

Invited Commentary

The Quest for Ordinary Lives: A Legacy and a Challenge to the Status Quo

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When “the severely handicapped” were brought under the umbrella of public education with passage of the Education of the Handicapped amendments in 1974–1975, many educators and psychologists rose to the occasion to help schools get a handle on their new responsibilities. Most pursued a rational–technical agenda: prepare specialized teachers to skillfully task-analyze requirements of assessed “next-step” behaviors and use behavioral instructional methods to teach those “functional life skills.” Since this emerging curriculum bore little resemblance to grade-level academic instruction, the “continuum” language of the least restrictive environment (LRE) section of PL 94-142 was interpreted generally to mean that “severe” means separate and congregate for teaching purposes.

In California, where I worked at the time, special facilities were acquired or constructed by County Offices of Education called Development Centers for the Handicapped (DCHs), and these became the “schools” for the “severely, multiply handicapped” (SMH) students. Interestingly, some of these facilities around the State were refurbished Japanese Internment Camps from the World War II era, a dark and shameful period in California history. However, the policy calls attention to a tendency in our culture: to segregate populations who we consider to be somehow different and perhaps threatening or in need of shelter and protection from possible harm.

Furthermore, during the period of PL 94-142, a debate had emerged in the special education literature over the reasonableness and appropriateness of the medical model for the organization of supports and services with which to assist students, newly entering education under 94-142, to successfully engage the teaching–learning process. Some questioned the need, not only for separate facilities, but for the need to diagnose, to categorically label, and to prescribe particular educational approaches geared to the label. The medical model prevailed, as did those whom Brown, Shiraga, and Kessler term “segregationists.”

It is hard to even do justice to the act of describing those for whom Lou Brown has devoted a distinguished career. The “handicapped” is certainly pejorative and thankfully appears to be on the way out in much of education. The term harkens back to an era in English history in which people excluded from the workforce for reasons of physical, or cognitive limitations were expected to sit on public sidewalks with their caps in their outstretched hands to receive casual public largess.

The current term in general use, “disability,” is not much of an improvement from the standpoint of those who share Brown’s perspective. First, it is a “dis” word. It puts down the person to whom it is applied. Second, it calls attention to limitations of an individual rather than his or her strengths. This, I believe, is the crux of the issue and why publication by TASH of this article by Brown, Shiraga, and Kessler is so important.

In the history of special education, there have been a few significant dissenters who have consistently resisted the “imposition” of the medical model of disability and its consequent industrialization of special education and post-school services. Jim Ysseldyke, for example, is one of these. Ysseldyke has consistently argued for and presented evidence in support of a “response to intervention” (RtI) logic model with which to organize and deliver specialized supports and services to those who need them in order to successfully engage the general education curriculum at any level. This logic model focuses on what students *need* rather than what they are in terms of a categorical service system. Lou Brown certainly stands as an exemplar of this resistance. Brown describes the population of interest in terms of its position on a service need continuum, “the lowest functioning 1% of a normally distributed population of public school students”. “Functioning” for Brown, consistently refers to ability and opportunity to live, work, and recreate alongside chronological-aged peers rather than as a limiting characteristic of the individual. Where Brown, Ysseldyke, and others stand apart from the many is on their laser-like focus on *strengths* of individuals who need additional supports and services, and how to build on those strengths to achieve desired outcomes.

I had the opportunity in the early 1990s to visit a number of the work sites in the Madison community that

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had been arranged by Brown and his students in conjunction with the Madison Metropolitan School District. I saw a number of the school district students who were transitioning to the support of Community Work Services, and many of whose histories are now reflected in Brown's Table 1. I remember one story Brown told me in particular, as we drove between sites. A young woman had the peculiar behavior of collecting bits of thread and string which she would add to an increasingly large ball. Thread gathering was nearly her exclusive focus and had been given as a primary reason for her previous institutionalization. Brown explained that his group had developed the perfect job training site for her: the local Yarn Barn store.

Where others saw debilitating deficits, Lou Brown saw strengths upon which to build meaningful lives. While others were placing fourteen year olds in preschool settings, Brown was coining the term "chronological age appropriate placement." While others were teaching young adults to "point to your nose," Brown was coining the term "criterion of ultimate functioning." While others argued for a "class within a class," Brown wrote and spoke of the "principle of natural proportion." I knew I was witnessing a slice of history when one of my students showed me a Papal Bull, direct from the Vatican, which made reference to the critical importance of adherence to the "criterion of ultimate functioning" and referenced a paper by Brown and his students.

The Quest for Ordinary Lives is Lou Brown's legacy. He, Betsy Shiraga, Kim Kessler, and others showed the world that people whom the rest of the service industry had written off as mainly in need of shelter and protection, could live, work, and recreate in the social world, have meaningful relationships, and enjoy a high quality of life despite major limitations. *What has been largely unknown up to this publication is the sustainability of those initial job/life training and placement events.*

The extensive database reflected in Brown's Table 1 can only be read as a continuing success story of significant proportions. It stands as a monument against the tide of support for state run institutions and other sheltered, congregate settings. Will publication of these data turn the tide and bring about a full scale policy commitment to community integration transition programs for all students exiting public education who need extensive supports and services? Probably not. We are up against a powerful industry with a demonstrated capacity to successfully lobby its agenda with Congress and state legislators. Further, we are up against a "feel good" ethic that manifests itself in symbolic events such as the Special Olympics, often at times when campaigning politicians can take advantage of the exposure. Look around the country at the number of "special schools" and post-school congregate shelters the names of which are those of politicians who successfully engineered public funds for their construction.

I have been involved now in major efforts in California and in Kansas to close state institutions for "the retarded" (or "developmentally disabled") partially on the grounds that the enormous percentage of state and federal tax dollars required to maintain those settings serves as a barrier to adequately funded community living and work opportunities for the same population. In both states, the primary arguments used in the state legislatures against closure were primarily about labor. The voices of a few institution supportive families were a distant second in the debate and were clearly out voted by community placement supportive families. Brown, Shiraga, and Kessler cite a report from the President indicating that in 2004, 90% of approximately 9 million adults in the USA with "intellectual disabilities" were unemployed. It is therefore at best, ironic that *millions* of Americans in need of specialized support in order to live, work, and recreate in freedom are confined to congregate settings so that *thousands* of service providers can enjoy full employment.

For those willing to challenge the status quo and engage the effort to liberate residents of state institutions and other sheltered environments, the paper by Brown, Shiraga, and Kessler offers some useful insights beyond those traditionally encountered in personnel preparation programs in "transition from school to adult living." First among these is the implicit admonition to pay attention to local economics. To propose closing an institution will require a plan to deal with the labor issues and the issue of capital investment in the facility (i.e., how to recycle the buildings).

A second lesson has major implications for schools and, perhaps, a need to rethink assumptions concerning inclusion. *Authentic* assessment and instruction implies an obligation to rethink the concept of a school, for example: Is it bricks and mortar? Or is it a constellation of opportunities to engage the teaching-learning process in the broader community? The concept and technology of community-based instruction has been around a long time, yet is still seldom seen in practice. What are the barriers in light of Table 1 that cannot be overcome to gain authenticity in public instruction?

What about "job coaches"? Brown's data suggest this particular labor category requires careful consideration. Attention to horizontal and vertical enhancements are critical to growth on the job. The coach cannot replace or become a barrier to natural interactions with coworkers. Natural supports are to be encouraged. A *whole life space* approach to coaching functions needs to be developed to help ensure sustainability of initial efforts. Attention to support needs in recreation, lunch, toileting, transportation, and social integration is becoming requisite to operationalizing authentic coaching support.

Multiple jobs for a single worker emerges as an interesting and highly suggestive implication for sustainability of effort. The idea that a worker may perform acceptably at one job in the morning, but need to shift to

a different type of job in the afternoon may be critical to successful job performance for this population.

Wage/benefit issues remain complex. Brown's group did not shy away from voluntary participation in the work force when it seemed to be in the best interests of the worker. In some cases, workers reportedly preferred to remain in a volunteer work situation even though they could earn money elsewhere, perhaps for reasons of social benefits. Interestingly, the number of volunteer jobs has decreased by half over two decades in the sample reported by Brown, Shiraga, and Kessler, possibly reflecting a softening of the wage/benefit constraints. Perhaps when a community such as Madison, Wisconsin, becomes used to hiring people with extensive support needs in the workforce, there is a greater willingness to explore various wage/benefit options within that community.

Finally, the paper suggests that there may well be another side to the "protectionist-feel good" ethic in our society. In all of the entire experience of MMSD and Community Work Services with respect to the clients

reflected in Table 1, not one instance of sexual abuse or physical harm was reported. Compare that finding with the number of physical/sexual abuse incidents reported annually in large, congregate facilities for the same population, and the popular conception of the need for shelter and protection begins to turn inside out with respect to form. Secondly, Brown, Shiraga, and Kessler reported anecdotal data from coworkers in these typical community work settings suggesting that their jobs became enriched and more satisfying and fulfilling for having had the experience of working alongside coworkers who are overcoming stereotypes and obvious constraints and limitations in order to enjoy the freedom to live and work in the real world. In terms of its own core values of freedom and liberty for all, what more could a society ask than to expand, replicate and validate the findings reported in Table 1?

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