Issues in Severe Disabilities

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The critical issues that arise in a field provide a focus for, and they define the parameters of, its professional discourse. Hence, knowing a field’s critical issues is to better understand a field’s culture and its primary activities.

Critical issues in severe disabilities have typically emerged out of concerns that have arisen during service provision. These concerns can be grouped into three broad categories. The first set of concerns are those associated with access, defined as the degree to which persons with severe disabilities are offered meaningful opportunities to participate in the events, activities, and life styles of their communities and of their age- and grade-level peers. The second set of concerns are those associated with equity, defined as the degree to which the magnitude and content of the educational experiences provided to students with severe disabilities are equivalent to those offered to students without disabilities. Third and finally, there are concerns for quality, defined as the degree to which prescribed educational ends are optimized through the selection of promising and/or proven instructional strategies, technologies, and interventions.

We will use these three categories to explore how certain concerns have come to predominate the discourse within severe disabilities, and how these concerns give rise to certain issues, and not others, as the critical issues. We begin this discussion with some historical trends, which provide a vehicle for understanding how particular concerns and issues have arisen and have evolved. Critical issues are then presented which are derived from these concerns. Finally, conclusions are drawn based on some of the historical and sociopolitical realities that our field presently faces. As noted in the foreword, persons who desire to comment or identify additional issues are encouraged to go to: http://vision.unco.edu/nclid/async-sp/board.html to add your ideas. [Ed. Note: This board has been closed]

Historical Trends and Their Implications

In an overview of trends related to the emergence of compulsory education in the United States, Richardson (1994) describes the development of three distinct systems of educational services that continue into the present day. These systems are (a) the special education service system, evolving out of earlier systems for students with sensory, physical, or mental handicaps who frequently resided in institutions such as hospitals and residential facilities; (b) the training schools and "correctional" service system, arising in the late 19th and early 20th centuries to both educate and contain truant and delinquent youth; and (c) the mandatory general education system for "regular" students, reflecting a complex coalescence of earlier educational systems associated with the privileged as well as the working and middle classes. Although the history of education in the United States is interspersed with calls for various forms of merger of these systems (e.g., Lipsky & Gartner, 1997), Richardson argues
that contemporary trends do not anticipate such a merger. While it is certainly true that more students with special needs are experiencing educational services within mainstream classrooms (McLeskey, Henry, & Hodges, 1998), the continued expansion of special education as a separate set of services and the "incarceration frenzy" associated with the management of students with behavior problems (Walker et al., 1996) speak to a widening gap between these three systems.

Historically, students with severe disabilities received services mostly from the first of these three systems and largely within institutional environments. Given the excessive levels of isolation, neglect, and abuse that were associated with institutional life (Blatt & Kaplan, 1966; Holburn, 1997; McCartney, & Campbell, 1998), pressing concerns during the late twentieth century were often framed as access concerns. Within this context, educational equity and quality concerns primarily arose out of the implementation of reforms designed to increase access to the life choices that participation in free society offers its citizens. For example, a driving force for the development of educational services for students with severe disabilities during the 1960's and 1970's was the deinstitutionalization movement (Larson, 1976). Framed as a due process issue, court decisions such as Wyatt v. Stickney made significant strides toward establishing that "restrictive environments" must serve a demonstrated educational function if individuals are to be held in such environments, and that the eventual return to the community should guide educational and placement decisions. Even as it promoted the closing of state institutions and the development of community living alternatives (Lakin & Bruininks, 1985; Lakin, Anderson, Prouty, & Sandlin, 1998), the deinstitutionalization movement also increased the provision of educational services to students with severe disabilities (equity), and it prompted concern for whether the instruction that was provided resulted in learning and educational growth (quality).

The focus briefly shifted from access to quality with the passage of Public Law 94-142 in 1975, which mandated a free, appropriate, public education for all children and youth with disabilities. In the 1970's, edited works by Thomas (1976) and Sontag (1977) reflect the exuberance and sense of high expectation that emerged among professionals and families as the promise of PL 94-142 blended with ongoing trends in deinstitutionalization to create greater educational opportunity and more life choices. Educational discourse during this period focused on such issues as whether children and youth with severe disabilities should be educated using "developmental" or "behavioral/remedial" techniques (Guess, Sailor, & Baer, 1977) and the importance of using "functional outcomes" to guide the construction of educational goals and objectives (Brown, Nietupski, & Hamre-Nietupski, 1976). Subsequent literature of the1980's and early 1990's (e.g., Chadsey-Rusch & Halle, 1992; Horner, Dunlap, & Koegel, 1988; Hupp & Mervis, 1981; Nietupski, Hamre-Nietupski, Clancy, & Veerhusen, 1986) documents a proliferation of research reflecting an intense concern for improving and refining (a) how the needs of students with severe disabilities are defined and (b) how instruction should be delivered for optimum learning.

However, persistent, less than acceptable educational outcomes for students with severe disabilities, coupled with a growing understanding of how access issues and equity/quality issues are intertwined, prompted critical reflection on the nature and value of the foregoing quality-oriented research (Meyer, 1991; Meyer & Evans, 1993). As an illustration, the development of the transition concept in the field of
mental retardation (McDonnell & Hardman, 1985) emerged with the growing awareness among families and professionals that "good instruction," no matter how frequent or intense, cannot ensure meaningful access to, or readiness to participate in, the broader community upon graduation from public education. Moreover, the inclusive education movement of the 1990's arose as research (Brinker, 1985; Brinker & Thorpe, 1984; Freeman & Alkin, 2000; Fryxell & Kennedy, 1995; Giangreco, 1986; Hunt & Farron-Davis, 1992; Hunt, Farron-Davis, Beckstead, Curtis, & Goetz, 1994; Hunt & Goetz, 1997; Ryndak, Morrison, & Sommerstein, 1999) tended to establish that educational benefits associated with being in an integrated setting outweighed the "intensive services" benefits presumably associated with segregated placements. By the 1990's, the major professional and advocacy organization for persons with severe disabilities (The Association for Persons with Severe Handicaps, or TASH) had established policy statements on inclusive education that presented it as the most viable, effective, and the only ethical educational option for students with severe disabilities.

Selected Contemporary Issues

At the outset of the twenty-first century, reminiscent of the civil rights struggles of the previous century (Kluger, 1976), both quality and equity concerns are typically framed as resolvable only when students with severe disabilities have genuine access to the full array of general education experiences. For example, policy resolutions within TASH (e.g., Personnel Preparation Committee, 2001) assert that "placement" along the continuum as part of the educational decision making process is, in and of itself, deleterious, and that placement of all students into general education classrooms must become the standard practice.

Given these points of view, the field of severe disabilities has an ongoing concern for the persistence of placing students in segregated settings (self-contained schools and classes) as a standard and acceptable practice in special education (Taylor, 1988; Meyer, 1991; Ryndak et al, 1999), and educational intervention issues are viewed as most aptly explored in research studies in which placement in the general education environment is a precondition (McDonnell, 1998). However, there is also agreement in the field with Richardson's (1994) assertion that present practices in which students who are "different" are served largely or exclusively in segregated settings will persist, unless there are reforms in how general and special education define their services. Thus, present issues in our field are often focused on identifying and impacting those institutions, beliefs, and practices that are barriers to meaningful access to general education. Three significant issues of this type are presented below: (a) the remedial paradigm and the least restrictive environment; (b) roles and responsibilities of the special education teacher; and (c) enhancing self-determination.

The Remedial Paradigm and the Least Restrictive Environment

Peck reported the following quote from a special education director in the state of Washington, "I'll believe that integration is a good thing when I see the data and not before" (Peck, 1991, p.1), and this attitude is still prevalent within education. Although IDEA '97 and related case law mandate that students with severe disabilities be placed in general education environments with accommodations
whenever appropriate, the majority of students with severe disabilities experience only minimal contact with general education students and curriculum (Davis, 1992; McLeskey, Henry, Hodges, 1999).

The mere fact that the routine separation of students with severe disabilities from the general population for their educational services is seldom questioned from a civil rights perspective is a troubling aspect of the broader picture (see Serow, 1983). The Brown v. Board of Education Supreme Court decision found that "separate but equal" systems could never be equal, and that they have definable and long lasting harmful effects on the populations that are excluded (Kluger, 1976). In disability law and practice, the legitimizing force that continues to drive separate educational services for students with severe disabilities flows from two concepts that define their placement decisions: the remedial paradigm and the least restrictive environment.

The first concept, the remedial paradigm, can be defined as an approach to education in which a student's disabilities and learning or behavioral limitations define his or her educational needs and goals (Cole, 1998; Hodapp & Dykens, 1994; Jackson & Panyan, 2002; Kliewer & Biklen, 2001). Derived from the medical model, this approach to education has resulted in students with severe disabilities being placed together not based on their age and grade levels but rather based on similarities in disability ("multiple handicaps"). Within this context, the goal of education becomes not the curriculum that is valued by the larger community but an alternative curriculum designed to help these students "overcome" their handicaps through intensive and repetitive services and instruction. Thus, an elementary school student is likely to be working on sorting and matching skills throughout his or her tenure as an elementary level student, and will have minimal, if any, exposure to the curriculum content of the sciences or literature. As another example, a high school student with a severe disability is quite likely to be working on "self-care" goals that he or she began working on at an earlier grade level, and he or she will leave the school system with minimal-to-no instruction in the culture and history of the United States. In fact, within the remedial paradigm, "integration" primarily involves ensuring that a student's social goals are met by exposing the student with a severe disability to students who are "typical." This has led to the large-scale practice of "mainstreaming" students with severe disabilities into lunch, hallways, art, music, and physical education.

The second concept that helps promulgate separate placements for students with significant disabilities is the concept of the "least restrictive environment" (LRE). As presently interpreted within special education, individual students are placed for their instruction based on their needs along a continuum that begins with general education classes, extends through resource rooms and self-contained classrooms, and ends with center-based schools and residential placement options. Kunc (1992) asserts that, for many in our field, the concept was initially viewed as a "meaningful step toward including children with physical, intellectual, and emotional needs within regular education" but has since come to be increasingly recognized as giving unwarranted "credence to segregated, self-contained classrooms" (p. 25). Kunc notes that, although the concept should drive regular education placement as a first step in service provision, the pattern that has emerged is one in which students are often first placed in self-contained settings, where they are then required to work on basic skills as if to earn the right, "if ever" (p. 26), to participate in general education. (For discussions of how the continuum
affects the lives of students with severe disabilities, see Fryxell & Kennedy, 1995; Taylor, 1988; and Wieck & Strully, 1991.)

There is an emerging alternative to both the remedial model and the LRE that is slowly gaining acceptance in special and general education (Jackson & Panyan, 2002; Luckasson, 1992; Smith, 1999), and it has the potential to reduce reliance on segregated placements. This is the support model, in which students begin and finish their educational careers within typical age-appropriate environments, with the provision of the necessary instructional and technical supports and services to ensure reasonable success in their learning and maturation (Ryndak, Jackson, & Billingsley, 1999-2000). The support model redefines special education as a set of services that are brought to the child with a special need rather than as a service delivery location to which the child with a severe disability is placed. This emerging perspective on services has placed many special education teachers in the awkward position of having to re-think their roles and responsibilities as service providers for students with severe disabilities. This topic is discussed next.

Roles and Responsibilities of the Special Education Teacher

In the decade following the passage of PL 94-142, when quality concerns were at their peak, the special education teacher's roles and responsibilities were conceptualized as exclusively self-contained in character and composition. As noted by Mary Falvey (Singer, Billingsley, Goetz, & Falvey, 1997), no one at that time even considered general education as a realistic option for students with severe disabilities. As illustrated in Striefel and Cadez (1983), the promising practices literature of this period describes an educational curriculum completely unrelated to general education; a preoccupation with self-contained classroom structure, design, and management; and a set of educational practices focused on discrete trial instruction for individual and small groups of learners with similar labels.

Analyses of the roles and responsibilities of teachers within inclusive settings suggest that many of the foregoing teaching practices are of less value than once supposed (Jackson, Ryndak, & Billingsley, 2000). Instead, skills of case management, collaboration with general education teachers, curriculum accommodation and modification, within-class support, and para-educator supervision come into the forefront (Jackson et al., 2000; Jackson, Ryndak, Keefe, McCabe, Moore, Holthaus, & Moore, 2000; Rainforth & England, 1997; Rainforth, York, & MacDonald, 1997). The ultimate success of inclusive education does not rest with proof that inclusive education works; rather it rests with the willingness of general educators, schools, special education professionals, and family members to honor, anticipate, and expect special education teachers to engage in these very different roles and responsibilities.

Enhancing Self-determination

The independent living movement of the mid-20th century (Budde & Bachelder, 1986) was an early attempt by disability activists to situate the control of services, mainly rehabilitation services, in the hands of the recipients, the people with disabilities themselves. Especially in the last decade, there has been significant growth in interest in self-determination as a factor and consideration within special
education for students with severe disabilities and their families (Turnbull, & Turnbull, 2001; Wehmeyer & Schalock, 2001). Just as with the independent living movement, a primary reason for the shift is the view that making education relevant to the lives of persons with disabilities requires giving them more direct control over these experiences. Just as in the independent living movement, a major thrust within the self-determination movement is helping service systems shift from a "functional skills" orientation that marginalizes and degrades the learner to an academic orientation that promotes authentic participation in our schools and broader communities: "Educators working with students with disabilities can no longer consider curricular and instructional content as separate from the general curriculum" (Wehmeyer & Schalock, 2001, p. 1). And, as with the independent living movement, interpersonal relationship choices are also part of self-determination (Wehmeyer & Schalock, 2001).

In the severe disabilities field, self-determination in choosing one's relationships, classes, and activity preferences is viewed as a process that must occur in typical home, school, and community settings. Self-contained settings are inherently too restrictive to provide the necessary range of options such that a student can increasingly assume responsibility for his or her social relationships and educational choices. Yet, when this point is raised by advocates within public schools where self-contained programs thrive, it is not uncommon for some member of the school team to exclaim that students with severe disabilities are often seen together at lunch and in other settings, and then to claim further that part of self-determination should be "letting them choose to be with each other in classes and other places." This argument for preserving self-contained programs is, of course, vacuous. Most students with severe disabilities have only had experiences with each other in their schools and classes throughout their school careers precisely because of educational placement practices in public education. As noted by Kunc (personal communication), this argument may reflect professional confusion between the consequences of segregated placements on people's social choices and the need for people with disabilities to show solidarity with each other when dealing with the larger community.

**Conclusion**

The exclusion of persons with severe disabilities from the experiences available to other citizens has an extensive history for which there are no simple explanations. Rather, like a chameleon, exclusion practices have been cloaked by whatever rationales make sense for the times. For example, as noted by Jackson and Panyan (2002), educational practices based on eugenics did not arise with the eugenics movement of the early 20th century; rather, eugenics simply provided the next "scientific" rationale for longstanding practices of isolation, neglect, and mistreatment (see also O'Brien, 1999; Smith & Mitchell, 2001). Today, eugenics has returned, now under a new guise: In the context of "bottom-line" cost benefit analysis and research findings that are simplified and distorted for general consumption, decision making practices that are based on discriminatory attitudes and beliefs about relative human "worthiness" have a new cover (Allen, 2001).

The potential danger of today's eugenics for persons with severe disabilities is significant: Relegation to self-contained placements based on "social worth" is likely to persist, just as institutional placements
were driven by similar values in the early 20th century. Certainly ignorance and fear can play roles in why students with severe disabilities are routinely placed in self-contained environments. Yet, just as with institutional placements of earlier decades, expressed concerns for assuring that "the best and most intensive services available" are provided to "those students" can also mask attitudes and perceptions that are laced with prejudice and malice.

As an analogy, it has been said that slave traders justified their vocation by arguing that while slavery may be bad, the natives were better off because they were now in the new world and not in Africa. Likewise, many special educators acknowledge that restrictive placements can be problematic because of their enforced isolation from peers and typical experiences of life, but some then argue that the educational benefits of such placements outweigh the negative effects of segregation. In severe disabilities, neither the research data nor the day-to-day experiences of persons who know the field support the educational benefits argument for segregation. Only when such reasoning is set aside can significant access concerns be resolved, and only at this point can equity and quality concerns assume their rightful place as important determinants of the critical issues in the discourse of our profession.

The larger dilemma that we face is a straightforward one. As noted by Pinsky (2001), a legislator in the State of Maryland, "the lesson of fifteen years is that real change requires a people's movement" (p. 18). This has certainly been the reality for people with severe disabilities and their families, from the deinstitutionalization movement through today's inclusive education movement. A real change to a different kind of educational service system will require people with disabilities and their families to unite with interested professionals, and to campaign for civil rights reforms that will broadly impact placement practices for students with severe disabilities in today's schools. Until this happens, it is likely that progress toward full equality for students with severe disabilities will be slow and fitful, at best.

References


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