America's hyper-commercialization which is also penetrating other societies, especially the emerging economies. Sachs argued that we need to reclaim our mental balance, because:

"The logic of profit maximization, combined with unprecedented breakthroughs in information and communication technology, has led to an economy of distraction ... the end result is a society of consumer addictions, personal anxieties, growing loneliness in the midst of social networks, and financial distress". (pp. 158-58)

Sachs' antidote is that we need to create "a mindful society" and re-conceive the idea of a good society through multiple acts of good citizenship, "... remembering that compassion is the glue that holds society together" (p. 5). The moral standing of people with intellectual disabilities, however, remains a challenge in a society which strives for perfectionism in body and mind.

Also writing in 1992, Paul Dokecki (75) was sanguine that by the year 2000 we would see the development of an ethical community that would be a counter to what Bellah et al (76) called "ontological individualism". Dokecki argued that "... we should work toward an ethical conception of community, which establishes that all persons are fundamentally equal as human beings" (p. 40). How then might we recapture Dokecki's enthusiasm; despite the continuing materialism, hedonism, privatization, and individualism which is still clearly apparent in our society in the second decade of the millennium?

H Rutherford Turnbull (77) in his keynote address to the annual meeting of the American Association on Mental Retardation in 1998 asserted that each member of a community must recognize that all are vulnerable in some aspects of their lives. As a first step, therefore, the ethical community must recognize what Turnbull eloquently suggested: "a mutuality of need and reciprocity of vulnerability". The increasing emphasis on supporting families and focusing policy research on the family's role in supporting their family member with an intellectual disability is a promising sign that the development of

the conception of an ethical community is not a pipe dream never to be achievable.

One critical way in which resources must be directed is towards building community capacity and the development of social capital. Whilst disability policies in the western world are moving strongly toward supporting person-centred planning, individual choice and the allocation of support resources to individuals, rather than to service organizations; there is a danger that generic community resources and natural supports will not be sufficient for personal plans to be realized.

Despite the rhetoric, I sadly believe most current western, and to some extent, developing country government policies remain captured in the belief that market forces result in a more equitable society. As indicated, this is a contestable position and leaves the most vulnerable, including those with intellectual disabilities, dangerously exposed. Hopefully, we shall see a return to a position where governments provide much needed leadership to inspire their communities to a higher plane than self-indulgent materialism.

The quality of life and social inclusion of people with intellectual disabilities will, to a large measure, depend upon external socio-political-economic forces. Their level of acceptance as fellow human beings and citizens will also be influenced by the humanity and compassion of the general community. Those advocating for this population need to engage with the wider community in its journey to quality of life and happiness. Thus far, we have been too focused on the needs of people with intellectual disabilities in isolation from those of the wider community. In other words, we have not been sufficiently strategic in our thinking, our policies or our actions.

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*Submitted:* August 10, 2013. *Revised:* October 10, 2013.  
*Accepted:* October 15, 2013.