Beyond introspection and navel gazing: Challenges for the study of intellectual disability
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It is ironic that in our quest for a more inclusive and welcoming society for people with intellectual disabilities, our research agenda tends not to engage with issues in the wider community context. Our agenda needs to be located within the broader philosophical, historical, ethical, social, spiritual, economic and political debates in order to counter an introspective approach which may be leading to an increasing marginalisation of our efforts. The concept of inclusion will be examined through the perspectives of the self-image and moral status of people with intellectual disabilities, economic and political barriers and the quality outcomes framework. Suggestions for the way forward will be proposed.

No man (sic) is an island, entire of itself;

Every man (sic) is a piece of the Continent,

A part of the main.

John Donne, Meditation XVII

A number of questions come to mind when reflecting upon what has research contributed to the study of intellectual disability? These include:

- What is science?
- What is intelligence?
- What is intellectual disability?
- What is the moral standing of people with intellectual disabilities, especially those diagnosed with a profound disability?
- Are we asking the right research questions?
- What are the reasons for the perceived gap between research and practice in the field of intellectual disability?
Has research been anchored within coherent theoretical/philosophical constructs?
What are the potential benefits and risks associated with genetic research?
How can we create a research environment where participatory action research is possible?
How and where should research proceed in the future?

My position is that past and current research efforts in the field of intellectual disability have not been sufficiently anchored within a coordinated philosophical and theoretical base. In essence, these research efforts can be classified into three areas; namely the medical, social and rights models of conceptualizing intellectual disability. Each of these approaches has addressed some form of “defectology”; be it in the person, in society or in the legislative frameworks.

In 1958 Clarke and Clarke suggested intellectual disability is a social-administrative, rather than a scientific concept, being subjected to and influenced by social, political and economic issues1. Michael Begab took up this theme in his remarks as the program chair of the Fourth Congress of IASSMD,

…the application of knowledge derived from research in service programs requires more than a free flow of information between scientist and practitioner. … It is imperative, therefore, that we recognize the broad social context that may impede the implementation of scientific discovery. The notion that we already know enough to reduce the incidence of mental retardation by half by the year 2000 may or may not be valid. But if we are to achieve this goal we
will need to modify our social values, upgrade the economy and resolve some of our moral and ethical conflicts. Only then will the fruits of science be fully harvested\textsuperscript{2}.

Indeed, the challenge goes beyond research to a large degree. Begab, in his presidential address to the Fifth Congress of IASSMD held in Jerusalem in 1979, commented,

Knowledge is not a guarantee of action. We have known from time immemorial that poverty and its correlates, in industrial and underdeveloped nations alike, are festering places for many of the world’s social ailments and deterents to optimal development and self-fulfillment. We know, too, that malnutrition and inadequate health care resources, endemic in many parts of the world, are breeding grounds for infant mortality and morbidity. …the implementation of knowledge goes well beyond the purview of science and service. Only as we make an impact on the political process and provide an empirical base for rational decision-making can significant inroads to global and complex problem of mental retardation be expected \textsuperscript{3}.

This challenge is relevant today as it was three decades ago. Now more than ever before, we also need to acknowledge that knowledge is not the sole province of the scientist. Again, Begab admonished,

We have much to learn from professional practitioners, from caregivers….and from parents whose individual and collective efforts to cope successfully with family problems and societal prejudices have inspired new insights into the resilience of the human
personality and the capacity of even the least fortunate among us to change and grow.

**Self Image**

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 discussing self-image through the lens of the epistemology of disability.

The negative stereotypes and attitudes toward people with intellectual disabilities are pervasive and impact upon the development of their self-image.
People with a disability are in a double-bind situation. In coming to terms with what it is 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. From a philosophical position there is a conflict between the existential nature of the person and the social nature of human experiences.

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, the needs and plans a person with intellectual disabilities has, and the supports s/he may need to perform them, has been a welcome initiative. Here the work of Vivienne Riches and Sam Arnold on the development of a supports needs assessment instrument has been an important initiative.

Elisabeth Dykens’ call for an emphasis upon positive psychology in the context of intellectual disabilities is apposite. She suggested that much of the research has focused on the external life conditions of this vulnerable population. She reported that of 25 years of research in the psychopathology of people with intellectual disabilities found in 1,825 articles in Medline; revealed that 28% were on
aggression, 25 % self-injury, 21 % depression, 19 % anxiety and 7 % stereotypies. Only 19 publications examined happiness. All human beings have the potential to bring gifts, but people with intellectual disabilities are often portrayed as being bereft of the capacity to make positive contributions\textsuperscript{5}. However, people with specific syndromes, such as Down and Williams syndrome, demonstrate enormous positive affect. Drawing upon the principles of positive psychology, she proposed that a future research agenda should be based on internal states; including happiness, contentment, hope, engagement and strengths.

The “capabilities” approach of Amartya Sen and Martha Nussbaum also focuses on positives rather than negatives. For instance, Nussbaum has proposed ten central human capabilities\textsuperscript{6} which are embedded in a social justice framework and resonate with many of the theories of quality of life. 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. This approach is also an antidote to utilitarianism, which I shall address 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

\begin{itemize}
\item Life
\item Bodily Health
\item Bodily Integrity
\item Senses, imagination and thought
\item Emotions
\item Practical Reason
\item Affiliation
\item Contact with other species (e.g. pets)
\item Play
\item Control over One’s Environment
\end{itemize}

\textsuperscript{5} 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
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 behaviour 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.

It is interesting that the special education curriculum for students with intellectual disabilities used to place strong emphasis upon the notion of “social competence”, but even here we chose the competencies, reminiscent of Wolf Wolfensberger’s social role valorisation approach.

Early research into the preparation for employment for this population emphasised the importance of building social skills and relationships. Social relationships and friendship networks for people with intellectual disabilities provide a mechanism for reciprocity and the development of a positive self-image. Vivienne Riches’ and Keith McVilly’s work in this respect is noteworthy.

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-centred approach to life-long planning.

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.

As principal of a special school for students with intellectual disabilities, one of my tasks was to help them 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 and behavioural disorders which were the reasons for their rejection.

**Moral Status of People with Intellectual Disabilities**

Historically, society’s continued denial of the humanity of a person with intellectual disabilities, as well as it 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. And Aristotle 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.

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.

In more modern times, the concept of otherness of persons with intellectual disabilities was developed by people such as the epidemiologist Dr F.G. Crookshank, who in 1924, asserted that Down syndrome represented a regression to non-human species. Likewise in 1968, Boyd and Fletcher proposed that someone with a disability such as Down syndrome is not even a person.

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 suggested that, “…intellectual disability strikes at the very heart of classical and modern ideas of value and humanness” (p. 115). Clapton 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 wrote:

Decisions about severely handicapped infant 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 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, basket baller or tennis player. (p.213)

Commentators, including Carlson, Kittay, Nussbaum, Reinders, and Sen, 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 and McMahan, who ascribe to the utilitarian reductionist approach to ethics, based on 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, suggested that philosophers need 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 don’t 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 and 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. Some would counter argue that humans possess a spirituality not present in sub species.

It is interesting that, as Singer over the years has come to recognise 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.

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 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 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.

**The Notion of Inclusion**

In her *A Transformatory Ethic of Inclusion*, Jane Clapton’s 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*

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. 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, were able to demonstrate the learning potential of this population. 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 behaviours of people with intellectual disability, but little attention was given to the development of relationship skills and friendship network building.

Schwartz 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 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 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 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 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. 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.

*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 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 and Nirje 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 commented that, “People can be forced to comply, but they cannot be forced to care” (p. 23).

Nirje, 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 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 indicated that inclusion, as a condition for citizenship in a society, is a moral imperative of the disability rights movement.

But Cumella 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.

I shall return to Clapton’s notion of ethical inclusion later.

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

*The dominance of market ideology*

Neoliberal economic policies of the major industrialised nations (e.g. the G20), 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 (*Caring for Older Australians*) and Disability (*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 labour.

One can sympathise with people in developing world countries who are feeling the effects of globalization. McKibben 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 marginalised and relatively powerless. Amartya Sen 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, 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 realisation of profit. In short, deinstitutionalisation rendered the socially dependent subjects without agency. This may be emblematic of the wider re-subjection 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 commodification 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 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 has 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?
Schalock argued that human services organisations 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 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.

But are we measuring “consumer” outcomes? The recent AIHW Australia’s Welfare reports on participation in major life areas, but points out that no data are available on the effectiveness of the services provided, in terms of outcomes for the individual. And I have been searching for decades for details of the outcomes for special education programs.

What is “science”?
A pivotal question, however, is what is science? From the time of antiquity the terms “science” and “philosophy” were almost used interchangeably. In more modern times, the meaning of “science” was narrowed to refer to the study of the “hard” sciences of physics, chemistry, geology and biology. For other areas of study terms such as social sciences, natural science and political science have been adopted. Interestingly, even in the so-called “hard” sciences, research students were often required to take a compulsory subject, the “philosophy of science”. I believe that an underlying gap in the study of intellectual disabilities is the absence of a clearly articulated philosophical approach that might assist in setting the directions and the methodologies used in this area of endeavour.

**What is intellectual disability and intelligence?**

Related issues are the questions what is intellectual disability and what is intelligence? As discussed above, there remains the notion that the qualification for personhood and for being a human being is related to cognitive capacities. It is not only the notion of intellectual disabilities that needs to be examined, but also the very notion of “disability”. Robert Schalock in his analysis of “What is intellectual disability?” suggested that we need to address a number of emerging epistemological issues. These include,

- the construct of disability and how intellectual disability fits within the general construct of disability,
• the relationship of intellectual disabilities to other developmental disabilities,
• The ethical analysis of the concept of disability,
• whether the elements of the construct and the construct itself are relevant internationally, given the cultural relativity of the constructs of intellectual functioning and adaptive behavior, and
• whether the “functionalist-objective paradigm” of intellectual disability can be reconciled with the “interpretive-subjective paradigm” of intellectual disability.

In the context of Schalock’s reference to the “functionalist-objective paradigm”, it is interesting to note that much of the research related to people with intellectual disabilities has addressed deficits in the cognitive and adaptive behaviour functioning of this population.

**Are we asking the right research questions?**

Scott Campbell Brown in his chapter “Methodological Paradigms that Shape Disability Research” called for a synthesis of research paradigms, together with a greater commitment of researchers to participatory action research involving people with disabilities at all stages of the research process. This suggestion is particularly relevant to the issue of how the research agenda is formulated. First, it is a fact that a researcher is influenced in the choice of research questions to explore by the research paradigm in which s/he has been trained. Second, by empowering the person with a disability as a research assistant, allows that person to participate in the design and conduct of all the phases of the research that affects them. Naturally, there are difficulties in applying this principle to people with intellectual disabilities,
but with increasing numbers of this population moving onto tertiary and life-long education, opportunities for their meaningful involvement as researchers have been facilitated beyond mere symbolic presence.

**The way forward**

*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 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 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 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 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 disability 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 an intellectual disability 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 are a part of ordinary psychosocial reality and of everyday life of all people.

Conceptualising 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 isn’t this 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 suggested that the power of social inclusion has stemmed from its flexible interpretation rather than its “analytical clarity”. Bigby and Wiesel 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.

Peter Di Rita has suggested that: “A contraction of choice through (this) dependency on service providers creates a coercive compromise which circumscribes the identification and achievement of aspirations. The net result is that Economic Rationalism’s utilitarian social response has transformed inclusion into assimilation.”

**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. More recently, Amartya Sen’s 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 recognising the need to focus on a new direction. For example, Relationships Global, founded by Michael Schluter, is a network of people and organisations which recognise 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, 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. He suggested that, “Our sense of identity does not simply come from within – what we want to be – but from our interconnectedness and interdependence”.

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. 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

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11 http://www.relationshipsglobal.net/Web/
Cummins 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 *HeraldAge-Lateral Economics Well-being Index* which aggregates individual economic circumstances and happiness into a measure of national social progress.

*Building an ethical community*

In 1992 John Ralston Saul, 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 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 an intellectual disability, however, remains a challenge in a society which strives for perfectionism in body and mind.

Also writing in 1992, Paul Dokecki 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 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 new millennium?

H. Rutherford Turnbull 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 recognise that all are vulnerable in some aspects of their lives. As a first step, therefore, the ethical community must recognise 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 organisations; there is a danger that generic community resources and natural supports will not be sufficient for personal plans to be realised. The building of informal supports is also critical to the success of the new paradigm, not necessarily from an economic position, but because they are more personal.

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 earlier, this is a contestable position and leaves the most vulnerable, including those with an intellectual disability, dangerously exposed. Hopefully, we shall see a position where governments will 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.

NOTE: This paper has drawn upon the texts of two book chapters where the references are cited.


PARMENTER, T.R (IN PRESS). INCLUSION AND QUALITY OF LIFE: ARE WE THERE YET? IN R.I BROWN & R. M. FARAGHER (EDS.) QUALITY OF LIFE AND INTELLECTUAL DISABILITY. KNOWLEDGE APPLICATION TO OTHER SOCIAL AND EDUCATIONAL CHALLENGES. NEW YORK: NOVA SCIENCE