

Narrowing the Breach:

Can Disability Culture and Full Educational Inclusion Be Reconciled?

Jean P. Hall, *University of Kansas, Lawrence*

Because of the long history of exclusion of people with disabilities, total inclusion in the educational environment has many outspoken proponents. People and organizations favoring inclusion, however, are overlooking the value of the disability culture that is fostered when children with disabilities have the opportunity to associate with and learn alongside other individuals who share similar identities and life experiences. The history of the disability rights movement clearly illustrates that major changes do not occur unless people with disabilities band together to address shared injustices (e.g., Shapiro, 1993). The phenomenon of a disability culture has been convincingly demonstrated by many researchers and writers, and its importance to the development and self-esteem of students with disabilities is discussed. Although the current special education system has many negative aspects, changes to the existing system rather than a movement to full inclusion will be more effective in supporting disability culture and, ultimately, the needs of children with disabilities.

Josh's Story

Cindy is the White mother of a 10-year-old Black child with cerebral palsy (see Note). She took Josh home from the hospital when he was 6 days old and weighed less than 5 pounds. Originally, she was to be his foster parent for 2 weeks, but eventually Cindy's family adopted Josh. From the start, Cindy made efforts to reinforce Josh's racial culture. She took him to Black churches and Black Expos, exposed him to books by Black authors, and had him participate in activities during Black History Month. She never really considered getting him involved with other people who had disabilities, however.

A local Black civil rights activist once told Cindy that Josh had two "whammies" against him: he was Black and he had a disability. Furthermore, he warned Cindy that Josh would experience discrimination on the basis of his disability much earlier than on the basis of his color. He was right. Cindy relates stories of how even medical professionals, noting Josh's obvious physical difficulties, were shocked by young Josh's sense of humor, his advanced vocabulary, and his obvious intelligence.

Josh attends public school in a rural area. One of his best friends in school was a White boy with spina bifida who used crutches like Josh. Recently,

the friend died due to surgical complications. When Josh found out, his response was: "Now there's nobody like me." Obviously, to Josh, his disability cultural affiliation was stronger even than his racial cultural affiliation, which had been actively fostered by his family. Furthermore, school was the only setting in which Josh had truly enjoyed the opportunity to experience that affiliation.

For most of U.S. history, schools were allowed to—and often did—exclude certain children, especially children with disabilities. In the 1960s, federal legislation began to address the educational needs of children with disabilities, culminating in the Education for All Handicapped Children Act of 1975. Subsequent amendments to the Act have changed its name to the Individuals with Disabilities Education Act (IDEA), which was last reauthorized in 1997. One tenet of IDEA is that education for children with disabilities be provided in the "least restrictive environment" (LRE), meaning that they receive their education, to the maximum extent appropriate, with nondisabled peers and are not removed from general education classes unless their education cannot be achieved satisfactorily there (20 U.S.C. § 1412(a)(5)(A)). Perhaps partly because of the long history of exclusion of people with disabilities, many outspoken reformers have equated LRE with full inclusion of children with disabilities in the general classroom. I argue, however, that inclusion proponents are over-

looking the value of the culture that is fostered when children with disabilities have the opportunity to associate with and learn alongside others who share similar identities and life experiences.

Furthermore, the movement toward full inclusion has the potential to undercut the ability of the disability community to advocate effectively for itself. The history of the disability rights movement has clearly illustrated that major changes do not occur unless people with disabilities band together to address shared injustices (e.g., National Council on Disability [NCD], 1996; Pfeiffer, 1993; Shapiro, 1993). Pfeiffer explained how the independent living movement, although initially spurred by the need for services, matured into an organization that was equally concerned with the civil rights of people with disabilities. He detailed how people with disabilities involved in the independent living/disability rights movement came together to lobby for signing of the Section 504 regulations in the early 1970s and how this cause helped to unite people with disabilities from across the country. Even Scotch (1984), who questioned how influential the disability rights movement was in the passage and implementation of Section 504, acknowledged that “[d]isabled people have begun a long march through the institutions of American life, and it is unlikely that they will be easily turned back” (p. 168). Scotch did, however, emphasize that sustaining a unified and effective political movement can be difficult. Charlton (1998) echoed this belief in his statement that “(t)he failure of people with disabilities to identify with other people with disabilities is . . . the principal contradiction that limits the disability rights movement’s potential influence and power” (p. 78).

A weakening of advocacy efforts can have monetary as well as civil rights implications. Braddock, Hemp, Parish, Westrich, and Park (1998), for example, clearly documented a direct correlation between the level of advocacy in a state and the level of funding for services for people with developmental disabilities. Another example of the monetary power of grass roots advocacy is the “Drive for 75” movement by independent living advocates. This effort to change the fiscal allocation under Title VII, Part C, of the Rehabilitation Act has resulted in a 21% increase for federal funding of centers, and efforts to increase these funding levels continue. Kimball Gray, executive director of the Maryland Statewide Independent Living Council, described the advocacy effort as follows:

[I]t’s good to see the power of the independent living movement in a proactive position with Congress, as opposed to our accustomed role of defending the civil rights of people with disabilities. I think we demonstrated the ability to have a presence in both arenas. (Topeka Independent Living Resource Center, 2000)

Understanding Disability Culture

To appreciate fully the importance of fostering disability culture for children, we must first understand that culture itself.

Many researchers have documented the existence of a disability culture, its functions, its “core values,” and its similarities to and differences from other cultural groups (e.g., Charlton, 1998; Gill, 1995; Gilson, Tusler, & Gill, 1997; Paradis, 1998; Shapiro, 1993). One distinct feature of disability culture that is not shared with any other cultural minority group is that in the great majority of cases, people with disabilities do *not* share that cultural affiliation with their families. As Gilson et al. pointed out,

[the] process of identity formation for persons with disabilities is complicated by a social marginalization so profound that it extends into the shelter of the family. A pivotal point in the identity development process is the individual’s recognition of corporeal and psychological distinctness from her/his nurturers, followed by a complementary recognition of similarity to others outside the family boundaries. (p. 13)

For this reason, the school environment presents a unique opportunity for children with disabilities to both experience and, more important, learn from educational experiences shared with their peers with disabilities. This is especially true for children whose disabilities preclude them from interacting with peers in other community settings due to medical, transportation, financial, or other limitations.

Regardless of when or how an individual acquires a disability, he or she can obtain both knowledge and support from other people with disabilities. Support groups for people with many different types of disabilities can be found in most communities. These groups provide an opportunity to exchange ideas, experiences, and coping strategies. Similarly, many hospitals have programs in place to match (a) patients who have been newly diagnosed with cancer with peers who have previously been diagnosed and treated or (b) people with recently acquired spinal cord injuries with veteran wheelchair users. Clearly, there is a recognized need for and a benefit from the exchange of insights and common concerns among people with disabilities, and these are recognized even among professionals who do not themselves have disabilities.

Disability culture extends beyond diagnoses, however. True disability culture embraces *all persons* who have been marginalized by society simply because they are viewed as defective, not valid (“invalid”), or somehow in need of pity. Even people with invisible disabilities such as chronic health conditions or mental illness experience this marginalization: Children with severe asthma often have to sit on the sidelines while their classmates participate in vigorous sports; people with systemic conditions or mental illness often experience extreme fatigue or somnolence due to their illness or medications and may feel excluded because their participation in many parts of life is limited; people with HIV/AIDS are still treated as pariahs by many individuals if their condition is revealed. Think of a child with a severe learning disability who is asked to read aloud in front of a class. Although his or her disability may be invisible to classmates, its manifestations certainly are not, and the resulting rejection is no less profound.

A 1986 Harris & Associates study found that 74% of people with disabilities reported feeling a sense of common “group” identity with other people with disabilities that cut across disability, age, and employment status. As Paradis (1998) noted, “Like other minority groups, we must struggle to . . . integrate with the ‘mainstream’ while preserving the meaning of our unique life experiences and our own separate identity” (p. 19).

Definition of Disability Culture

In reviewing various definitions of the term *culture*, Barnartt (1996) noted that “all emphasize norms, values, symbols, language, ideational systems, . . . and arts such as . . . humor” (p. 3). Gill (1995, 1999) defined *disability culture* as including shared, long-standing social oppression; art; humor; history; evolving language and symbols; a unified worldview; beliefs and values; and strategies for surviving and thriving. Although many people are familiar with deaf culture and its accompanying sign language, few are perhaps aware of a larger, more inclusive, cross-disability culture and its language and symbols. Publications such as *Disability Rag* (now *Ragged Edge*) and *This Brain Has a Mouth* (now *Mouth Magazine*) exemplify the often graphic and powerful language and symbols used by disability rights advocates representing all types of disability groups, including people with cognitive impairments and psychiatric disabilities. A *Mouth* staff member, Tom Olin (cited in Gwin, 2000), noted that the magazine’s “essential function is to develop a language, a vocabulary to describe us and the inside-out lives we lead, the tyrannies we endure Language gives knowing.” These and other magazines, such as *Mainstream*, emphasize the injustices experienced by almost all people with disabilities and illustrate how mistreatment of one disability group directly or indirectly results in the mistreatment of all people with disabilities. Stand-up comedians such as Chris Fonseca and Kathy Buckley and cartoonist John Callahan share with fellow people with disabilities and with mainstream society the humorous—and often ironic—aspects of living with a disability. Groch (1994) listed many other such “cultural artifacts.”

Centers for Independent Living, which are mandated by the Rehabilitation Act to be “cross-disability,” recognize the universality of the disability experience in their core service of peer counseling. Peer counselors are veterans of disability who serve as role models and mentors. They do not necessarily share the same disability as the people with whom they work, but they do encounter the same societal barriers and attitudes that may hinder true independence.

Core Values of Disability Culture

The language and symbols of disability culture seem to reflect a series of core values. Although more research may be needed to confirm the presence of these values across disability groups, many people with disabilities appear to share them, regardless

of the individual circumstance. Some of these values have been described by Gill (1995) and Kemp (1999), and they include the following:

1. *An acceptance of human differences.* Because people with disabilities are different from the persons who make up the majority population, they are more accepting of others who are also different.
2. *A matter-of-fact orientation toward helping.* People with disabilities often depend on others for assistance with even the most basic and personal of life’s daily activities; thus, they view helping others as a natural and right thing to do. Interdependence is a normal part of their lives.
3. *A tolerance for lack of resolution.* People with disabilities, especially individuals with chronic illnesses or progressive conditions, have learned by necessity to live with a great deal of uncertainty in their lives.
4. *Disability humor.* Often seen as a very dark humor by the nondisabled, disability humor frequently plays on the stereotypes of disability held by the majority culture. Disability humor also gives people permission to laugh about circumstances that some individuals see as pitiable but that the disability community take in stride. For example, Kemp (1999), a quadruple amputee, shared the story of how each year he must reapply for his handicapped parking placard. He related how he goes to the motor vehicle office and, after showing them he hasn’t “grown any arms or legs,” asks “Could you . . . give me 18 months, maybe two years? I don’t feel any growth coming on yet.”
5. *A sophisticated future orientation.* Think of the person with paraplegia who uses a wheelchair and has been invited to present at an out-of-town conference in 6 months. He or she will immediately begin inquiring about accessible airlines, accessible transportation to and from the airport, accessible lodging, reimbursement for the use of a personal attendant, and so forth. Similarly, an individual with a chronic mental or physical illness requiring medication will be sure to bring a sufficient supply and will probably also locate a place to obtain this medication in the place being visited. Finally, someone with a brain injury or learning disability who is contemplating which college to attend will likely check into the process of obtaining, and the quality of, note takers, readers, or other similar accommodations before applying. Simply put, many people with disabilities are—and must be—great planners.

Importance of the Disability Culture for Children with Disabilities

Although Barnartt (1996) questioned the applicability of the term *disability culture*, he did acknowledge that this concept serves as a frame “around which disability consciousness can be built” (p. 2). Groch (1994) suggested that people who possess a disability consciousness have developed a sense of collective identity and acknowledge their oppressed position. These views are incorporated in some of the functions of disability proposed by Gill (1997):

1. fortification against oppression;
2. unification across disability, age, race, gender, socioeconomic status;
3. communication developed through art, language, symbols, and rituals that help to articulate to the world and to others with disabilities their distinctness; and
4. the offer of a sense of belonging to marginalized individuals.

These functions can obviously be quite valuable to children who may feel isolated. For example, a young woman described how her involvement with the disability community not only helped her resolve her own feelings about her disability but also resulted in better relationships for her with people who did not have disabilities. Unfortunately, she was not able to experience this involvement until she entered graduate school.

I . . . began to look at my disability in a very different way. This change was catalyzed by experiences I started to have with other disabled students. We began to “hang out” and I enjoyed their company . . . I had finally found a group of people with whom I did not have to consistently play the role of the “happy overcomer.” I no longer regard disability as an inherently negative condition, but rather as one of the unique and positive characteristics that comprise our society as a whole. . . . And as I have come to value my disability as an integral part of who I am, others have too. For once, I began to let people pass through the carefully guarded gate of the wall which I built to separate me from others. After having reached the point of accepting and respecting myself and my differences, it has been much easier for me to form a positive relationship with society. (Gill, 1997, p. 44)

Charlton (1998) remarked on a similar phenomenon whereby the new consciousness of self derived from interacting with others who have similar experiences “allows individuals to recognize themselves in the context of something bigger than themselves and enables them to appreciate the commonalities they have with others. . . . Isolation and es-

trangement are replaced by association and connection” (p. 118). If we value these roles that disability culture can offer children, we must find a way to support the culture’s involvement in their development. A logical place for this support is school, where children spend much of their formative years. First, however, we must understand how current special education and full inclusion practices have evolved and whether they bolster disability culture or suppress it.

Special Education Legislative and Judicial Histories

As Lipsky and Gartner (1996) discussed, the history of education of students with disabilities ran parallel to that of other minority groups in U.S. society and consisted of three distinct stages: exclusion by law or regulation; formal inclusion, based on judicial and/or legislative requirements; and progress toward defining the nature of inclusion (policies and practices). Up until the 1960s, children with severe disabilities either stayed home with their families or were placed in private schools or institutions. Children with less severe disabilities were generally served in special classes, day schools, or residential facilities. With the advent of the civil rights movement, public education for children with disabilities began to be addressed. Generally, the legislative trend from the 1960s through the 1990s has been toward expanding eligibility for special education and increasing opportunity for students with disabilities to participate in classrooms with nondisabled students (National Information Center for Children and Youth with Disabilities, 1996).

In most instances, legal cases have reflected the same trend toward increasing opportunities for students with disabilities to participate in the general education classroom. Most litigation has centered on the concepts of LRE and appropriateness, which are addressed in IDEA. IDEA specifically requires that “to the maximum extent *appropriate* [italics added], children with disabilities are educated with children who are nondisabled” (20 U.S.C. § 1412a(5)).

IDEA also requires local education agencies to ensure the availability of a continuum of alternate placements, from least restrictive to most restrictive, within which a child’s program can be delivered. Federal regulations indicate that the continuum may include (but is not limited to) general and special education classes (34 C.F.R. § 300.551(b)(1)).

The U.S. Supreme Court has not addressed the LRE issue directly, but federal circuit courts have generated a range of decisions concerning it. In reviewing circuit court cases addressing LRE, Thomas and Rapport (1998) found that both general education and segregated placements have been upheld in different cases. The courts have appeared to recognize that there is no “one size fits all” standard for the most appropriate placement of a child, and they have reaffirmed the need for a continuum of placements, as required by law. Further, in *Clyde K. v. Puyallup School District No. 3* (1994), the 9th Circuit Court

found that not only were the plaintiff's educational needs more effectively met in a segregated setting, but also he had become socially isolated in the general education classroom.

Understanding Full Inclusion

It should be noted at this point that the legislation and litigation previously cited focused primarily on the concept of LRE. The inclusion movement stemmed from but also broadened the concept of LRE. Although the term *inclusion* has become common in the discussion of the placement of students who are eligible for special education services, it has no legal definition. It does *not* represent a *legal* requirement that every child should be educated in the same way or the same place (Bard, 1995). A broadly accepted definition for inclusion might be the one developed by the National Center on Educational Restructuring and Inclusion (1995), as follows:

Inclusion is the provision of services to students with disabilities, including those with severe impairments, in the neighborhood school, in age-appropriate general education classes with the necessary support services and supplementary aids (for the child and the teacher) both to assure the child's success—academic, behavioral and social—and to prepare the child to participate as a full and contributing member of the society. (p. 3)

Full inclusion proponents have generally advocated for the total disbanding of special education and the merging of special and general education programs such that all children are educated in the same environment (e.g., Stainback & Stainback, 1984). The inclusion philosophy is reflected in the following excerpt from Downing (1996): "Although some children, especially those with severe and multiple disabilities, may have unique ways of learning, separating them from others who learn in a different way is unnecessary and could prevent them from achieving their full potential" (p. xii). As Block (1999) suggested, to many people, full inclusion has become a human rights issue and even a moral imperative, but "in their zest to promote inclusion, many inclusionists forgot about the child" (p. 31). Put another way, by blindly pursuing absolute adherence to a concept, inclusionists have neglected the educational and social needs of *individual* children.

Although inclusion is not a mandated public social policy per se, in that it is not codified in IDEA, it is a practice that affects the social relationships of individuals and their relationship to the society of which they are a part. This makes it a social policy. As such, inclusion can be analyzed using frameworks developed for conducting policy analyses.

Policy Analysis of Inclusion

When the analytical framework developed by Chambers (1993) is applied to inclusion, many notable weaknesses in this pol-

icy emerge. Chambers's framework directs us to disaggregate the policies in question into their component parts (operational characteristics) and examine them separately. Each part is then critically evaluated using value-based criteria to judge its effectiveness. This framework is especially useful in examining LRE and inclusion policies, because only by looking at the individual parts of these policies do we find their shortcomings. In addition, Chambers's framework consistently prompts the analyst to consider the needs of diverse groups under each of the operational characteristics.

Characteristic 1: Policy Goals and Objectives

One of the evaluation criteria for policy goals and objectives is whether the goals are concerned with the end or outcome rather than only the means. Inclusion policy would seem to fail this criterion because it focuses on the *means* of providing the education rather than the *outcome*, which according to IDEA is that children with disabilities receive educational services that are "designed to meet their unique needs and prepare them for employment and independent living." The outcomes of full inclusion must therefore be considered as part of a policy analysis. Although perhaps representing an extreme view, an attendee with a disability at a round-table discussion held during a meeting of the Society for Disability Studies asserted the following: "The outcome of inclusion is exclusion. Inclusion is a conscious method to keep us from our identity and group identity formation" (Gilson et al., 1997, p. 12). Even a less extreme analysis of full inclusion, as discussed next, indicates that inclusion by itself does not satisfy the stated legislative purpose of meeting the unique needs of children with disabilities.

Characteristic 2: Entitlement Rules

To be effective, a policy must not result in the stigmatization and alienation of the individuals it was designed to help. Full inclusion subjects students to an environment in which they may be rejected consistently by their classmates and in which they are always in the minority group. As Charlton (1998) stated, these "groups exist as collectors of people whom the dominant culture selects for exclusion" (p. 81).

Researchers have suggested that this exclusion can be manifested in groups as early as the preschool age. In a study of inclusive preschool programs, Wolfberg et al. (1999, p. 78) noted,

A common thread of experience was that each child [with a disability] encountered either brief or prolonged periods of social isolation. In some cases, children with disabilities experienced isolation collectively, as a separate subculture formed within the dominant peer culture composed largely of typically developing peers.

The children in the Wolfberg et al. study had a diverse range of both visible and invisible disabilities (e.g., autism, Down

syndrome, attention-deficit disorder [ADD], cerebral palsy, hearing impairment/cochlear implants). Not only did these children experience alienation from their nondisabled peers, but they also naturally congregated (across disability types) and provided support for one another. Unfortunately, the context in which they came together was generally a negative one—as the minority “out” group. When the other children in the class did interact with them, it was often in a “helping” role that reinforced a benefactor/recipient relationship between the nondisabled children and the children with disabilities.

Another recent investigation indicated that the isolation does not improve and may actually worsen as children advance through the upper elementary grades. Hall and McGregor (2000) examined the peer relationships that developed between three children with disabilities and their nondisabled peers in an inclusive setting and compared the former’s levels of social isolation in kindergarten and Grade 1 with the same levels in Grades 4 through 6. The authors found that the children experienced fewer reciprocal peer relationships during the upper elementary grades and that “in contrast to typical peers during preadolescence, the focal children in this study spent less time in large-group activities, more time alone, and received fewer nominations as preferred playmate” (p. 125). The children with disabilities met the definition of *neglected social status* (Wentzel & Ascher, 1995). In this study as well, one of the main contexts in which any interaction between nondisabled children and children with disabilities occurred was that of helper/recipient.

Foster (1987) conducted a study of the mainstreaming experiences of a group of deaf high school students. She found that many of these students, like the younger students discussed previously, felt “lonely and left out” (p. 3) in regards to social interactions. Perhaps more important, though, she found that the study participants also encountered a range of obstacles and challenges to their *academic* success. These findings suggest that “while there is a formal dimension to classroom learning, there is also a less clearly defined but equally important informal dimension to learning” (p. 17). According to Foster, this informal dimension includes discussion with classmates, teamwork, and out-of-class study or information sharing, activities in which students with disabilities were often not included. Foster suggested that classroom supports provided by the school system in inclusive settings are not very successful in facilitating these informal interactions that are so necessary to the learning process.

Finally, a personal account by a person with a disability reinforces the fact that a feeling of loneliness exists *throughout* the various levels of an inclusionary education:

As a survivor of “inclusion” in neighborhood schools for nine years, my most vivid [re]collection of this process was how excluded I felt . . . I was subjected to ridicule from my peers, I was painfully and constantly made aware of my disability . . . Many of my Deaf colleagues and I still bear many emotional

scars and continue to feel socially dysfunctional in many ways from such an experience (Carver, 1994).

Ohlson (2001), who is a parent of a child with a disability, wrote, “Mainstreaming isn’t so bad if you’re part of the mainstream . . . I take little solace in the possibility that all those other kids got a lesson in compassion by being around Matt” (p. 4). In fact, many students with disabilities who have previously attended inclusionary programs in public schools and then enrolled in private, segregated special education programs related that they did not have any friends until they changed schools (Ohlson, 2001; Pierce, 1994).

Characteristic 3: Service Delivery Systems

Two criteria for examining the service delivery system are relevant in analyzing inclusion policies. The first of these is *accessibility*. According to Chambers (1993), cultural differences can hamper the access clients have to important benefits and services. One recommendation for addressing this problem is the use of *indigenous workers*, which in the context of education means teachers, paraprofessionals, and allied health providers with disabilities.

The literature on inclusion has not made any reference to the importance of teachers and other role models with disabilities for the positive educational experiences of children with disabilities. Part D of the 1997 amendments to IDEA does address the marked shortage of teachers representing racial minorities (specifying African American and Hispanic individuals) and the need to increase their numbers to more effectively meet the needs of the growing numbers of African American and Hispanic students in special education programs. IDEA even funds initiatives to train and recruit minority teachers. Although some, even many, students in special education are members of racial minorities, *all* of them have disabilities. Does it not seem obvious that recruiting teachers with disabilities is even more essential? Neither inclusion policy nor IDEA addresses this critical and fundamental need, however. In fact, Charlton (1998) noted that he has several colleagues and friends who were told they could not become teachers simply because they used wheelchairs. A cultural view of disability clearly indicates that teachers with disabilities are uniquely qualified to meet the needs of their students in a culturally sensitive manner. Charlton illustrated this point when he wrote that other colleagues and friends who are deaf went through 12 years of school without ever once having had a teacher proficient in sign language. According to Charlton, “They were told that it was good for them because they should learn to read lips” (p. 32).

Perhaps an even more compelling reason to recruit and retain teachers with disabilities was provided by Groch (1994). She found that although students with disabilities who attended school in segregated settings had stronger interpersonal links with other children who had disabilities, they were less likely to develop a strong oppositional consciousness, which

Groch believes to be a prerequisite for taking social action. Groch contended that part of the reason this consciousness did not form is that the segregated programs were administered and operated by nondisabled professionals. Students who have teachers with disabilities will be much more likely to associate a positive status with having a disability. Recently, the Office of Special Education and Rehabilitative Services [OSERS] perhaps became aware of this issue and began awarding bonus points to research and personnel-preparation grant applicants who demonstrated that they would recruit and advance staff members with disabilities (OSERS, 1999).

The second of Chambers's criteria for evaluating the effectiveness of service delivery systems is the *ability to relate to diversity in client populations*. Chambers suggested that access to appropriate services for certain groups can be increased by developing separate systems to serve their needs exclusively. Clearly, the establishment of a special education system with a full continuum or array of services follows this strategy.

Some people, including Judy Heumann, the former assistant secretary of the federal Office of Special Education and Rehabilitative Services, have compared special education to racially segregated programs (cited in Pierce, 1994). Using this analogy, they have argued that special education, like racially segregated education, is not "separate but equal." This argument is spurious because unlike racially segregated education, special education was created to help the many children with disabilities who have *unique educational needs* related to those disabilities. Arguably, even education for children whose disabilities do not affect their learning style could be "unequal" because the opportunity to develop a disability identity remains a unique need for these children. As one professional put it, "We live in a diverse culture, and the ordinary classroom should reflect our diversity, but it should not trivialize it" (Schroeder, 1993).

Negative aspects of special education, such as lower academic standards and expectations for children with disabilities or the use of special education classrooms as a "dumping ground" for problem students, do exist, of course (e.g., Shapiro, 1993). Full inclusion proponents have repeatedly focused on these shortcomings as a reason to disband the entire system. Conversely, full inclusion opponents have used related arguments about the shortcomings of full inclusion to justify the complete abandonment of this effort. The more logical choice, however, seems to be to find a middle ground that is sensitive to the needs of children with disabilities and provides a quality educational experience for them.

Additional Considerations

A final pair of analytical frameworks that can be applied to the evaluation of inclusion as a policy were discussed by Skrtic, Sailor, and Gee (1996). These authors cited Boulding's (1967) work in which it was claimed that social policy should be concerned with building an inclusive system, one that "includes those aspects of social life that are . . . justified by [an] appeal

to . . . identity or community . . . to build the identity of a person around some community with which he [*sic*] is associated" (p. 7). Skrtic went on to cite Moroney's (1981) analytical framework to explain that identity and inclusion must be central to social policy because their opposite—alienation—threatens community itself. Although Skrtic et al. used these analytical frameworks in support of inclusion as a policy, the frameworks actually seem to support the policy of fostering a disability culture even more strongly. For example, I have suggested in this article that children with disabilities need the opportunity to develop an integrated identity that incorporates their disability and that such integration is facilitated by interaction with other children who have disabilities. I have also documented that full inclusion can lead—and has led—to feelings of alienation for many children with disabilities.

What, then, are the best strategies for supporting disability culture, increasing the effectiveness of educational experiences for children with disabilities, and recognizing the importance of integration as a civil right? It is not necessary to take an "all or nothing" stance, refuting the value of any level of inclusion. I do, however, dispute the practice of *full* educational inclusion at the expense of any opportunity for segregated educational experiences. The great majority of children with disabilities have the opportunity to interact with the nondisabled population not only at school but also in their homes and communities. On the other hand, they may have no opportunity other than school to interact with their peers with disabilities.

Some individuals might suggest that school-sponsored segregated clubs or extracurricular activities would suffice for this interactional opportunity. Such clubs and extracurricular activities are not typically offered at the elementary school level, however. At the secondary level, clubs represent one way to foster disability identity, but they should not necessarily replace other opportunities for school-related interactions. Clubs by themselves do not address Foster's (1987) finding that "informal" learning is an important aspect of the educational process that may be missed by students with disabilities in an inclusive classroom. Segregated programs are not only about identity, they are about learning.

In the following section I identify some recommendations for improved practices that might provide a foundation for future policies that incorporate the positive aspects of both inclusive and segregated settings. These suggestions demonstrate that special education as defined in IDEA can work and that the breach between full inclusion and segregation can be narrowed peacefully and productively.

Suggested Improved Practices

1. Parents, teachers, and administrators must begin to recognize and learn about disability culture and its importance in the emotional and social development of children with dis-

abilities. They should work to provide opportunities for children with disabilities to interact in meaningful ways.

2. Special education teachers and other service providers with disabilities must be aggressively recruited because they are the most qualified to understand disability culture and to serve as appropriate role models for their students.
3. Schools must establish high educational expectations for all students and be held accountable for the results. The National Council on Disability (1996) has endorsed this practice.
4. School systems must provide a full range (or continuum) of placement options that are consistent with IDEA. Many groups, including the National Education Association (1999), the Council for Exceptional Children (1993), and the Learning Disabilities Association (1993), have endorsed this recommendation. A further suggestion in this area is that the term *continuum* be changed to *array*. The former word connotes an ordered sequence of placements from most segregated to least segregated, suggesting a hierarchy of classes in which students graduate or get promoted to higher and higher (more segregated) levels. An array, on the other hand, implies a *range* of services, none inherently better than any other, from which a person can choose the service that best meets his or her needs.
5. As suggested by students at the National Summit on Disability Policy (NCD, 1996), if students with disabilities decide to form peer groups or clubs, school administrators should support them. In addition, all students should participate in a curriculum that covers the Americans with Disabilities Act, the history of disability culture, positive attitudes, listening skills, patience, and appropriate terminology (NCD, 1996). I would add self-advocacy to this list.

Perhaps the parent of a child with a disability said it best (personal communication, February 13, 2001):

I have observed that Jessica [her daughter, who has cerebral palsy] enjoys being in situations that she is not the only one with a disability. She actually WANTS to attend programs that are only for children with disabilities. I'm sure part of this is because for once everyone isn't in a hurry and things may be more in her time frame. I think there needs to be opportunity for kids with disabilities to interact with other children and adults with disabilities, but that those opportunities need to be with a positive ap-

proach toward disability. So often when we have found groups of kids with disabilities they tend to be "special groups" (Special Olympics, special camps) and the volunteers assisting with those groups want to *help* those special children So I guess I have mixed feelings I do agree [that children with disabilities should have the opportunity to interact in their own time and space in school]; I also do know that inclusion is important and has great benefits. So, what is the answer . . . some of each I suppose.

ABOUT THE AUTHOR

Jean P. Hall, MS, is a project coordinator at the University of Kansas Center for Research on Learning. She is also a doctoral student in disability studies. Her current interest is systems change issues for people with disabilities. Address: Jean P. Hall, University of Kansas, 521 J. R. Pearson Hall, 1122 West Campus Rd., Lawrence, KS 66045-3101.

AUTHOR'S NOTE

The author would like to thank Rosemary Chapin, Daryl Mellard, Kathy Parker, Belinda Schuman, Julie Tollefson, Rud Turnbull, and three anonymous reviewers for their comments on various drafts of this article and especially Gary Clark for his comments and support. She would also like to thank the two parents who provided personal accounts of their children's experiences in school.

NOTE

All names have been changed.

REFERENCES

- Bard, J. F. (1995). *Pennsylvania inclusion policy* (State Basic Education Circular BEC-2-95). Retrieved October 4, 1999, from www.kidstogether.org/ed_policy.html
- Barnartt, S. N. (1996). Disability culture or disability consciousness? *Journal of Disability Policy Studies*, 79(2), 1-19.
- Block, M. E. (1999). Did we jump on the wrong bandwagon? Problems with inclusion in physical education. *Palaestra*, 15(3), 30-36.
- Boulding, K. (1967). The boundaries of social policy. *Social Work*, 12, 3-11.
- Braddock, D., Hemp, R., Parish, S., Westrich, J., & Park, H. (1998). The state of the states in developmental disabilities: Summary of the study. In D. Braddock (Ed.), *The state of the states in developmental disabilities* (pp. 22-53). Washington, DC: American Association on Mental Retardation.
- Carver, R. (1994, December). Inclusion or illusion? *DCS Newsletter*, November/December 1994. Retrieved October 6, 1999, from <http://dww.deaf-worldweb.org/pub/c/rjc/inclusion.html>
- Chambers, D. E. (1993). *Social policy and social programs: A method for the practical public policy analyst* (2nd ed.). New York: Macmillan.
- Charlton, J. I. (1998). *Nothing about us without us: Disability oppression and empowerment*. Berkeley: University of California Press.
- Council for Exceptional Children. (1993, April). *Statement on inclusive schools and communities*. Reston, VA: Author.
- Clyde K. v. Puyallup School District No. 3, 35 F.3d 1396 (9th Cir. 1994).
- Downing, J. E. (1996). *Including students with severe and multiple disabilities in typical classrooms*. Baltimore: Brookes
- Education for All Handicapped Children Act of 1975, 20 U.S.C. § 1400 *et seq.*
- Foster, S. (1987). *Life in the mainstream: Reflections of deaf college freshmen on*

- their experiences in the mainstreamed high school*. Rochester, NY: National Technical Institute for the Deaf.
- Gill, C. (1995). A psychological view of disability culture. *Disability Studies Quarterly*, 15(4), 16–19.
- Gill, C. (1997). Four types of integration in disability identity development. *Journal of Vocational Rehabilitation*, 9, 39–46.
- Gill, C. (1999). Disability culture: A framework for understanding disability, family and community. *The Disability Messenger*, 11.
- Gilson, S. F., Tusler, A., & Gill, C. (1997). Ethnographic research in disability identity: Self-determination and community. *Journal of Vocational Rehabilitation*, 9, 7–17.
- Groch, S. A. (1994). Oppositional consciousness: Its manifestations and development. The case of people with disabilities. *Sociological Inquiry*, 64, 369–395.
- Gwin, L. (2000). *Incoming! Watch out!* Retrieved March 19, 2001, from <http://www.mouthmag.com/number60/number60.htm>
- Hall, L. J., & McGregor, J. A. (2000). A follow-up study of the peer relationships of children with disabilities in an inclusive school. *The Journal of Special Education*, 34, 114–126, 153.
- Harris & Associates. (1986). *The ICD survey of disabled Americans: Bringing disabled Americans into the mainstream*. New York: Author.
- Individuals with Disabilities Education Act Amendments of 1997, 20 U.S.C. § 1401.
- Kemp, J. (1999, May). *Keynote address*. Presentation at the ADA Symposium, Kansas City, MO.
- Learning Disabilities Association. (1993, January). *Position paper on full inclusion of all students with learning disabilities in the regular education classroom*. Pittsburgh, PA: Author.
- Lipsky, D. K., & Gartner, A. (1996). Inclusion, school restructuring, and the remaking of American society. *Harvard Educational Review*, 66, 762–796.
- Moroney, R. M. (1981). Policy analysis within a value theoretical framework. In R. Haskins & J. J. Gallagher (Eds.), *Models for analysis of social policy: An introduction* (pp. 78–101). Norwood, NJ: Ablex.
- National Center on Educational Restructuring and Inclusion. (1995). *National study of inclusive education*. New York: City University of New York.
- National Council on Disability. (1996). *Achieving independence: The challenge for the 21st century*. Washington, DC: Author.
- National Education Association. (1999). *Policy statement on appropriate inclusion*. Retrieved October 4, 1999, from <http://helpfrom.nea.org/publiced/idea/ideaplyc.html>
- National Information Center for Children and Youth with Disabilities. (1996, October). The education of children and youth with special needs: What do the laws say? [Electronic version]. *NICHY News Digest*, 15.
- Office of Special Education and Rehabilitative Services. (1999). Notice Inviting Applications for Fiscal Year (FY) 2000. 64 Fed. Reg. 167, 47310–47330.
- Ohlson, K. (2001, April 5). *Faith in the baby*. Retrieved April 6, 2001, from <http://www.salon.com/mwt/feature/2001/04/05/faith/index.html>
- Paradis, L. (1998, December). Beyond fear and pity. *Mainstream*, 15–19.
- Pierce, B. (1994). Are specialized educational settings for children with disabilities immoral? *The Braille Monitor*, February 1994. Retrieved November 1, 1999, from <http://www.nfb.org/brlm9411.htm>
- Pfeiffer, D. (1993). Overview of the disability movement: History, legislative record, and policy implications. *Policy Studies Journal*, 21, 724–734.
- Schroeder, F. (1993, July). *Mainstreaming, schools for the blind, and full inclusion: What shall the future of education for blind children be?* Presentation at the 1993 National Federation for the Blind National Convention, Dallas, TX.
- Scotch, R. K. (1984) *From good will to civil rights: Transforming federal disability policy*. Philadelphia: Temple University Press.
- Shapiro, J. (1993). *No pity*. New York: Random House.
- Skrtic, T. M., Sailor, W., & Gee, K. (1996). Voice, collaboration, and inclusion: Democratic themes in educational and social reform initiatives. *Remedial and Special Education*, 17, 142–157.
- Stainback, S., & Stainback, W. (1984). A rationale for the merger of special and regular education. *Exceptional Children*, 51, 102–111.
- Thomas, S. B., & Rapport, M. J. K. (1998). Least restrictive environment: Understanding the direction of the courts. *The Journal of Special Education*, 32, 66–78.
- Topeka Independent Living Resource Center. (2000). *TILRC news*. Retrieved July 12, 2001, from <http://www.tilrc.org/docs/national2.html>
- Wentzel, K. R., & Ascher, S. R. (1995). The academic lives of neglected, rejected, popular, and controversial children. *Child Development*, 66, 754–763.
- Wolfberg, P. J., Zercher, C., Lieber, J., Capell, K., Matias, S., et al. (1999). “Can I play with you?” Peer culture in inclusive preschool programs. *Journal of the Association for Persons with Severe Handicaps*, 24(2), 69–84.

