The Social Construction

Of

Profound Mental Retardation

Shannon Boon
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Nancy Marlett
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Introduction

Throughout history, people with disabilities have been viewed from different perspectives. Whether seen through a medical model as people who are sick and in need of a cure, through a sociological model where people with disabilities are labeled and stigmatized by others, or through a psychological model where their experiences have been individualized and pathologized, these traditional approaches have one thing in common. All of these models point to individual limitations found within the disabled person as the principle cause of the multiple difficulties experienced.

In contrast to traditional approaches, the social model of disability has argued that “people with accredited (or perceived) impairments are disabled by society’s blatant failure to accommodate their needs” (Barnes, Mercer, & Shakespeare, 1999, p.2). This approach does not deny that there are differences, either physical or mental, between people, but rather argues that “the nature and significance of these differences depend on how we view and interpret them” (Bogdan & Taylor, 1994, p.8). Disability, in this case, is considered to be a “social construction”.

The philosophy of social constructionism looks at how beliefs and understandings taken to be objectively real by people in daily encounters, are more accurately seen as subjective constructions of thoughts, words, and interactions. “Social constructionism emphasizes the centrality of language, thought, interaction, politics, history, and culture in the making of human meaning in lived contexts” (Danforth & Rhodes, 1997, p.359). In looking at the “reality” of disablement then, social constructionism “assumes that the various forms of ‘disability’ are not physical absolutes but social designations that are made by people in interaction and relationship” (Danforth & Rhodes, 1997, p. 359).
This paper reports on my observations of the social construction of “profound mental retardation”. Several individuals that I work with have this label attached to their beings. In addition, our culture has classified them using other titles such as “severe physical impairment”, “sensory deficit”, “non-verbal”, “non-ambulant” and “medically fragile”. Using the model provided in class, I have explored the social construction of profound mental retardation within the four circles (health, coping, inclusion, meaning), listened to contributing voices within each area, and extracted some common themes. These themes, which include “the pervasiveness of norms in our world” and “extreme powerlessness”, structure the discourse of these clients’ existence. Because I have not experienced the same stigmatizing labels, I cannot know their lived reality. The greatest value in examining this reality as a social construction is in reminding myself how much I do not understand about “the way it is”. “The apparent ease of intuitive knowledge is really another aspect of discrimination against people with disabilities” (Davis, 1997, p.2).

Health Circle

In seeking out “the truth” about these individuals, as defined by the health circle, I was surprised at the large number of contributing voices. I examined medical texts from several disciplines, as well as educational textbooks, and Internet websites. I also talked to (or listened to conversations of) several medical professionals including a general medical practitioner, an anesthetist, a nurse-manager, an occupational therapist, and several of my co-workers. One of the most intriguing sources of the “reality” constructed for these clients came from their personal medical charts, which included items such as professionals' assessments, and medical test results. The overwhelming messages that came from this investigation were that 1. we live in a world of norms, and 2. the clients I work with generally do not conform to these standards.
To begin this exercise in deconstruction, I looked at the label “profound mental retardation” as defined by professional texts. The official meaning of mental retardation (MR) seems to be interpreted as “a constellation of behaviors or deviations from expected norms of behavior that are attributable to subaverage intellectual functioning (as indicated by an IQ score)” (Biklen & Duchan, 1994, p.174). A normal or average IQ (intelligence quotient) is considered to be 100; an individual may be labeled “mentally retarded” with “an IQ score of approximately 70 or below” (Mash & Wolfe, 1999, p.345). To be classified as “profound” MR, one must present with an IQ level below 20 as determined by formal intelligence testing or clinical judgement (in the case of an infant or an untestable subject). According to the medical histories of the clients in question, all were deemed “untestable subjects” and categorized with profound MR in the early 1960’s. The literature admits that clinicians sometimes make “educated guesses”, and that “such estimates clearly reduce the reliability of the test and, in turn, the degree of faith one can place on the diagnosis” (Mash & Wolfe, 1999, p.346). Yet, in progressing through their medical histories, this label seemed to transfer from year to year unquestioned. Furthermore, this label was most prominently displayed in all documentation. From the perspective of the health circle then, these clients are considered to be “extremely cognitively impaired”.

In addition to having “significantly subaverage intellectual functioning” (DSM-IV, 1994, p.39) as described by the IQ score, the definition of mental retardation involves “concurrent deficits or impairments in present adaptive functioning” (DSM-IV, 1994, p.46), which refers to the ability to perform daily activities. Again, the literature admits that “whether someone exhibits these various adaptive skills is related not only to ability but also to experience and opportunity” (Mash & Wolfe, 1999, p.346). From what we know about the “deplorable and inhumane conditions” (Blatt & Kaplan, 1966, p.v) found in institutions in the 1960’s, it is quite possible that these clients did not have the “experiences” or “opportunities” needed to
demonstrate their innate abilities. Yet again, once initially tested in the 1960’s, there appeared to be no further formal assessment of adaptive abilities. These people are simply considered “unable”. In reading through their charts, I was struck by the stagnant nature of the diagnoses.

The theme of “measurement against norms” was once more evident in examining assessment reports within the clients’ charts. Height and weight were listed and graphed on a monthly basis, as well as the client’s current BMI (body mass index) and “ideal” BMI. Laboratory results compared each person’s blood, urine and stool specimens to a reference range considered to be normal. I also found numerous rating scales judging many aspects of each client, including such things as mobility (good, fair, poor), dexterity, use of arms/legs, comprehension, chewing, swallowing, appetite, elimination, hearing, and sight. One female person actually had her breast size assessed (they were deemed to be “average”). Professionals within this health circle seemed to have a loud voice in defining these people as “subnormal”.

This strong professional “voice” leads into another theme, which was evident throughout this circle – the theme of “father knows best”. Clinical labels pervade these people’s documented “reality”. For example, one client I am acquainted with “has problems” including profound mental retardation, epilepsy-tonic clonic, severe spastic quadriplegia, shortened limbs and limb contractures, severe dysphagia and esophagitis, hiatus hernia (reflux), weight fluctuations, occasional constipation, rotary nystagmus, severe structural right scoliosis, left divergent strabismus, recurrent UTI’s, clawed toes, inability to ambulate, inability to speak, sensory impairment, and cerebral palsy. In the same client’s medical reports, I found statements such as “her problems started when she was born”, “she of course, can’t communicate”, and “she seems unaware of her surroundings”. Scattered throughout her chart were words such as dependent, severely limited, affected, incapable, deficient, unable, unproductive, untrained, incomplete, fragile, slow, poor, minimal, and lacking. This list of personal descriptors leaves one with an impression of extreme impairment.
Yet another theme which evolved in reading these medical charts was a sense of “fragmentation of the individual being”. These binders full of assessment reports read like a maintenance manual for a used car. Each part of the body (i.e., neurological system, urinary tract, oral hygiene, respiratory system, skeletal system, integumentary system, circulatory system, sensory system, reproductive or hormonal system, and behavior) was isolated and investigated for “issues” and “problems”. Included were photographs of approved client positioning for activities such as feeding and bathing. Also, the reader could find step-by-step instructions for personal care, dressing, meals, dental care, washing, toileting, transfers/mobility, medication administration, communication, and community experiences. The majority of chart entries described only directly observable features (i.e., body mechanics rather than personality attributes). I found only three instances where the client in question was actually referred to by name.

As well as looking at written documentation for the social construction of profound MR, I also observed personal interactions between clients and professionals. Again, I noted several instances of the same unemotional and detached flavor found within this circle. For example, one medical specialist (who has known the individuals for seven years) is still skeptical about their abilities. Comments such as “he can’t really do that”, “it must be a fluke”, and “she’s such a little druggie” are common, and damaging to their social identities. Hospital personnel have told us that “antibiotics will only prolong his life”, putting into question the very worth (quality of life) of the person. Another example involved taking a client to a dentist, where I was asked to complete a “form for patients with disabilities” requiring information such as “describe any dangerous/violent behaviors (i.e., biting, striking out)”. A third example happened recently, when an anesthetist met a particular client and said, “Oh my God! He’s a pretzel! Guess he can’t do anything, eh?” Then he asked, “how many people do we need to hold him down?” (this client is only 55 lbs). It seemed odd to me that a large, able-bodied man would be worried about
possible violence from a 55 pound contorted “pretzel”. Fear and doubt seem to be common reactions to interactions with these people.

To be fair, in my investigation I did find a few positive (perhaps even flattering) words to describe these individuals. Especially in more recent years, personal characteristics such as likes and dislikes, strengths, wishes or goals, and demonstrated abilities started to show up in documentation. Comments such as “she has a ready smile and a good sense of humor” attempted to construct this person as a “full-fledged human being”. Although not surprising, it was interesting to note that the more personalized characterizations came from staff with regular direct contact with clients. Within this health circle, professionals seemed to rely more on formal documentation (presumably due to lack of time and contact), and appeared to be somewhat less aware of the whole person. And unfortunately, most of this formal documentation appeared to perpetuate the clients’ reality as one of “defects, deformities, and disease whose origins and treatment are within the individual” (Meyerson, 1988, p. 186).

Coping Circle

The previous section constructed a person with profound mental retardation from the perspective of impairment, which refers to a “medically classified condition” (Barnes, Mercer, & Shakespeare, 1999, p.6). The coping circle looks at a person’s “reality” from the standpoint of disability, defined by the World Health Organization (WHO) as “any restriction or lack (resulting from impairment) of ability to perform an activity in the manner or within the stage considered normal for a human being” (Batavia, 1993, p.735). The concept of rehabilitation seems to be central to this circle.

I began my deconstruction process by returning to the DSM-IV (1994) diagnostic criteria for profound mental retardation. This source classifies MR as an Axis II disorder, distinguishing it as “more chronic” and “less amenable to treatment” than others linked to environmental
circumstances. In looking for evidence of attempts to rehabilitate adults with profound mental retardation, I found research pointing to the stability of IQ over time in persons with MR (Mash & Wolfe, 1999, p.341). While one source promised that “mental ability can always be modified by experience” (Mash & Wolfe, 1999, p.341), it also admitted that “the best window of opportunity for influencing intellectual ability… is from infancy through early childhood” (p.341). And rather than being conceptualized along a continuum of intellectual ability, “the more severe forms of MR are considered categorical– present or absent- due to unusual events that have powerful influences on development” (Mash & Wolfe, 1999, p.358). Thus, while children are directed toward early intervention programs, and adults with milder forms of MR may learn vocational and independent living skills (Batshaw, 2001), it appears that adults with profound MR can be seen to be stuck in a developmental “holding pattern”.

So then, what do the authorities claim “works” with adults with profound MR? In considering how some of the clients I work with cope with their lived realities, I turned to the concept of “normalization” (Wolfensberger, 1972). Normalization plays a powerful role in the dominant discourse of community living, and calls for “socially valued roles and life conditions for people” (Wolfensberger, 1983, p.234). In my experience it seems that this philosophy, which calls for “community integration”, is what authorities believe will ultimately “fix” my clients, or at least make them less abnormal. Being in the community is what “works”. Thus, these people have access to a myriad of activities including “wheelchair square-dancing”, “wheelchair bowling”, “wheelchair ice-skating”, “Bloomin’ Humans” (art class for the disabled), “Social Club” (a weekly dance for people with disabilities), “Easter Seals Camp” (summer camp for people with disabilities), “Special Woodstock” (a musical event for the disabled), “Operation Trackshoes” (trackmeet for the disabled), and “Operation Wheelchair” (X-mas shopping for the disabled). On the surface, their experience of “community” seems to be rich; on the other hand, their experience of “integration” may leave something to be desired.
Of course, these people have the right to participate in community activities alongside “able-bodied” people. And my clients have had positive experiences where, for example, restaurants have prepared special diets, or movie theatres have let them in at no cost. The majority of people will try to accommodate the particular needs of these individuals. But there still seems to be a barrier to full inclusion. It seems that the very existence of these “special” activities instructs the public to view my clients as qualitatively different. Last week, I inquired at the local recreation center about activities that were wheelchair accessible. After stumbling for words, the front-desk person finally said, “well there’s that Social Club thing…” It was as if she hadn’t considered the possibility that one of my clients could join in a craft class or go swimming.

In our community, a study was done which looked at the lived experience of deinstitutionalized clients. Results showed that “‘actual’ life in a community group home does not exactly fit with the ideological construction of normalization” (Drummond, 1998, p.121). The documented production of reality, on the surface, may have claimed improvements (i.e. effectiveness) for these people, but in reality did not often capture the “essence” of daily life for clients. The people I work with, though they are non-verbal, have stories that would support this conclusion. For example, one woman (labeled “medically fragile”) has been waiting over six months to have a simple filling replaced in her tooth because the community-based anesthetists will not give the required IV sedation to her. Another client recently had to wait ten minutes outside in the rain for someone to unlock a handicapped accessible door into a building downtown. While it is true that these clients are “in” the community doing “normal” things, I’m not sure they would claim effectiveness.

Coping appears to be a challenging circle for these people. The authorities within this area see adults who are unable to meet the tasks of their particular life stage, such as generativity and independence (Quinn, 1998). And due to their apparent lack of intellectual ability,
educational equipment and opportunities are considered redundant. Instead, coping seems to be about basic maintenance rather than growth. A teacher once told me that I “must lower my expectations… don’t push them or frustrate them… don’t expect much”. So then, what “works” with individuals with profound MR? Answers seem to revolve around safety, protection, and striving for the status quo. Quality of life may be questionable; personal control is almost completely externalized.

Inclusion Circle

The “truth” about a person with profound MR, as defined by this circle, is determined by his/her worth in society. This truth relates to the term “handicap”, a “generic term used to denote the social disadvantage experienced by people with an accredited impairment” (Barnes, Mercer & Shakespeare, 1999, p.6). A person’s worth is directly related to his or her power.

In looking at the worth of individuals with profound mental retardation, from a social construction perspective, I thought about developments in disability discourse over the past twenty years. With a major increase in emphasis on human rights, due to the advent of the Canadian Charter of Rights and Freedoms (1981), we saw institutions close in British Columbia and community living alternatives arranged. At that time in history, “public awareness of and outrage at the treatment of persons with MR had reached an all-time high” (Mash & Wolfe, 1999, p.338). The people I work with were part of a lived reality that was constructed as a social problem. Today, with their new “normalized” lives in the community, it seems that the perception of mental retardation as a “problem” has faded. As Loseke (1999) states, “the social problems game involves competition. Only a few problems can receive our time, attention, and money… audiences must be convinced why we should care” (p.69). For the clients I work with, their “turn” in the game seems to be over, at least for now.
In deconstructing “the way it is” then, from the perspective of inclusion, I was aware of two distinct “realities”. My clients have a mediated existence (i.e. through the media), and an everyday “behind closed doors” existence. In my experience working with persons with profound MR, these two realities are often qualitatively quite different. But because the public is only given the opportunity to understand and react to knowledge constructed from a mediated place, these “extremely cognitively impaired”, “subnormal” and “unable” clients are left with no voice in our society. And no voice equals no power.

Within this circle, I looked at ways that reality was constructed on paper, such as policy and procedure manuals, mission statements, clients’ personal service plans (PSP’s), and quarterly reports. What I found was language that imitated normalization principles and the guidelines set by the Ministry of Children and Families. Group home contractors are ultimately accountable to the Ministry in order to remain “in business”; the government controls “the purse strings”. Documentation must satisfy families as well as public standards; therefore, “group home managers must produce the action which is properly reportable” (Drummond, 1998, p.91). It would be naïve to assume that contractors are responsible only to their clients. Everyday needs of the people who live in the home may actually find themselves secondary to accountability requirements. Reality, in this case, is socially constructed through formal documentation. Client lives are typified as of an excellent quality; client voices, however, are buried somewhere under the hierarchy of bureaucracy. The public does not perceive MR as a social problem, since conditions do not appear to be "troublesome and in need of repair" (Loseke, 1999, p.13).

The Victoria Times Colonist newspaper recently published an article discussing the soaring costs of caring for developmentally disabled persons in the community. An extreme example was used of a man who “required two caregivers to watch him constantly at a cost of $430,000 a year” (Pemberton, 2001, p. A3). The author constructed an image of a high quality lifestyle at an exorbitant cost; the underlying message was that larger groupings would be
cheaper to maintain. Standardization of services is often presented as a solution to the costs of care, even though “standardization” goes against everything we value about human life (i.e., individuality, uniqueness, treatment within context). But at a time when the BC government is looking for ways to cut its budget by 20-50 per cent, these mediated news stories will help to gain public support for such ideas as congregate care facilities.

If these clients were indeed given a voice, I believe they could surprise the public by telling many accounts of “second class citizenship”. As I collected information for this paper, I spent time in a number of group homes watching for examples of how these people were valued (or devalued) in everyday “behind closed doors” interactions. The results were disturbing. For instance, attempts at communication were often just considered behaviors by staff- and treated as such- with responses like “don’t be a baby”, “you should be happy with what you’ve got”, and “you’d better be nice to me and listen to me, because without me, you’re dead!”. I saw staff take clients out into the community, under the guise of a special activity, and then use the time to do their own personal errands. I watched staff spend clients’ money to buy themselves deluxe coffee drinks (and the client plain coffee, if anything at all). The most blatant example of clients’ worth, though, came when a staff member was alone in a house with four non-verbal clients. As she carried on a conversation with them, her co-worker came in and said, “who are you talking to… there’s nobody here…”.

While investigating “reality” from an inclusion perspective, I found more examples of the everyday worth of these people as demonstrated by management personnel. For instance, in the recent past I have been instructed by a supervisor not to put clients on commodes because “it is an extra lift” and “they are used to doing it in their pants”. I have known clients who have not received medical attention for broken bones and medication errors because management didn’t want to be accountable. I have regularly seen clients forced into activities when they were unwell (or uninterested) simply because the activity was “on the schedule”. Even the physical
environment of many group homes is not optimally accessible to its clients (i.e., pictures mounted on the wall too high to see from wheelchairs; clients’ computer equipment kept locked in the manager’s office). If society could see even these few examples of “the way it is” for people with profound MR in the community, they might realize that reality is far from “normalized”.

I have one final example of a devaluing experience for my clients, which took place in a most ironic setting. Each year in Victoria, there is a televised community fundraiser for individuals with disabilities. This organization receives a large donation annually from a disabled man in our community, who spends hundreds of hours working for that money. Last year, this man invited two clients (who are his friends) to the ceremony, to watch him present his fundraising efforts. When we arrived at the television studio, we were turned away at the door. The reason we were given was that “there was no room for the wheelchairs… it was ‘standing room only’… and we would have to go home and watch it on television”. I thought it was sad that the organizers of the fundraiser could not make room for two “wheelchairs”.

This inclusion circle seems to be a vast and discouraging one for people labeled with profound mental retardation. MR is “a defective concept… a demeaning concept which implies a deficiency in the humanity of those tagged” (Bogdan & Taylor, 1982, p. 5-6). Our society values intelligence; people with apparent lowered intelligence are difficult to value. Furthermore, “to be a client is, by definition, to be a person in need; to be a person in need is to be a weak person” (Loseke, 1999, p.160). With our culture’s “morality of individualism… leads to an evaluation that to be ‘needy’ is not good” (Loseke, 1999, p.160). “It’s better to be self-sufficient than to be dependent; it’s better to be strong than to be weak; it’s better to be well than to be sick (Loseke, 1999, p. 160). Clients “share a discredited identity. They are identified… as people who have problems” (Loseke, 1999, p.161). In deconstructing reality for the individuals I work with then, I came to realize just how powerless these people are; the quality of their
“reality” can shift from moment to moment as they depend on the staff’s approach, and all things external.

**Meaning Circle**

People, labeled as profoundly mentally retarded, have been routinely excluded from the mainstream of our society, and subjected to the worst kinds of treatments in institutional settings (Blatt & Kaplan, 1966). Because those with obvious and multiple disabilities do not fit into the norms our society has constructed, their “humanness is often considered problematic” (Bogdan & Taylor, 1989, p.137). Many would say they lack the ability to think. Metaphors such as “vegetable” and “pretzel” are not uncommon descriptors. Identities are socially produced.

The meaning circle is about challenging these constructions. The “truth” here, is based on personal discovery by the clients themselves. This is where traditionally devalued individuals can reclaim their voices, and find meaning for themselves and others.

In taking apart the construct of profound mental retardation, I was interested in the different metaphors that could be applied. As my clients began their lives, passive terms such as “victim” and “sufferer” were used. The institution was a “warehouse” and the care- an “assembly-line”. A “child” metaphor fits here also, in the sense that these people can be seen as infantile, helpless, and in need of protection. Life in the institution was the reverse of a “journey” metaphor- the process of development ended before it really began.

In my mind, deinstitutionalization was like a “rebirth” or “second chance” for these individuals. The philosophy of normalization created the opportunity (i.e. the “springboard”) to jump in and actively experience life first-hand. This is where the locus of control shifts inward somewhat.

The other metaphor that seemed powerful in the lives of these people was that of “war”. It seems like they are always in a “fight”- with medical illness, with physical barriers, with negative beliefs and attitudes of others, with the system that controls their care. As staff, we
sometimes think of the clients as “troopers” or “survivors” while admiring their stamina to overcome difficulty. The government (i.e. Ministry of Children and Families) can sometimes be seen as an “enemy” of sorts because they have the power to enforce “the way it is”, whether it makes sense for our specific clients or not. We “fortify our defenses” against “invading” professionals who want to “fix” our clients. Occasionally we want to run “under the radar” to avoid interference from these enemies. It was interesting to explore how the metaphors shifted from powerlessness (i.e. “vegetable”), to more powerful (i.e. “trooper”), in the lives of these clients.

Today, I believe the people I work with, if they could speak, would tell stories of power and accomplishment. As a team, the clients and staff have created an environment, which strives to oppose the dominant discourse. Individuals are valued and celebrated; people are known for their abilities, not disabilities. Stories are about “being listened to, being given responsibility, having choices, (and) being expected to try to do new things” (Marlett, n.d., p.11). Everyday these persons, who have been given the label of profound mental retardation by others, are challenging the negative connotations that have been attached to their conditions.

From the perspective of the meaning circle then, I believe the clients I work with have several “truths” to offer. Firstly, as disabled individuals in an able-bodied world, it is true that they have very little power. Their lives are full of routines- controlled by others. It is also true though, that these people can express their needs and desires, as well as make choices if other people care to listen. Our non-verbal clients tell us many things through facial expressions, vocalizations, and body movements such as pointing or pushing things away. If we care to stop and pay attention, they are exceptionally skilled at teaching us how to listen. Without using words, my clients and I converse all day long. They tell me their favorite foods and clothes, what music or TV show they prefer, how they are feeling, their activity choices, discomfort with temperature, body position or illness, preferences in staff, and many, many more things. In the
beginning, these interactions take time, patience, and practice; the end result is an empowered human being.

A second “truth” that my clients have to offer is that the able-bodied world sees everything from a standpoint of differences, not commonalities. At best, people with MR are defined as “special”; more often they are perceived as deviant and scary “non-persons”. The staff who work with them are also seen as “special”, and even “brave” for the work that they do. Visitors to the group home are usually surprised to see how “normal” the environment actually is. They expect something different. The label “mental retardation” seems to obscure both the individuality among the people so named, and their similarities to those not so named.

“Labeling entails defining a person in terms of a single dimension and then generalizing about that person’s overall character on that narrow basis” (Bogdan & Taylor, 1982, p. 13). But apart from a clinical judgement made back in the early 1960’s, these clients do not necessarily have more in common with each other than they do with “non-retarded” people. They are as individual as you or I, with unique abilities and personalities to offer; they are capable of incredible intimate connections with able-bodied others, if given the chance. Children set a good example in encounters with these people, because children often do not see differences as negative- my clients are simply their friends. I believe these individuals long to be seen as “more than an aggregate of quantified characteristics” (Bogdan & Taylor, 1982, p. 18). Unfortunately though, most of society continues to use the label of “mental retardation” to separate them from the rest of humanity… to define them as “not one of us” (Bogdan & Taylor, 1982, p. 14).

The third and possibly most damaging “truth” found within this circle, is that our able-bodied world sees my clients not only as different, but also defective. This is a truth that we try to keep outside the walls of the group home. Clients “reflect the attitudes of those around them. They act according to others’ cues of what others want of them” (Frank, 1991, p. 127). In their home, we focus on each person’s strengths. The staff challenge the planned and cautious
practice in discourse, by allowing individuals to risk, to take chances, and to learn from failure as well as success. The clients, in turn, challenge the dominant discourse by demonstrating that they are curious (thinking) persons, who are caring, creative, strong, and able human beings.

As I examined “reality” from the perspective of the meaning circle, I noted several client scripts. Probably the most powerful of these was the “professionals were wrong” script, or the “they said I couldn’t do it and I did” script. In the case of the clients I work with, past professional and clinical evaluations have been proven incorrect a number of times. For example, one of these individuals is assessed as being blind, as well as having no receptive or expressive language ability. All have been proven wrong. This client demonstrates understanding of much conversation, she has a spoken vocabulary of about twenty words, and she reaches out for objects in her environment (using no other cue than sight). Another individual, who is considered to have profound mental retardation, has demonstrated his knowledge of colours, numbers, simple sight word recognition, and many other things. All of the clients are now using commodes, skateboards (or walkers) for independent mobility, and switches to control objects in their environments (i.e. TV channels, computer games, kitchen appliances, sensory equipment). The excitement, empowerment, and self-esteem that has developed in the lives of these people is difficult to describe on paper. They are proud of their stories. As staff, we do not see these people as disabled; furthermore, we endeavor to keep video and photographs as means for our clients to keep telling their stories to others.

Another way these clients are able to share their stories, is through a new Day Program developed in the home. Private funding makes it possible for clients to visit from other homes, to participate in our activities, and to find their own successes. For example, we have one visiting client who previously screamed and cried for most of each day, and didn’t enjoy outings into the community. Since coming to the program, she often laughs all the way there, and only cries when it is time to leave. The staff are now able to take her out to other places as well.
With the assistance of specialist consultants who can understand and help overcome the obstacles, clients from other homes are showing that they, too, have the strength to risk, to explore, to reach out, and to be successful. These people seem to appreciate the positive and accepting environment, while demonstrating their abilities, and practicing new roles within scripts of empowerment. Furthermore, in their own ways, these people are defying the dominant discourse. They are challenging standard images of what persons considered to have profound mental retardation can accomplish. New social roles are being created, practiced, and taken into the future.

“A disabled person carries the torch of empowerment and change, but at the same time he is constantly undermined” (Marlett, n.d., p. 19). Unfortunately, while the clients in this program are making significant gains, it is ironic that a number of the visiting staff are having difficulty being successful. The staff seem resistant to change; they are afraid to risk. Moreover, they are struggling with their own beliefs, and standard images of what their clients can do and be (i.e. the dominant discourse). “To question what is assumed to be true in the field of mental retardation is to risk seeming unreasonable” (Danforth & Rhodes, 1997, p.364). Unfortunately, this program is currently at a critical point, because staff are not following through with activities and program goals. This is discouraging to program organizers and funders. If it does not continue, this will be due to a failure of the able-bodied participants, rather than those with apparent disabilities. If attitudes within the program cannot be influenced, we certainly will not change the dominant discourse of society.

Conclusion

This exercise in deconstructing profound mental retardation was both intriguing and discouraging. I was reminded just how powerless my clients are within an able-bodied world. The dominant discourse has a loud voice, and still points to deficits within the individual as the
main cause of difficulties experienced. There is still a “tendency for the disability (the alleged difference) to take on tremendous significance in the non-handicapped person’s mind: it becomes the master status” (Bogdan & Biklen, 1977, p.15). And with few opportunities for intimate relations with so-called normal people, the disabled “have little chance of disproving the stereotypes” (Bogdan & Biklen, 1977, p. 14).

This paper has reported on my observations of the social construction of profound mental retardation. Within the health circle, I found an impersonal, sterile approach which focused on deficits. The coping circle offered little hope for advancement, while the inclusion circle described these people as powerless (voiceless), and devalued individuals. Finally, the meaning circle showed optimistic evidence to counter the dominant discourse; yet, the challenge still remains for my clients to have their voices heard.

In assembling the different constructions society has created for profound mental retardation, I was not surprised that my clients’ quality of life is in question. It is likely difficult for “outsiders” to recognize and appreciate the progress of these people, without having intimate knowledge or historical context. Relationships are often “based on different ways of knowing and seeing” (Bogdan & Taylor, 1989, p. 141). The new Day Program referred to previously, represents one way to challenge existing stereotypes of what persons with mental retardation can do and be. It appears, though, that changing the attitudes of the dominant discourse will be a challenging task.
References


