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Success, Disabilities, and Adult Education: A Historical Journey

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Keywords: disability, history, education

Abstract: Through historical analysis, adult education is shown to perpetuate widespread social practices of oppression for learners who experience intellectual and other disabilities. A redefinition of whom and what makes a valuable contribution to society is offered; a shift to more inclusive thinking is recommended and a practical necessity due to recent federal legislation.

Modern Alaska Native tradition from the Tlingit culture holds that a family member who experiences disability can sometimes take the role of the spirit keeper, who will hold the family accountable for showing respect and kindness to one another. A current spirit keeper will take the name of a past spirit keeper. This role was held by S'kaawan, a Tlingit man who experienced intellectual and physical disability. S'kaawan was cared for by family members as a young child; at the behest of the Bureau of Indian Affairs, he was sent to live in an institution in Washington state at age three (Paulette, 2000, unpublished manuscript).

S'kaawan spent many years in the institution, during which time family members assumed him dead. He returned to Alaska as a thirty-something adult and reunited with his family. S'kaawan became a central member of his family's dance group, dancing in full regalia in his wheelchair. He was assisted in dancing by a care provider who also became part of the dance group. He became well known in the community and advocated for better accessibility to public buildings in which the dance group performed.

S'kaawan passed away in 2000. His family best expressed his role in their writings about him, showing acknowledgement of and reverence for the wisdom of S'kaawan as his family knew him, and for his active role in the spirituality of the group (Thrasher-Livingston, 2006):

> S'Kaawan! Oh boy of brown earth! You came to show us the way! The way of Raven's flight within your soul. You traveled… and we began to notice our hands warmer, the fire waits to lighten us... Warmness to the moon, you are so close, and we know your strength. Your button robe embraces us and we dance with you. In the heavens and on the earth, we will become all you have taught us. (Paulette, 2000, p. 2)

Each day S'kaawan made contributions to multiple communities that were acknowledged and respected, and that he made on his own terms. He experienced disability, a part of identity. The social group and culture around him received and encouraged his self-identification, and he grew to claim social roles not necessarily tied to disability. Disability came to be seen simply as an attribute of S'kaawan's life and persona. If, like S'kaawan, we redefine the concept of success in a way that is less in line with typical notions of accomplishment (e.g., advanced education and high-status careers), we create an opening for alternate perspectives.

In this paper we consider success, disability, history and adult education. First, we review literature with respect to disabilities and adult education; next, we examine the history of disabilities in the United States and how this relates to marginalization of disabled people as adult learners. We conclude with an analytical discussion and thoughts for future efforts.

Adult Education Literature

There were two main areas in which we found articles on disability – Adult Basic Education, which accounted for the bulk of the literature, and the rest of the field. There was an approximate balance between policy/theory, application, and research articles. Topically there was an emphasis on learning disability (e.g. Covington, 2004; Ross-Gordon et al, 2003). Additional publications addressed accommodation of those with disabilities (NIFL et al, 2000; White & Polson, 1999; Polson, 2000; UNESCO, 1997; Adult Learning, 2001). A third area of literature decried the failure of adult education to engage with disability and suggested ways in which the field could become involved (Clark, 2006; DuBois, 1998). Other topics included disability as an axis of difference (Ross-Gordon, 2002), as an issue of marginalization (Rocco, 2006), personal experiences (Clark, 2005; Rocco, 1997), and intellectual disability (Bochner, Outhred, & Pieterse, 2001; Buckingham, 2005; Gorman, 2000; Moni, Jobling, & van Kraayenoord, 2004).

In the 1970 *Handbook of Adult Education*, there is no specific mention of persons with intellectual or other disabilities, though there is a chapter on health and welfare agencies. In the 1989 *Handbook of Adult and Continuing Education*, Klugerman emphasized the lack of options for adults with intellectual disability to access postsecondary education. She noted that persons who reached age 21 before 1975-1980 are the least served by their early experiences (or lack thereof) with education. This group is identified as the most likely to benefit from adult education, and the least represented in higher education (Klugerman, 1989). Both chapters call for reform and change such that adult education ultimately includes all learners.

Disability as an imperative was established in the field at several different points, perhaps most recently about ten years ago with Confintea V (1997), NIFL et al (1998), an issue of New Horizons (1998), an issue of *Adult Learning* (2001), and a small spurt of full-length texts.

"Marginalization," Rocco writes, "is perhaps the most dangerous form of oppression. A whole category of people is expelled from useful participation in social life…" (2006, p. 169). Clark (2006) would probably agree with Rocco's assessment; she argues that adult education has done analyses along axes of difference such as race, class, and gender, yet neglected this additional major area of difference. Clark also makes the point that disability is equal-opportunity; it does not recognize class, race, gender, or other divides. Few authors in the field address disabilities even though the disabled population grows. We would like to add that the disabled population burgeons further yet with an influx of disabled war veterans from Iraq and Afghanistan. These veterans will in many cases be seeking adult education.

Clark (2006) offers a good working definition of disability. Her definition includes elements from the Americans with Disabilities Act (ADA), law, and social description: "The ADA defines disability as a physical or mental impairment that substantially limits a person's life in one or more major life activities. The law further defines disability as having a historical presence (impairment) or lifelong impact in a disabled person's life" (2006, p. 312). Disease and disability are not the same thing; disease is a biological process from which one may and often does recover. She then continues to argue that disability is a social phenomenon, experienced socially even though it is most often examined and understood from a disease or medical perspective. In short, a disabled person is impaired in some way from which he or she is unlikely to 'recover'; not only does s/he have a disability, but s/he experiences it socially – people react to disability, constructing and treating it in a variety of acceptable and unacceptable ways. Ross-Gordon (2002) touches on this when she describes schooling and other elements of learning experiences in the lives of people with disabilities.

Rocco, Clark, Gorman, and others have done an excellent job linking adult education to disability; underscoring the field's continued oppression of an already oppressed group; and indicating a need that is legal, ethical, and practical to engage the topic. We wondered about the field's continued reluctance to address what appears to be a pressing issue for adult educators; as such we decided to look historically at disability and education to see what we could learn. We focused to some degree on visible physical disability (e.g. amputation, paralysis), but we took greater care to emphasize intellectual and "invisible" disabilities (e.g. Down syndrome, autism, or the neurological condition of epilepsy).

People with Disability and History in the United States

People who experience disabilities have always been a part of our human family. Through history, they have been defined in the US as feeble, idiots, imbeciles, low grades, retarded, a pity, saviors, mascots, pariahs, visionaries, closer to emotions/nature, simple, bringers of disease, study cases, lessons to those more fortunate, a social menace, and in need of extermination to preserve the gene pool (Trent,1994; Snyder & Mitchell, 2006). Historically, people experiencing disability have been marginalized; through traditions of separation from society physically, mentally, and emotionally, people who experience disability have come to be seen through a gaze created of the sum of imposed definitions.

Prior to the Industrial Revolution in the late 18th and early 19th centuries, people with intellectual disability were typically cared for within families. In addition, there were early forms of social services such as almshouses (where people received aid at a location such as a church or prison) and "outdoor relief" (in which people received food/clothing or other "handouts" but was not located in a place) (Trent, 1994). Many of these charities were token, offering reassurance that people were cared for while relieving society of the responsibility for fully including all members. People were seen to be at fault for their disability, or the disability was attributed to a bigger force (for example, God's Will). People experiencing disability were exposed to living conditions and social attitudes that were as harsh as we might care to imagine. These conditions provided fertile ground for the work of Edward Seguin, a French educator who argued in 1837 that young people with intellectual disability could learn (Trent, 1994).

Seguin's work was innovative. His basic premise was that if one can move the body, one can also move the mind. Seguin established a classroom at Saltpetriere, France, in 1840, where children were taught using practices such as sensory-motor exercises, repetition, and moving the body to establish muscle memory. By Seguin's logic, the inadequate intellectual will of a person is compensated by exercising the body, with the stated objectives being a "cure" and return to society (Trent, 1994). For Seguin, bodies served as a replacement for or key to the mind. His work can be considered progress in the sense that people with disabilities were "promoted" to the status of "educable"; simultaneously, the denial of intellectual capacity provided the groundwork for systemic educational oppression of this group.

During the Industrial Revolution, people with disability were seen as needing to return to a simpler, pastoral time, to a manufactured utopia separate from the problems of modern life (naïve ideals applied to people with disability even today). The outcome of Seguin's early educational efforts and such social ideals was institutional expansion and increased placement of people in institutions in rural settings. The concept of persons with disability being educated to return to society faded, ceasing to be a realistic option (Snyder & Mitchell, 2006; Trent, 1994).

Many of Seguin's practices are still in place today, aligned with physical training more than education. This lack of progress raises questions about what is missing from education for adults experiencing disability. Is there a lack of substantial reform due to success in established

practices? Is encouragement of developing the skills of critical thinking present? Why or why not? The absence of the moment of true integration with society in a person's life, after so-called education, continues to be a central part of oppression of people with intellectual and severe physical disability -- and is a "tradition" unto itself. Self expression and self identification by people who experience disability continue to be missed by adult education. The absence of contributions to and participation in society by all adult members creates unwilling silence, and offers tacit permission for continued oppression.

People with disability came to be defined as a social menace who were ruining the country's gene pool and whose presence/disability should be prevented and/or eliminated for the greater good (eugenics). This became a nationwide concern, especially from 1910-1945, and contributed heavily to persecution and marginalization that can still be seen today (Snyder& Mitchell, 2006).

Subsequent advances in medical science and the rise of psychology contributed to a change in direction. People with disability were redefined as medical cases, their disabilities defined less in terms of personal deficiency than of illness. This simultaneously "dignified" disability, raised it "above" social menace, and reinforced the notion that people with intellectual, neurological, or other severe disabilities could not learn. It is not difficult to understand why families frequently welcomed the medical diagnosis: illness was preferable to poor character. People continued to be placed in institutions, and custodial care of people who were defined as incurably ill prevailed. In the case of both the eugenics model and the medical model, people with disability were symbols of the social outcast and the object of medical study/research/intervention, and pity (Snyder & Mitchell, 2006). Damage resulting from the medical model of disability is recognized and contested, as evidenced by Clark's (2006) definition of disability and its explicit separation of disability and disease.

In the 1940s and 50s parents and human service workers began to question the institution as unsafe conditions and abusive practices were exposed (Trent, 1994). The idea of the American family was romanticized as, after World War II, adults began to expect to be part of the growing middle class. The "rituals" of growing up and living in postwar years became very important and families with children who experienced disability desired, but often could not achieve these same rituals (K. Jones, in Noll, Trent, 2004). Conformity was simply not possible.

Education of children with disability was once again a possibility outside of an institution. In most cases it occurred in settings that were outside the public school, such as the family home or a community church basement. The institution evolved; families advocated for placement in new "state schools" that appeared as the medical model for people with disability gained strength. This continued the shame, stigma, and hiding of disabled family members from society as achievement-oriented ideals for families became stronger (K. Jones, in Noll, Trent, 2004). The pervasive tendency to define people in terms of deficits continued, as well as the idea that answers for questions related to disability existed outside of the people. What was largely missing is the thought that people and their families can and should engage in self-definition, where authentically defined selves are unconditionally valued within the family, the society, and the moment in history.

We argue that after World War II, treatment of people with physical and intellectual or neurological issues developed differently. Many men returned from World War II with various forms of physical disability – and these disabled veterans were heroes. In the decades immediately following, the nation experienced similar influxes of disabled veterans from Korea and Vietnam. While they may not have been regarded as heroes to the same degree, the veterans

were not shameful or particularly hidden unless they were exceptionally disfigured, or had suffered such mental and emotional damage that their behavior became socially unacceptable and embarrassing to families and friends. Over time, general support and public accommodation of people with physical disabilities has become more accepted. People with intellectual and other disabilities did not experience a similar change in status and treatment.

Society is replicating what was important to the postwar middle class today, as may be seen in this list of common educational and social goals defined for adults with disability: learning to modify communication habits to fit in to the general public, learning to not call attention to oneself, "making good choices," being independent, getting into a routine, staying calm, and having a job (Alberto, Cihak, Frederick, 2007; Dowrick, 2004). Families and people with disability understand that achievement of these goals can bring some measure of inclusion in society. It is up to the individuals and their families to do the work and make the changes—again, starting from a deficit model of the person with disability. Defining personal control of behavior as a goal indicates that responsibility exists on the most private, individual level. Here the learner is somehow unacceptable and not in control of the self. The learner is in a circuitous pursuit of static behavioral goals that may or may not be achieved or relevant to the learner's life. Adult educators are generally not responsible for teaching adult learners with disability who are very rarely included in mainstream learning spaces. Learners with disability are instead set upon the task of learning lifelong self control; when they are unsuccessful in teaching themselves socially defined self control (e.g. not doing anything embarrassing), they are pushed farther out of society and into more restrictive settings.

The main ingredients of The American Dream remain out of reach for many people with disability, especially intellectual disability. What is missing from the list of educational or habilitative goals and objectives currently offered to persons experiencing disability? Much of what is missing is forward thinking, an assumption that educational goals for today's adults could not possibly apply to those with disability. The goals cited as relatively current are much the same as they were 150 years ago when Seguin started his work – train the adult with disability not to be a burden or embarrassment. The degree to which a disabled adult achieves the goal is directly related to allowable social participation. It simply determines *presence.* A large scale revision of educational goals for people with disability might include the fostering of critical thinking skills, relevant self advocacy, and emancipatory learning; our failure to move in a progressive direction has contributed to continued oppression of people with intellectual, neurological, or other "icky" disability in the modern era (Gorman, 2000; Ross-Gordon, 2002).

Moving into the Present Day: A Discussion

In some ways trends have changed. Children with many kinds of disabilities, including intellectual, are "mainstreamed" in K-12 classrooms. There is a sense that education past high school must be more readily accessible to adults who experience disability, as indicated by the approximately 110 postsecondary programs in 28 states available to adults who experience intellectual and other disabilities. These programs fall into adaptive categories, and in most cases serve learners age 18-25 who do not need financial aid; the programs may or may not provide supports for social inclusion (Hart, 2006). People with disability continue to be vastly underrepresented in post secondary learning and informal adult learning, despite desirable outcomes such as the increase of the likelihood of employment, better health, and living above the poverty level (Frieden, 2003; McConkey, 1998: Roeher Inst., 1995).

The Higher Education Act, originally adopted in 1965, helps people with financial and other disadvantages to access higher education. The July 2007 reauthorization of this act better

serves students with disabilities and in particular those with intellectual disabilities (DPC, 2007; Ford, 2007; Frieden, 2003; The Arc of the US, 2007). It does not directly address the needs of adults who have not attended available conventional schooling, due to their age, where they grew up or reside as adults, or other factors. The need for continuous learning, community involvement, and supports for adult learners with disability is most often met by social service agencies and families. Note, however, that the social service agency is financially dependent on sources such as charity, donations, state and federal grants, and Medicaid -- all of which necessitate the perpetuation of deficits and need for intensive support for the agency's clientele. Agencies frequently become focused on trying to meet the financial bottom line necessary to operate on behalf of those who "depend" on them. Paid, direct supports, in short, appear to blur the line between support and control of agency clientele. This argument underscores the near impossibility of truly emancipatory learning occurring within social service agencies. The oppression of adults who need lifelong learning, through the lack of practical, accessible, affordable, and learner-driven opportunities, continues to grow without significant challenge. Although social service agencies provide valuable services, they are a product of our historically developed need. We suggest that education would be better addressed in places that any adult learner may access, whether informal learning or formal postsecondary inclusion, rather than in places that are financially driven by the presence of medical diagnoses of disability.

Practical answers may perhaps be found in the strengthening of partnerships across disciplines, agencies and with families to be better able to assist the person with a disability in a personal learning journey (Braddock & Rusch, 2002). Funding sources that are not based on proving learner deficit could be utilized. The assumptions made by a proposed educational program or setting must be critically examined before educational programs and processes commence (Titsworth, 1999).

Conclusion

The paucity of literature in Adult Education and its nature are very much in line with the historical development of oppressive attitudes and practice relative to people with disability for the last few hundred years. There is a lack of educational options, continued marginalization, and a focus on basic skills for the purpose of "fitting in" to the degree possible with society. Adults with intellectual and other disability are adult learners who need options for learning throughout life. All adults can and should be free to authentically self identify, with their contributions to society accepted on the terms of the contributor. Adult education as a field has its work cut out to develop practices that better include all adult learners.

The unanimous endorsement of the Higher Education Amendments of 2007 (S.1642) indicates that people who experience intellectual disability are coming to post secondary learning and adult education. It shows that society is changing in progressive ways as we begin to welcome all to the opportunities offered by adult education. Opening minds and changing attitudes on a personal level are perhaps the first and most effective steps for educators to fully interact with *all* adult learners.

If success means being able to contribute to society authentically, as S'kaawan did, then surely success in adult education means making our practice fully inclusive. Success for adult educators means facing our historically evolved prejudice against people with disabilities of all kinds and working through it. It means acknowledging and accepting our responsibility, and using that to strengthen both mission and practice.

The references are available upon request.