



Foundational Concepts and Practices for Educating Students with Severe Disabilities¹

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Charles Dickens (1859) wrote the famous words, “It was the best of times, it was the worst of times . . . the spring of hope . . . the winter of despair” to describe the conditions that preceded the French Revolution. This chapter explores how today’s educational environment might be considered the best

and worst of times for educating students with severe disabilities. The chapter presents a series of foundational concepts and practices organized into three major sections. The first major section addresses the sometimes elusive question, “Who are students with severe disabilities?” by examining definitions, how societal perceptions of people with severe disabilities can affect their lives, as well as reciprocal benefits of interactions between people with and without disability labels. The second major section addresses *the best and the worst of times* by highlighting some of the key areas for optimism and key areas of concern for students with severe disabilities. Finally, the bulk of the chapter addresses *access to appropriate education* by delving into four interrelated aspects of quality education for students with severe disabilities: (a) access to the least restrictive environment, (b) access to appropriate curriculum, (c) access to effective instruction, and (d) access to individually determined supports.

¹In loving memory of the vibrant life of Erin McKenzie: August 9, 2004 to August 24, 2004.

Who Are Students with Severe Disabilities?

Definitions

Although the phrase “severe disabilities” is used extensively in the professional literature, no single authoritative definition exists. The amendments to the Individuals with Disabilities Education Act (IDEA) (1997), a common source of special education terminology, do not define *severe disabilities*. IDEA and its corresponding Code of Federal Regulations (CFR) (1999) do define 13 distinct disability categories (CFR 300.7), several of which reasonably include students considered to have severe disabilities (e.g., autism, deaf-blindness, mental retardation, multiple disabilities, traumatic brain injury), though not all students within these categories have severe disabilities.

Not surprisingly, many definitions describing individuals with severe disabilities focus on deficits such as intellectual, orthopedic, sensory, behavioral and functional impairments; unfortunately, such definitions tell us very little about them as people (McDonnell, Hardman, & McDonnell, 2003). What can be said with some confidence is that individuals with severe disabilities include a widely heterogeneous group in terms of their disability characteristics, capabilities, and educational needs. Their nondisability characteristics (e.g., interests, preferences, personalities, socioeconomic levels, cultural heritage) are as diverse as the general population. What they share in common is the need for extensive and ongoing supports. Sometimes people with severe disabilities are described as having *low-incidence* disabilities because it is estimated that less than 1% of the general population has severe disabilities (see chapter 3 for specific incidence and prevalence information).

The international organization TASH (formerly The Association for Persons with Severe Disabilities) has identified the persons for whom it advocates as those

who require ongoing support in one or more major life activities in order to participate in an integrated community and enjoy a quality of life similar to that available to all citizens. Support may be required for life activities such as mobility, communication, self-care, and learning as necessary for community living, employment, and self-sufficiency. (TASH, 2000)

Snell (2003) reminds us that in addition to their collective diversity and need for lifelong support, individuals with severe disabilities share “the capacity to learn” (p. 2210). Though this may seem too obvious to mention, as recently as the early 1980s there were heated debates in the professional literature about whether individuals with the most severe disabilities were capable of learning and how such judgments affected their rights to be educated. While some questioned the educability of children with the most severe disabilities and the wisdom of educating them (Kaufman & Krouse, 1981), others offered persuasive arguments favoring the pursuit of education for every child, regardless of the perceived severity of their disability (Baer, 1981; Noonan, Brown, Mulligan, & Rettig, 1982). As Baer pointed out, in addition to the potential benefits associated with students learning skills that will be useful to them, approaching *all* students as capable of learning provides us with the opportunity to extend our own understandings of teaching and learning:

To the extent that we sometimes finally succeed in teaching a child whom we have consistently failed to teach in many previous efforts, we may learn something about teaching technique. . . . Too often, in my opinion, we teach children who are not only capable of teaching themselves, but eager to do so; in their wisdom, they cheat us of learning completely how the trick is done because they do some of it for us and do it privately. It is when they cannot do much if any of it for us that we get to find out how to do all of it ourselves, as teachers. (p. 94)

The stance favoring education for *all* was then—and continues to be—consistent with the federal, *zero reject*, principle embedded in IDEA. The zero-reject provision established that *all* school-aged children, regardless of the severity of their disability, are entitled to a free, appropriate public education (H. R. Turnbull & A. P. Turnbull, 2000). The zero-reject principle was tested in the case of *Timothy W. v. Rochester School District* (1989). A student with severe, multiple disabilities had been denied admission to his local public school because school officials deemed him too severely disabled to benefit from education. Although the federal district court agreed with the school, the U.S. Court of Appeals for the First Circuit overturned the lower court’s ruling and strongly affirmed the zero-reject principle as a core component of IDEA.

Societal Perceptions and Expectations

An experience people with severe disabilities often share in common is that frequently the rest of the world seems to define them primarily, sometimes exclusively, by their disability characteristics. This has been referred to as *disability spread*, the tendency to make broad inferences, assumptions, and generalizations about a person based on disability stereotypes within the society (Dembo, Leviton, & Wright, 1975). Some common stereotypes portray persons with disabilities as sick, subhuman, a menace, an object of pity, an object of charity, or a holy innocent (Wolfensberger, 1975). As pointed out by Van der Klift and Kunc (2002), “When disability is seen as the largest component of a person, much of what is unique and human about him or her is obscured” (p. 25). Biklen and Mosley (1988) explained that people with disabilities may not think of themselves in ways that put their disability characteristics at the forefront of their self-perception, instead “preferring to identify with members of particular religious groups, as certain kinds of workers, employees of particular companies, or as fans of particular sports teams (p. 155).

Opportunities for Interaction and Reciprocal Benefit

Since people with severe disabilities require ongoing supports, the ways in which they are perceived and subsequently treated by others can have a major impact on the quality of their lives. While we are quite certain that disability spread adversely affects people with disabilities, we suspect that far too many people without disabilities are missing out on potentially important relationships with people with disabilities because of this artificial, socially constructed barrier to interaction (Bogdan & Taylor, 1989). If you accept the notion that personal relationships are among a small set of the most defining characteristics that influence the quality of a person’s life, then disability spread is a problematic issue for those with and without disabilities alike (Taylor & Bogdan, 1989).

So as you continue to read this chapter and the rest of this book about people who have the label of *severe disabilities*, you are encouraged to think about how these individuals are like all other people, like some other people, and uniquely like no other people. Keep in mind that first and foremost they are human beings—they are someone’s child, someone’s sibling,

someone’s classmate, or someone’s friend. Though they have been born with or acquired disability characteristics that are considered so severe in today’s society as to require ongoing and intensive supports, our collective attitudes and responses to a person’s disability characteristics can influence how much of a barrier those characteristics are to leading a regular life. As an *Nth Degree* T-shirt worn by a self-advocate says, “Your attitude just might be my biggest barrier” (Wilkins, 2003).

The Best and Worst of Times

In many ways, from an historical perspective, this is the best of times for individuals with severe disabilities, at least thus far. I write this with the full recognition that our current *best* is relative and is a long way from *good* for far too many people labeled as having severe disabilities (more about that when the “worst of times” are discussed in the next section).

The Best of Times: Reasons for Optimism

Table 1-1 highlights areas for optimism about the present and future. Such optimism about our collective potential to make a positive difference in the lives of students with and without disabilities is an essential ingredient of the creative problem solving necessary to tackle such important challenges.

First, nowhere is progress more evident or reason for optimism more warranted than in regard to *inclusive educational opportunities* available to students with severe disabilities (Downing, 2002; Giangreco, Dennis, Cloninger, Edelman, & Schattman, 1993; Jackson,

TABLE 1-1
Areas for Optimism

1. Inclusive education
2. School reform and restructuring
3. Access to the general education curriculum
4. Alternative assessment in statewide accountability systems
5. Transition to adult life (e.g., postsecondary education, supported employment, community living)
6. Positive behavior supports
7. Partnerships between families and professionals
8. Self-determination

TABLE 1-2
Characteristics of Inclusive Education

1. All students are welcomed in general education. The general education class in the school the student would attend if not disabled is the first placement option considered. Appropriate supports, regardless of disability type or severity, are available.
2. Students are educated in classes where the number of those with and without disabilities is proportional to the local population (e.g., 10%–12% have identified disabilities).
3. Students are educated with peers in the same age groupings available to those without disability labels.
4. Students with varying characteristics and abilities (e.g., those with and without disability labels) participate in shared educational experiences while pursuing individually appropriate learning outcomes with necessary supports and accommodations.
5. Shared educational experiences take place in settings predominantly frequented by people without disabilities (e.g., general education classes, community work sites, community recreational facilities).
6. Educational experiences are designed to enhance individually determined valued life outcomes for students and therefore seek an individualized balance between the academic-functional and social-personal aspects of schooling.
7. Inclusive education exists when each of the previously listed characteristics occurs on an ongoing, daily basis.

(Giangreco, Cloninger, & Iverson, 1998)

Ryndak, & Billingsley, 2000; McGregor & Vogelsberg, 1998). In schools across the country, students with severe disabilities increasingly are accessing general education schools and classrooms; such options were rare or nonexistent just a decade or two ago. The literature now is replete with examples, strategies, and research focusing on inclusive schooling across the age span (Hunt & Goetz, 1997; Meyer, 2001; Ryndak & Fisher, 2003)—from early childhood education (Wolery & McWilliam, 1998), to elementary school (Janney & Snell, 1997), through middle school (Kennedy & Fisher, 2001) and high school (Fisher, Sax, & Pumpian, 1999; Jorgensen, 1998). Table 1-2 lists seven prominent characteristics of inclusive education.

Inclusion-oriented people seek to establish an ethic that welcomes all children into their local schools and simultaneously pursues a range of individually meaningful learning outcomes through effective educational practices. Though prompted by the needs of students with disabilities, the concept of inclusive education is broader. The outcomes it seeks to promote (e.g., equity, opportunity, social justice) are relevant for any student across a range of diversity characteristics (e.g., race, culture, socioeconomic level) as well as any students (without a specified diversity characteristic) who simply are having difficulty becoming part of the classroom's learning community.

Second, inclusive schooling increasingly is being linked with broader *school reform and restructuring* efforts designed to improve educational opportunities for *all* students (Lipsky & Gartner, 1997; Peterson, Beloin, & Gibson, 1997; Sailor, 2002; Villa & Thousand, 2000). Third, curricular options for students with severe

disabilities have extended beyond functional life skills to include greater alignment and *access to the general education curriculum* in this era of standards-based reform (Ford, Davern, & Schnorr, 2001; Gee, 2002; Udvari-Solner, Thousand, & Villa, 2002). Correspondingly, a fourth area for optimism is that students with severe disabilities are now being included in statewide accountability systems using *alternative assessment* approaches (Klienert & Kearns, 2001). This helps ensure the educational progress of students with disabilities is monitored within schoolwide improvement efforts.

Fifth, a significant volume of literature exists on promising practices on *transition to adult life* (Chadsey-Rusch & Rusch, 1996) leading to *supported employment* (Wehman, 2001) and supported *community living* (Horner et al., 1996) (see chapters 15 and 16). An emerging set of examples exist describing *college options* for young adults with moderate and severe disabilities (Doyle, 2000; Grigal, Neubert, & Moon, 2001; Hall, Kleinert, & Kearns, 2000).

Sixth, further cause for optimism comes from the rapidly developing technology of *positive behavior support* (see chapter 6). Increasingly, teams are conducting functional assessments of student behavior in an effort to better understand the functions of those behaviors and their communicative intent (Carr et al., 1999; Dunlap, Newton, Fox, Benito, & Vaughn, 2001; Durand & Merges, 2001; Horner, 2000). Behavior support plans are being developed and implemented by teams to teach students social, communication, and other functional skills as a way to replace problem behaviors. Within the positive behavior support framework, change does not focus exclusively on an individual's

TABLE 1–3
Professional Assumptions About Families That Facilitate Partnership

1. Families know certain aspects of their children better than anyone else.
2. Families have the greatest vested interest in seeing their children learn.
3. Families should be approached in culturally sensitive ways.
4. Family members are likely to be among the only adults involved with a child's educational program throughout his or her entire school career.
5. Families have the ability to positively influence the quality of educational services provided in their community.
6. Families must live with the outcomes of decisions made by educational teams, all day, every day.

(Giangreco, Cloninger, & Iverson, 1998)

problem behaviors but rather more comprehensively on changing environmental conditions that may be contributing to a person's challenging behaviors. Positive behavior support is an evidence-based practice that is designed not only to reduce problem behaviors (e.g., aggression, self-injury, property destruction) but also to "build prosocial behavior, document durable change, generalize across the full range of situations an individual encountered, and produce access to a rich lifestyle" (Carr et al., 1999, p. 4).

Seventh, the continuing development of *partnerships between families and professionals* is an encouraging trend (see chapter 2). Parents are taking an ever-increasing role as full team members rather than passive or perfunctory recipients of professional perspectives (A. P. Turnbull & H. R. Turnbull, 2000). Professionals have increasingly recognized that it is in everyone's best interest for families to be informed and effective consumers of educational and related services. Table 1–3 offers a list of professional assumptions about families that can facilitate constructive partnerships.

Finally, over the past several years, the focus on family involvement has expanded beyond parental involvement to include *self-determination* by individuals with disabilities. Self-determination is pursued by teaching individuals skills to make decisions about their own lives, providing them with opportunities to make decisions, and then honoring their decisions (Bambara, Cole, & Koger, 1998; Wehmeyer, Agran, & Hughes, 2000). As succinctly summarized in self-advocacy circles, "Nothing about me without me!"

The Worst of Times

Though the eight areas of optimism presented in the previous section are encouraging trends, the field of special education is not at a stage of development

where the curricular, instructional, and support needs of students with severe disabilities are consistently and sufficiently addressed. Table 1–4 lists six continuing areas of concern.

First, although inclusive educational opportunities have expanded, *uneven and inconsistent access to inclusive classrooms* continues to plague the public school system, especially for students with severe disabilities. The U.S. Department of Education (2002, p. A-138) indicates that placement rates of all students with disabilities in general education classrooms vary substantially from state to state. In only 11 states (Colorado, Idaho, Kansas, Massachusetts, Minnesota, North Dakota, New Hampshire, Ohio, Oregon, South Dakota, and Vermont), between 70% and 88% of all students with disabilities (ages 6 to 21) have their primary placement (at least 80% of the time) in general education classes. In a small number of other states (Hawaii and Texas) and Washington, D.C., the overall placement rates are below 25%. Only half the states report the general education class as the primary placement for more than 60% of their students with any type of disability.

A closer look at categories most likely to include students with severe disabilities (e.g., autism, deaf-blindness, mental retardation, multiple disabilities, traumatic brain injury) depicts a more stark reality. For example, rates of placement in general education

TABLE 1–4
Areas of Continuing Concern

1. Uneven and inconsistent access to inclusive classrooms
2. Questionable quality of curriculum and instruction
3. Too many families are frustrated by the lack of professional responsiveness
4. Continued use of aversive procedures
5. Challenging working conditions for special educators
6. Limited postschool options

classes as the primary placement for students with the label “mental retardation” (p.A-144) are dismal—below 10% in 20 states and a scant 11% to 30% in 23 other states. The general education class placement rates in six states (Colorado, Idaho, Iowa, North Dakota, Ohio, Oregon) range from 31% to 48%. Only two states exceed 50% general education class placement rates for students with the label “mental retardation”—New Hampshire (56%) and Vermont (80%) (U.S. Department of Education, 2002, p.A-144). Unfortunately, the odds that any particular student with a severe disability will be included in a general education class currently depends, in large part, on where that student lives and what disability category has been assigned to him or her. Although placement doesn’t equal inclusion, it is a telling indicator of access to general education environments and a first step toward inclusive opportunities.

As we move slowly closer to realizing promises of the IDEA and toward an educational system that supports access to general education curriculum and environments for students with disabilities, serious questions remain about whether progress is simply too slow (Brown & Michaels, 2003):

How long should educators accept that in many locations across the country the more “primitive” steps toward inclusion continue to be accepted and reinforced? Can they afford to wait another decade . . . ? In the meantime, what happens to children, especially those with the most severe disabilities . . . ? Is it acceptable for the education field to praise its progress when generations of these students continue to be excluded? (p. 240)

Second, even in situations where access to inclusive environments is better, *questionable quality of the curriculum and instruction* for students with severe disabilities in general education classrooms continues to be a serious and ongoing issue. Being physically present in settings with same-age peers who don’t have disabilities is necessary but not sufficient to be included. Too many students with severe disabilities placed in general education classes are subjected to undesirable conditions, such as being (a) separated within the classroom (e.g., taught primarily by a paraprofessional), (b) taken through the motions of a lesson or activity without having appropriately targeted learning outcomes (i.e., not learning much of value or importance to them), or (c) presented with lesson content that is inconsistent with their level of

functioning or learning and communication characteristics. Such practices obviously limit a student’s learning opportunities and may contribute to internalized (e.g., withdrawal, lack of responsiveness) or externalized (e.g., self-stimulation, aggression, tantrums) problem behaviors.

In some cases the very concept of inclusive education has become distorted because fragmented, partial, or low-quality implementation efforts have been mislabeled as “inclusive” (Davern et al., 1997). Clashing ideological views and rhetoric among special education scholars has increased confusion about exactly what inclusive education is, and what should be done about it (Brantlinger, 1997). While public debates continue to be waged regarding the *least restrictive environment* provision of IDEA, years pass, and the lives of real children and their families are adversely affected.

Third, *too many families are frustrated by the lack of professional responsiveness* to their children’s educational needs (Soodak & Erwin, 2000). While some educators certainly interact with parents and students as consumers and embrace them as partners in the educational process, others still resist, preferring to retain the role of professional as *expert*. Although professionals have expertise within their discipline, those who spend the most time with people who have disabilities often have a different yet equally valuable type of expertise and knowledge about an individual. Family members, close friends, and persons with disabilities themselves have access to expertise and knowledge concerning things such as an individual’s likes and dislikes, behavioral tendencies, rest/sleep patterns, idiosyncratic communication behaviors, personal history, and other important information that may contribute to educational and service planning. It is when the respective expertise of professionals and families are combined that teams have the opportunity to experience the synergy that comes from true collaboration.

Fourth, concern exists about the *continued use of aversive procedures* to manage challenging behaviors. Shockingly (pun intended), in an era when electric cattle prods are becoming a thing of the past in American agriculture, some students with severe disabilities continue to be subjected to an arsenal of aversive procedures and punishments in the name of “treatment,” resulting in lost learning opportunities, degradation, psychological trauma, physical injury, and, in a small number of cases, even death (Evans, Scotti, & Hawkins, 1999; Weiss, 2003). This problem persists despite the

availability of effective, positive alternatives (Horner, 2000; Janney & Snell, 2000).

Fifth, *challenging working conditions for special educators* contribute to the challenges facing students with severe disabilities. Of particular concern is the national shortage of qualified special educators as well as the need to train and retain more of them (Billingsley, 2002). The shortages interfere with students with disabilities receiving an appropriate, quality education (McLeskey, Tyler, & Saunders, 2002). Kozleski, Mainzer, and Deshler (2000) highlighted some of the key factors contributing to special educators leaving the field (e.g., excessive paperwork, large caseloads, lack of administrative support). The field needs a full and capable cadre of special educators to team up with parents, related services providers, and teachers. As so eloquently stated by Brown, Farrington, Ziegler, Knight, and Ross (1999), “because learning is so difficult for students with significant disabilities, they are in dire need of continuous exposure to the most ingenious, creative, powerful, competent, interpersonally effective, and informed professionals” (p. 252).

Finally, *limited postschool options* adversely affect people with severe disabilities. As noted in a report of the National Council on Disability on the implementation of IDEA, “After years of public education, youth with severe disabilities all too often exit school unemployed, without basic skills, lonely, isolated from peers, and disenfranchised from the larger society” (Giangreco & Snell, 1996, p. 100). Unfortunately, this statement is as true today as it was in 1996.

If you are interested in improving the lives of people with severe disabilities through education, there is plenty to motivate you to act, regardless of whether you see this point in time as the best or worst of times. For those of you motivated by positive news, there is a continually growing set of examples and body of literature documenting steady progress to encourage your continuing contributions to these efforts. If it is the slow pace of progress or ongoing injustices facing people with severe disabilities that fuels your fire, there is plenty of motivation to act and work to do!

Access to Appropriate Education

The remainder of this chapter offers foundational information and ideas about access to appropriate education of students with severe disabilities in four main areas: (a) access to the least restrictive environment,

(b) access to appropriate curriculum (c) access to effective instruction, and (d) access to individually determined supports.

Access to the Least Restrictive Environment

IDEAS’s least restrictive environment (LRE) provision clearly establishes that “to the maximum extent appropriate, children with disabilities... are educated with children who are nondisabled” (CFR 300.550 [b][1]). The LRE provision states that “special classes, separate schooling, or other removal of children with disabilities from the regular educational environment occurs only if the nature or severity of the disability is such that education in regular classes with the use of supplemental aids and services cannot be achieved satisfactorily” (CFR 300.550 [b][2]).

Ironically, it has been this second part of the LRE provision that, at times, has been used to justify the continued segregation of students with the most severe disabilities. Across the country, far too many students who are designated as having severe disabilities are almost automatically placed in self-contained special education classes or schools, sometimes requiring them to travel far greater distances than their siblings and neighbors each day to attend school as they are bussed to regional programs. IDEA provides clear and compelling clarification about placement and LRE issues in Appendix A (Notice of Interpretation) of the Code of Federal Regulations (CFR) (1999):

Even though IDEA does not mandate regular class placement for every disabled student, IDEA presumes that the first placement option considered for each disabled student by the student’s placement team, which must include the parent, is the school the child would attend if not disabled, with appropriate supplementary aids and services to facilitate such placement. Thus, before a disabled child can be placed outside the regular education environment, the full range of supplementary aids and services that if provided would facilitate the student’s placement in the regular classroom setting must be considered. (p. 12472)

IDEA is clear that the default placement—in other words, the starting point—for *all* students with disabilities is the general classroom with appropriate supports. Many school districts never seriously consider

general class placement of students with severe disabilities because they rely on the part of the LRE provision that allows for removal of students with disabilities if “the nature or severity of the disability is such that education in regular classes with the use of supplemental aids and services cannot be achieved satisfactorily.” Appendix A of IDEA offers some powerful language that provides additional clarification on this point:

In all cases, placement decisions must be individually determined on the basis of each child’s abilities and needs, and not solely on factors such as category of disability, significance of disability, availability of special education and related services, configuration of the service delivery system, availability of space, or administrative convenience. Rather, each student’s IEP forms the basis for the placement decision. (CFR, 1999, p. 12472)

Teams that are responsible for making placement decisions must make those decisions in ways that are consistent with the law. This means discarding many of the common reasons students with severe disabilities are denied access to general education classes. IDEA does *not* say students with disabilities should be denied access to general education classes

- if they have a particular label (e.g., autism, mental retardation) or are at a certain level (e.g., severe),
- if they function at different levels than their classmates,
- if they are pursuing different learning outcomes than their classmates,
- just because it hasn’t been done that way before in the school,
- if it is administratively inconvenient or if needed services are not currently in place,
- if they require supports or accommodations, or
- if the adults in the school are unaccustomed to the characteristics presented by the students.

Therefore, placement teams should shift away from asking, “Who is appropriate to exclude?” It would be more constructive and consistent with IDEA to ask, “How can we change our practices so that more students with disabilities can be successfully included and educated?” By approaching this challenge proactively, people with varying philosophical orientations can, it is hoped, come together around a simple purpose to ensure that students’ lives should be better because they went to our schools.

Access to Appropriate Curriculum

IDEA provides a potent framework to enhance the lives of students with disabilities through *special education* and the development of an *Individualized Education Plan (IEP)*. Special education is defined as “specially designed instruction, at no cost to parents, to meet the unique needs of a child with a disability” (20 U.S.C. secs. 1400 [sec. 602][25]). Specially designed instruction means “adapting . . . content, methodology, or delivery of instruction to meet the unique needs of the child that result from the child’s disability; and to ensure access of the child to the general education curriculum” (34 CFR 300.26 [b][30]).

As described in IDEA, special education is a service, not a place (Taylor, 1988). At its heart, special education refers to the *individualized* ways we provide instruction to students in an effort to respond to their unique learning characteristics resulting from their disability. This can take a variety of forms or combinations. Sometimes individualization means (a) *changes in curriculum* to account for a student’s present level of functioning or special learning needs, (b) *adaptations to the delivery of instruction* (e.g., sensory, physical, behavioral, environmental) that allow a student to have access to learning opportunities, or (c) use of *different instructional methods* applied to the general education curriculum or to individually determined learning outcomes that extend beyond the general education curriculum.

Individualized Participation Options Within General Education

One of the most basic barriers for students with severe disabilities accessing special education within general education settings is the difficulty some people have conceptualizing how to retain curricular and instructional integrity. People ask logical questions such as, “I don’t understand. How does it make sense for a student with a severe cognitive disability to be in a fifth-grade class when he can’t do fifth-grade work?” Such legitimate questions deserve answers. But placing a student in an age-appropriate general education classroom does make sense when we shed the notion that the student must participate at the same level or necessarily should have the same learning outcomes as his or her classmates without disabilities. The question isn’t whether the student performs at grade level but whether his or her individual needs can be met within the general class context with special education plus supplemental supports and aids.

Within general education classes and activities, the participation of students with severe disabilities can be broadly characterized along two dimensions: (a) their *program* (e.g., individualized curriculum, IEP annual goals, learning outcomes from the general education curriculum) and (b) their *supports*, namely, what is provided to assist the student in accessing and pursuing achievement of his or her educational goals (e.g., materials, adaptations, learning strategies, personnel). As shown in Figure 1-1, this can be conceptualized as four basic options for including students with severe disabilities (or any student for that matter) within typical class activities; each is described in the following sections. During the course of a school day, even sometimes within a single activity, an individual student will move within these different options depending on the nature of the activity and their individual needs. This approach requires deliberate collaboration between teachers, special educators, and related services providers (Janney & Snell, 1997; Snell & Janney, 2004).

Option A: No Accommodations Required

Option A exists when a student is pursuing the general education program available to students without disabilities and can pursue that program with typically

available supports (e.g., teacher, classmates, classroom equipment). It should be noted, however, that supports that are typically available can vary widely from class to class or school to school.

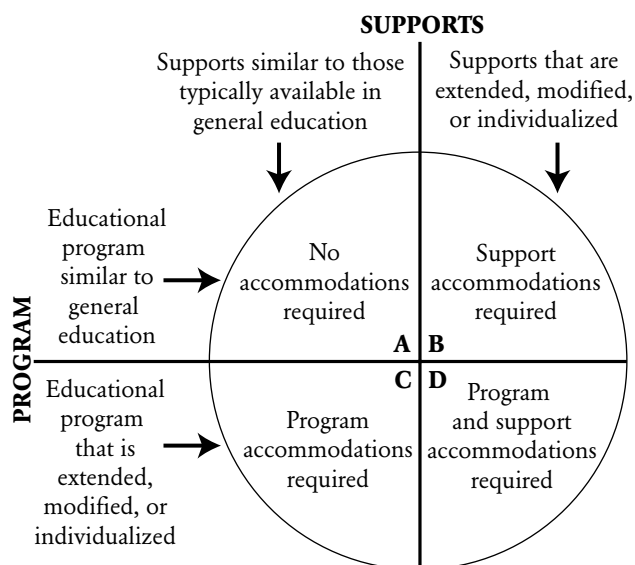
The participation of students with severe disabilities can be characterized as option A during certain parts of the day (if it were all of the time, they would not be in need of special education). For example, in a primary classroom, when the teacher is reading the class a story, the student with severe disabilities may not require a specialized program or supports. The teacher may position the child close to her so that she can show each page and respond if the student's attention wanders. The teacher may have a peer sit close in case the student starts to lose her balance while seated on the floor with the rest of the class; but these types of simple actions are not specialized.

It is important to recognize times when the participation of a student with a severe disability can be within option A because (a) it provides opportunities for teachers to interact with students who have disabilities in typical (nonspecialized) ways, (b) it allows classmates to see that the student doesn't always need extra help, and (c) it allows the student to avoid unnecessary supports that may inadvertently interfere with peer interaction or teacher engagement. Many students with severe disabilities have paraprofessional support while they are in general education class activities. There can be a tendency to provide such support, even at times when it is not needed. Using the previous example, having the student with a severe disability sit beside or on the lap of the paraprofessional not only may be unnecessary but also may have unintended negative consequences (e.g., stigma, create unnecessary dependency, interfere with peer interactions, interfere with teacher engagement). Teams should continually look for option A opportunities by considering how naturally available supports can be utilized (Nisbet, 1992).

Option B: Support Accommodations Required

Option B exists when a student with disability requires extended, modified, or otherwise individualized supports while pursuing the general education program. For example, in order for a student with deaf-blindness to access the general education program, he may require tactile signing from an interpreter as a necessary support. Similarly, a student with severe orthopedic or multiple disabilities might require a tape recorder and adapted switch to "take notes" during a high school class.

FIGURE 1-1
Inclusion Options Within General Education Environments and Activities



(Adapted from Giangreco & Meyer, 1988)

Option C: Program Accommodations Required

Option C exists when a student requires extension, modification, or individualization to the content of the general education program but does *not* require specialized supports. For example, the teacher might adjust the (a) amount (e.g., 4 new vocabulary words instead of 10), (b) the level (e.g., posing less complex questions), or (c) the type of content (e.g., 1:1 correspondence instead of fractions). Across each of these possibilities, once the content adjustment is made, the student does not require other specialized supports—though like option A, natural supports might be provided.

Option D: Program and Support Accommodations Required

Option D exists at times when a student needs extension, modification, or individualization of both the general educational program and the supports to participate.

Following a small-group geometry lesson on calculating the angles of various types of triangles, the teacher has planned a variety of activities for students to practice what they learned during the lesson. For Jamie, a student with severe disabilities, the content of the lesson and follow-up activities have been focused on discriminating triangles from other shapes; this represents individualization in the content of the general education math program. Making such discriminations also supports his communication; he is learning to extend his ability to discriminate beyond actual objects to symbolic representations. Additionally, rather than being asked to complete a paper-and-pencil task, he requires tactile materials that he can hold and feel, visual cues to highlight the three sides of the triangles, as well as individualized prompting and feedback on his performance; these represent support accommodations. So, for this math activity, Jaime receives both program and support accommodations (option D).

Within both options C and D, teams may employ the *principle of partial participation* (Baumgart et al., 1982). This principle asserts that it is important for individuals with severe disabilities to participate in whatever parts of activities they can, even if they cannot participate in every aspect and that they “can acquire many skills that will allow them to function, at least in part, in a wide variety of least restrictive school and

nonschool environments and activities” (Baumgart et al., 1982, p. 19). Ferguson and Baumgart (1991) remind us that, like any principle, partial participation can be misused. They identified passive participation, myopic participation, piecemeal participation, and missed participation as common error patterns that have occurred when people have attempted to apply the principle of partial participation. Partial participation is designed to foster socially valued roles for people with disabilities that have a positive influence on their image and personal competencies (Wolfensberger, 2000).

Consider Kendra, a middle school student with multiple disabilities who has severe oral-motor problems (e.g., difficulty chewing and swallowing). Many foods that Kendra is helped to eat fall out of her mouth. When in the noisy, bustling cafeteria, she seems particularly distracted. Her parents identified eating in busy environments as a priority because the family often finds themselves eating in these types of public places.

School personnel, however, were concerned that eating in the cafeteria was socially problematic for Kendra and would detract from how she was perceived by others. So since she moved into this school district a year ago, she has been eating lunch in a private area while working on goals to improve her eating and drinking skills with a paraprofessional. Unfortunately, this practice, while intended to be respectful of her, took an all-or-nothing approach. A subgroup of Kendra’s educational team, including her mother, special education teacher, and occupational therapist, came up with a plan that was designed to respect her dignity while also providing her with access to the cafeteria with classmates.

The Principle of Partial Participation was key to various aspects of their plan that systematically shifted from eating alone to eating with peers in the cafeteria. First, recognizing that Kendra quickly became fatigued and her eating skills deteriorated as time went on, they decided that rather than having Kendra eat her entire lunch in one 20-minute sitting, she was offered four 5-minute minimeals spread out over 90 minutes. During the regularly scheduled lunch period for her class, she spent only 5 minutes in a private area working on her eating and drinking goals with a paraprofessional. The remaining 15 minutes was spent in the cafeteria with her peers, hanging out just like everyone else—eating is only a small part of lunchtime in a middle school cafeteria. After she had

been going to the cafeteria for a couple of weeks and seemed more comfortable, 5 of the 15 minutes were spent working on eating and drinking goals, though slightly differently than in the private setting. Kendra's parents and occupational therapist identified a specific set of foods that she was able to chew and swallow most effectively without spilling. She would still lose food occasionally; this would also allow her peers to learn that some people eat differently and for the adults to model that it's not a big deal. Kendra continued to work on eating more challenging, messy foods in private. The team met regularly to discuss Kendra's progress. As time passed, they gradually shifted her eating to the cafeteria completely, though she still didn't eat her entire meal during the scheduled lunchtime. The team used partial participation by offering her only certain foods in the cafeteria and using only part of the time for eating; these modifications in the usual lunch routine allowed Kendra to be more fully part of the life of the school.

While option D (program and support accommodations required) will be necessary, at least part of the time, for students with severe disabilities, teams should make every effort to consider when options A, B, or C are possibilities and be conscious of not over using option D. Even when a student has a severe disability, it is rare that their participation would need to be characterized as option D all the time.

Understanding how the participation of a student with severe disabilities can be characterized using these options can help some team members conceptualize the inclusion and meaningful participation of these students. Equally as important, some general education teachers experience great uncertainty when they are unclear about the nature of a student's participation in their class and their role with the student. These teachers want to know what is expected of the student in their classroom and what is expected of them as teachers. Clarifying the options for participation in a variety of class activities can help alleviate teachers' anxieties and establish a firm foundation on which to establish inclusion that retains curricular and instructional integrity.

Multilevel Instruction and Curriculum Overlapping

Inclusion options C and D often lead teams to ask an important question "How can individualized curricular content be addressed appropriately in the classroom

when students without disabilities are pursuing different curricular content?" Lack of clarity about this issue can lead to one of the most common and anxiety-producing questions asked by classroom teachers: "How do you expect me to incorporate an individualized curriculum for a student with disabilities while teaching the rest of my class?" Unfortunately, all too often the solution to this challenge is for a paraprofessional to operate a parallel educational program in the back or side of the classroom. Such an approach minimizes the potential benefits of participation in a general education class. Delegating primary instructional responsibilities to a paraprofessional also may relegate students with disabilities, presumably the students with most significant learning challenges, to receiving their instruction from the least qualified personnel who tend to be undertrained and undersupervised (Giangreco & Doyle, 2002). Two alternatives include *multilevel curriculum/instruction* and *curriculum overlapping* (Giangreco & Meyer, 1988).

Multilevel curriculum/instruction occurs when a student with disabilities and peers without disabilities participate together in a shared activity such as a science lab experiment. Each student has individually appropriate learning outcomes that may be at any of multiple levels (i.e., below, at, or above grade level), all within the same curriculum area (Campbell, Campbell, Collicott, Perner, & Stone, 1988). This approach builds on classic concepts presented in the *Taxonomy of Objectives* (Bloom, 1956). While one student may be learning at a basic knowledge or comprehension level, another student simultaneously may be working on a more advanced application or synthesis levels.

Imagine fourth-grade students playing a small-group social studies board game designed by their teacher and special educator to learn about their neighborhood, town, and state. The teachers have prepared a set of 10 game cards for each student that target individual learning outcomes. For one student, the game cards require applying knowledge about the roles of community helpers (police, firefighters, store clerks, postal workers) by moving game pieces to respond to scenarios on cards (e.g., "Move your player to the place where you might go if you wanted to send a card to your grandmother for her birthday"). For another, game cards have the student answer questions about where she lives (e.g., street address, phone number, recognizing photos of neighbors). A third student is using map skills such as north,

south, east, and west to respond to questions (e.g., "If you started at the Bookstore, went two blocks north and one block east, where would you be?"). In this example, all the students have individualized social studies learning outcomes.

Multilevel curriculum/instruction can include variations across subject content, level of learning outcomes pursued, or both.

In one seventh-grade social studies class focusing on American history from the Revolution through the Civil War, the topic is the same for Joseph, a student with disabilities, and his classmates without disabilities. But his level of learning outcomes is adapted to suit him (e.g., historical people, places, events). In Joseph's algebra class, however, the subject content for Joseph is different than for many of his classmates, focusing on counting and basic computation (e.g., adding). In this case, the level and quantity of the learning outcomes would be adapted as well. In both classes, Joseph is working on individualized learning outcomes within the same curriculum content area as his classmates, just at a different level.

Curriculum overlapping starts in the same way as multilevel curriculum/instruction; a student with disabilities and peers without disabilities participate together in a shared activity where each student has individually appropriate learning outcomes. Curriculum overlapping differs in that the learning outcomes being pursued within a shared activity come from two or more different curriculum areas; this is unlike the multilevel curriculum/instruction examples, where they were all within the same curriculum area.

In a middle school biology class, students are grouped in teams of three for lab. They are assembling a model of a human heart. Two of the students have goals related to the identification, anatomy, and physiology of the human heart. The third student, who has severe disabilities, participates in helping to assemble the model heart but is working on communication and social skills (e.g., taking turns, following instructions, responding to yes/no questions, maintaining socially acceptable behavior for longer periods of time).

Curriculum overlapping tends to be used more frequently when the differences between the level of learning outcomes being pursued by most of the students in class and the student with a severe disability

are the greatest. So as you consider the following example, remember that before employing curriculum overlapping, the team should first consider whether the student could pursue the same learning outcomes as the rest of the class or whether multilevel curriculum/instruction is a viable option. If neither of those options is appropriate, it is time to consider curriculum overlapping.

In a middle school math class, six students are arranged in a circle for a game that involves throwing and catching a beach ball covered with numbers to practice multiplication. The game starts by having one student call a classmate by name and then toss the ball: "Terry, I'm throwing the ball to you." After catching the ball, the student is asked to multiply the two numbers touching his or her thumbs. All the students have math learning outcomes except for Jesse, a student with profound intellectual disabilities. Jesse participates in the same activity but with a series of nonmath goals. He is learning to orient toward a person who calls his name, react to the tossed ball by moving his arms to attempt a catch, and match to a sample by pointing to a photograph of a classmate who is in the group, then orienting toward that classmate before being assisted to toss the ball.

At times, both multilevel approaches and curriculum overlapping can be used within the same activity. By pursuing more than one learning outcome within class activities, students with severe disabilities are provided with numerous opportunities to learn and practices skills throughout the school day. Recent research has demonstrated the effectiveness of embedding individually determined learning outcomes within general class activities (McDonnell, Johnson, Polychronis, & Risen, 2002). In rare instances, it may be necessary to plan an alternate activity if a student needs to work on a high-priority goal that doesn't lend itself to being incorporated into multilevel or curriculum overlapping options.

Curricular Balancing Act

Ensuring access to a relevant, individualized curriculum for a student with severe disabilities also requires a balancing act in at least two ways. First, a sound curriculum establishes a *balance between focus and breadth*. Providing access to a breadth of learning outcomes that includes but is not limited to general education curriculum ensures that students with disabilities will have opportunities that may have been denied

them in the past. A sound curriculum establishes a clear focus, based on a reasonably small set (e.g., five to eight goals and related objectives) of the highest educational priorities agreed to by the team; these are documented as IEP goals (Giangreco, Cloninger, & Iverson, 1998).

Historically, curriculum for students with severe disabilities has emphasized the identification of chronologically age-appropriate and functional skills needed to function in current and future environments (Brown, Nietupski, & Hamre-Nietupski, 1976; Brown et al., 1979). While these foundational concepts remain contemporary 30 years after they were first articulated in the professional literature, variations on the themes have been expanded.

Today, the basis for selecting IEP goals and objectives for students with severe disabilities has shifted to place a greater emphasis on determining which goals and objectives are most likely to result in positive lifestyle improvements (Carr et al., 1999; Horner 2000). Research is beginning to tackle elusive concepts such as identifying, validating, and increasing the indices of “happiness” in individuals with profound, multiple disabilities (Green & Reid, 1996; 1999; Logan et al., 1998). By asking parents who have children with disabilities and people with disabilities themselves what does or would contribute to living a “good life,” we can better identify and select goals and objectives that will contribute to the development of *valued life outcomes* (Giangreco et al., 1998) such as the following:

- Being safe and healthy
- Having a home now and in the future
- Having meaningful relationships
- Having choice and control that matches one’s age and culture
- Participating in meaningful activities in various places

The Perez family has three children. Their youngest, Juanita, has severe disabilities and is in first grade. Juanita’s special education teacher, Ms. Brown, shared information with the team, including Mr. and Mrs. Perez, about an educational planning process called “COACH” (Choosing Outcomes and Accommodations for Children) (Giangreco et al., 1998). After becoming familiar with the process, Mr. and Mrs. Perez agreed to try this approach to planning Juanita’s IEP. The first step was a structured family interview during which the parents were

asked questions about valued life outcomes for Juanita and then guided through a series of questions about potential learning outcomes. The questions then assisted the family in identifying the five highest priorities for Juanita that would be translated into IEP goals and objectives to be focused on during the school year. These priorities included (a) expressing “more,” (b) making choices when given options, (c) responding to yes/no questions using eye gaze, (d) calling others to her using a switch and recorded message, and (e) using a switch to activate leisure devices (e.g., CD player, battery-operated toys). Each of these priorities was cross-referenced to one or more valued life outcomes. For example, being able to activate toys was designed to give Juanita more choice and control and was hoped to be a point of connection that might serve to extend her relationships with other children her age. In step 2 of COACH, the team considered a set of additional learning outcomes to establish the breadth of Juanita’s educational program. They did this by systematically looking at the general education curriculum in each subject area as well as nine functional skill categories included in COACH to decide what learning outcomes would make the most sense for Juanita. From these listings, they selected a series of skills, such as imitating skills used in daily life, eating finger foods, drinking through a straw, and increasing the amount of time she could sustain attention to a task, among others. From the general education curriculum, they started with skills such as recognizing symbols, distinguishing between shapes, writing her name using an adapted stamp, and using a variety of art media, among others.

Second, a sound curriculum *balances the assessed level of appropriateness with a measure of challenge*. An age-old tenet of instruction is that a student’s learning outcomes should be selected at an *appropriate level of difficulty* based on assessment data—neither too easy nor too difficult. Rather, targeted learning outcomes should be reasonably attainable yet challenging, though not so challenging as to be unattainable or frustrating. Although it is logical to select instructional targets based on the student’s current level of functioning and known learning characteristics, quality instruction should *provide ample opportunities for students to surprise us with their capabilities*.

Therefore, we should never presume to know the upper limits on a student’s abilities, especially if the

student has not been sufficiently exposed to a concept or skill or has not received ongoing, competent instruction. This is consistent with Donnellan's (1984) *criterion of the least dangerous assumption*, which asserts that "in the absence of conclusive educational data, educational decisions should be based on assumptions which, if incorrect, will have the least dangerous effect on the student" (p. 142). For example, if an individual with a severe disability is nonverbal and does not have a fluent augmentative method of language or communication, it would be most dangerous to assume that he or she does not understand much, if any, of what is said to or near him or her. It would be less dangerous to assume that he or she understands everything being said to or near him or her. Similarly, it would be most dangerous to prevent the student's exposure to general education curriculum and least dangerous to provide not only exposure but also instruction.

Juanita's team did not select any science learning outcomes for her because they felt, based on existing assessment data, that the concepts were too advanced for her. Recognizing that this could be a dangerous assumption given her limited communication skills, they decided to include her in science class and start with curriculum overlapping so that the learning outcomes she focused on during science were primarily communication and social skills. By including her in the science activities and exposing her to instruction in this area along with her classmates, they are providing her with opportunities that would not deny the possibility that she understands more than they were currently able to discern. At least at the outset, accountability for learning during science class will focus on the non-science communication and social skills. Over time, based on the teacher's observations during science activities, Juanita's additional learning outcomes may be expanded in the future to include science outcomes.

Access to literacy instruction is a prime example of how curricular balance and applying the criterion of the least dangerous assumption have changed the educational opportunities available to students with severe disabilities and corresponding professional practices (Erickson & Koppenhaver, 1995). Historically, literacy instruction has been extremely limited for individuals with moderate or severe disabilities

(e.g., teaching functional sight words). Conventional wisdom suggested that our limited teaching time should be spent almost exclusively on teaching functional life skills rather than selected academics. To date, professionals have not been successful in teaching literacy skills to the majority of students with severe disabilities, but increasingly this option is being explored. Additionally, there is a recognition that every child, regardless of the severity of their disability, can begin to work on some early literacy skills. Some students, many of whom people previously would have not considered teaching literacy skills, are developing skills in reading and writing (Erickson, Koppenhaver, Yoder, & Nance, 1997). This has occurred because of a change in attitude, followed by opportunity, and effective instruction.

In Juanita's case, the team agreed that as a first grader she was much too young to forgo literacy instruction. Instead, they made a conscious effort to expose her to books in English and Spanish since her family is bilingual. Daily she was shown books, read to, assisted to turn the pages, and otherwise shown the wonders of stories and reading. At the same time, she worked on skills such as (a) directing and sustaining attention to objects, books, activities, or interactions; (b) establishing consistent response modes (e.g., pointing, eye gaze, activating a switch); (c) differentiating or discriminating between various objects, photos, or symbols; or (d) matching to a sample. While everyone was hopeful that these efforts would provide important foundations for literacy, they agreed that working on these skills was worthwhile regardless of whether Juanita's literacy proficiency ever reached the heights of functional reading. Her pursuit of important early literacy skills would likely have generalized implications for the development of related skills in domains such as communication, social skills, and recreation.

Although access to the general education curriculum is designed to give students opportunities to learn a wide variety of new skills, exposure to new curriculum content can initiate curiosity about a topic that can become a lifelong interest and a point of connection to others regardless of an individual's skill level. We all know people who are not great musicians but who love music. You may know someone who is not particularly versed in science but through exposure to astronomy has become fascinated with the moon and



Box 1-1

March 24, 2003

Dear Mrs. B. & Mr. G.

Erin attended the State Thespian Conference with the Drama Club this past weekend. When she saw that *The Tempest* was the Friday night play and it was by Shakespeare she was all excited; she definitely knows his name from your classes. On Sunday morning, there was a comedy entitled, *The Works of Shakespeare*. Erin insisted on attending after she heard that it was about Shakespeare and she loved it!

Saturday night, we saw one of the best musical presentations I have ever seen, of *Les Miserable*. Now Erin says she has to get the CD. She was mesmerized, but then we all were—just a phenomenal performance. At intermission she said the play was about what she had learned in history class. She made that connection!

This reinforces for me the need for all students to access the general education curriculum, even if they can't describe all the nuances of what they are learning about. I doubt very much that Erin would have been exposed to Shakespeare or any other great literature in the special education classroom for students with cognitive and developmental disabilities. That would have been unfortunate. Theatre has helped Erin to continue to make connections between literature and what she has learned in class. She watches the video from last year's school performance of "The Crucible" all the time.

Please keep Erin's experiences in mind when you and your colleagues are planning. *All* students, with any disability label, should have the opportunity to be part of the mix. You never know what any particular student might get out of a lesson or experience.

Thank you for giving Erin the opportunity to access great literature in your classes.

Barb McKenzie

stars. Such interests can hold great meaning to people. Consider the above letter (see Box 1-1) written by a parent to two high school English teachers about her daughter, Erin, who has a passion for theater (Erin has Down syndrome).

Access to Effective Instruction

Over the past several decades, the field of educating students with severe disabilities has relied extensively on the use of systematic instructional methods to pursue meaningful curricular outcomes because of their strong theoretical foundation and documented effectiveness (Alberto & Troutman, 1995; Snell & Brown, 2000). This set of instructional methods, such as chaining, shaping, prompting, and error correction, offered a bright spot in a special education system that was all too often characterized by unnecessarily low expectations, too much instructional downtime, limited access to peers without disabilities, and questionable curriculum. Use of these and other systematic

instructional methods played a major role in documenting the wide range of skills and functional routines people with severe disabilities could learn if offered consistent, quality instruction (Brown, Evans, Weed, & Owen, 1987). In fact, the use of these methods was instrumental in helping to establish, once and for all, the educability of people perceived as having the most profound disabilities.

Ironically, as students with severe disabilities have gained more access to general education classes with higher expectations, peers without disabilities, and a broader curriculum, new questions have been raised about the integrity of their instruction. The field is wrestling with the challenge of how to utilize the time-tested, evidence-based, systematic instructional approaches in new and contextually viable ways (Logan & Malone, 1998; McDonnell, 1998). In part, this has included a shift from individual instruction and small homogeneous groups to mixed-ability groupings where there is only one student with a disability with classmates who do not have disabilities.

Consider the case of Lisa, a high school student with severe disabilities. In the past, although she was included in general education classes, typically she was separated from the rest of the class for individualized instruction with a paraprofessional who implemented a systematic instructional plan that had been developed by the special educator. Although this plan had certain positive features (e.g., use of systematic instructional procedures, attention to functional skills), the lessons had no contextual relevance to the classrooms where they were being delivered. This resulted in Lisa's not being a true member of the classroom community since she had no substantive involvement with the classroom teachers or peers. When the team began planning ways to embed important learning outcomes for Lisa into class activities and creating opportunities for classmates to help each other learn, Lisa actually had more real opportunities for learning than ever before. The team met on a regular basis in an effort to evaluate how their plans were working and continually explore ways to use the best of validated instructional approaches in ways that were more natural and contextually grounded.

As teams pursue instructional integrity, it is important to remember that the principles of teaching and learning do not change because a child gets a disability label or because those who were once in a special class are now supported in a general class (see Box 1–2). Many doors have been opened for people with severe disabilities using foundational principles of instruction, and these remain critical for learning in inclusive settings. As with all strategies, however, the specific and changing learning environments and individual learning needs of each student will shape how strategies are used and adjusted to fit the evolving context.

Know Each Student's Characteristics

Quality instruction always starts by making sure you know your students. This means more than being familiar with their disability diagnosis, though that is important to understand. It means understanding their cognitive, physical, and sensory characteristics that affect instruction. It also means being cognizant of their social/emotional traits (e.g., temperament, behaviors), motivations, preferences and dislikes, interaction patterns, and creative attributes. Understanding such aspects of your students supports *individualization*, a hallmark of special education, and encourages the development of instructional approaches that build on each student's strengths and preferences.

Select Meaningful Learning Outcomes

Quality instruction really matters only if it is applied to meaningful learning outcomes. Highly effective instruction applied to irrelevant, nonfunctional, or chronologically age-inappropriate learning outcomes is a waste of the student's time as well as your own. Effective teams establish and maintain a positive sense of urgency about their work without simultaneously creating undue stress on the student or team. They know that, relatively, they have precious little time to teach, so their curricular selections and instructional intensity matter. Though much of the curricular aspects related to instruction were mentioned earlier in this chapter (e.g., functionality, age appropriateness, balance of breadth and focus), there are a few additional considerations when selecting meaningful learning outcomes.

Consider the frequency with which a learned skill will be used both now and in the future. Clearly, skills that are used frequently and have current and future utility generally are more important than those that are used infrequently or won't be useful in the future. Selecting meaningful learning outcomes is always a



Box 1–2 Generic Principles of Quality Instruction

1. Know each student's characteristics
2. Select meaningful learning outcomes
3. Establish shared expectations among team members
4. Create a motivating learning environment
5. Select effective teaching methods
6. Provide sufficient and consistent learning opportunities
7. Use data to make instructional decisions

judgment. Sometimes, skills with a lower frequency of use can be extremely important to being safe (e.g., street crossing, evacuating a building in response to an alarm) or to personal preferences (e.g., the leisure skills one enjoys, predictable environments, unstructured time). For individuals with the most severe and multiple disabilities, a major consideration is the extent to which a learned skill will allow a person to control his or her environment (Brown & Lehr, 1993). For example, learning to use an adapted microswitch may allow a person with severe, multiple disabilities to activate a wide variety of electrical or electronic devices across a range of places and activities (e.g., communication, cooking, leisure, work).

Establish Shared Expectations Among Team Members

As curricular and instructional planning continues, team members need to establish shared expectations. From a logistical standpoint, ensuring that team members strive toward being on the same wavelength regarding philosophy, curriculum, and instruction can be a challenge simply because students with severe disabilities typically have teams with numerous members. Such teams often include parents, teachers, special educators, paraprofessionals, and related services providers such as speech-language pathologists, physical therapists, occupational therapists, orientation and mobility specialists, and psychologists. When teams are too large, it poses challenges in selecting meeting times and communicating. Team membership often changes substantially each school year with parents and students being the members most likely to remain on the team for extended periods of time.

Having multiple perspectives from numerous members can be a valuable asset to an educational planning team. Managing the group's size and diversity of input is important to enhance the productivity of the group and to avoid the stereotypical problems of team meetings, such as (a) being unclear about the purpose of the meeting, (b) getting off on tangents, (c) having the meeting dominated by one person or more members, or (d) leaving the meeting feeling like it was waste of time. Effective interactions among members can be facilitated through a variety of collaborative teamwork practices (Rainforth & York-Barr, 1997; Thousand & Villa, 2000). Establishing shared expectations means that all members should (a) know the student's learning-related characteristics, (b) be aware of the student's priority learning outcomes (e.g., IEP goals), (c)

be aware of the breadth of learning outcomes that are targeted for instruction (e.g., general education curriculum), (d) know when learning outcomes will be addressed throughout the school day, (e) know what general supports or accommodations need to be made for the student, (e) know the student-specific instructional procedures and adaptations, and (f) know what information to collect about the student's progress.

It is critical that all team members clearly understand the distinction between a *learning outcome* and a *general support*. A learning outcome is a goal or objective the team has targeted for the student to learn, such as "pointing to a desired food item on a communication board" or "finding one's own locker." This requires student responding and is designed to result in a change in student behavior (e.g., the acquisition of a new skill). A general support, on the other hand, refers to what will be provided for a student so that he or she may have access to education, participate in school, and pursue identified learning outcomes. On IEP documents, the terms used to describe general supports vary from place to place (e.g., accommodations, modifications, supports, management needs). General supports tend to cluster in one of six main categories (Giangreco et al., 1998):

1. Personal needs (e.g., support to eat, catheterization, provide medication)
2. Physical needs (e.g., repositioned at least hourly)
3. Teaching others about the student (e.g., teach staff and classmates about the student's augmentative communication, teach staff seizure management procedures)
4. Sensory needs (e.g., auditory amplification system, tactile materials, large-print materials)
5. Providing access and opportunities (e.g., environmental modifications, access to cocurricular activities, access to materials in the student's native language, computer access)
6. Other general supports (those not clearly addressed in any other category) (e.g., class notes recorded, extended time to complete tasks, communication with the family)

Drawing a distinction between general supports and learning outcomes is important because too often goals and objectives listed on IEPs for students with severe disabilities are written as passive general supports (e.g., repositioned at least hourly) rather than active learning outcomes (Downing, 1988; Giangreco, Dennis, Edelman, & Cloninger, 1994).

The volume, range, and complexity of information that teams exchange in the process of establishing shared expectations require practical documentation in addition to the IEP. There are a variety of ways that a team's shared expectations for a student can be clarified. First, a one- or two-page *program-at-a-glance* is a simple and concise way to summarize a student's learning outcomes and general supports for daily use (Giangreco et al., 1998, p. 132).

A second way to clarify the team's shared expectations are in lesson or program plans that explicitly describe how a student with a severe disability will pursue his or her learning outcomes within typical class activities. Such plans can also be effective reminders of basic information such as (a) operational definitions of target skills, (b) how to arrange the environment to facilitate learning (e.g., seating arrangement, materials), (c) methods for introducing tasks, and (d) what to do if the student doesn't respond in a reasonable length of time, responds incorrectly, or responds correctly. Having all team members clear about how to respond under these varying circumstances is critical to ensuring instructional consistency.

Third, general supports can be effectively documented through photographs or video clips, such as (a) how to safely transfer a student between their wheelchair and other places (e.g., stander, toilet, floor), (b) how a student should be appropriately positioned in his or her wheelchair, or (c) specialized feeding techniques. Finally, a *transition book*, which presents photos and short descriptive information, can be a friendly and effective way to introduce the personal and learning characteristics of a student with a severe disability to new team members and peers (Doyle, 2000).

Create a Motivating Learning Environment

Although it may seem obvious, the importance of *creating a motivating learning environment* where all students feel welcomed cannot be underestimated. Establishing a sense of belonging is considered a key building block for effective learning (Kunc, 2000). Studies of students with severe disabilities in elementary and middle schools highlight the limitations of part-time participation in general classes and the importance of participating in shared experiences (Schnorr, 1990, 1997). In order for students with disabilities to develop meaningful relationships with peers who do not have disabilities and access to a broad range of meaningful learning outcomes, they

must share learning experiences with peers on an ongoing basis.

Select Effective Teaching Methods

Part of instructional access involves selecting effective teaching methods as a starting point for intervention. Students with disabilities often respond favorably to many of the same teaching methods that are common and effective for students who do not have disabilities. Some of these common methods include modeling and demonstration, repeated practice, guided discovery, participatory activities, using educational games or play, using positive and negative examples, giving corrective feedback, or cooperative group learning approaches. Challenges arise when students do not progress adequately when you have relied on typical instructional methods. In such cases, it is often necessary to be more precise in the application of methods, break the skills down into smaller components, or use different instructional methods, such as task analysis, chaining, shaping, and time delay (see chapters 4, 9, and 13). Consider the case of Tom and how he learned a new skill because of the use of a systematic instructional procedure and how it had an impact on his life.

Tom had a traumatic brain injury resulting in severe physical, cognitive, and sensory disabilities including blindness, loss of language, the inability to walk, sit up independently, or use his arms and hands. Tom was fed through a stomach tube, though his parents had worked with him so that he could eat soft foods and drink by mouth. His only consistent, voluntary skill was some head movement side to side when supported from behind, the ability to open and close his mouth, and some chewing. Tom communicated primarily through vocalizations. For example, he made a groaning sound that everyone easily recognized as discomfort. This usually meant it was time to get him out of his wheelchair for a while. At a meeting when Tom was 14 years old, his parents were asked for their input into Tom's IEP goals for the year. Tom's father said, "I don't care what he learns; I just want to know that he can learn." Building on Tom's strengths, the team decided to teach Tom to respond to the verbal instruction, "Open up" to open his mouth to receive, food, drink, medicine, and have his teeth brushed. The team knew that Tom currently didn't respond to "Open up" or any other instruction, but he did open his mouth wide when his lower lip was touched lightly (e.g., by

a spoon with food). Some team members wondered if he was actually responding to the lip touch or something else, such as the air movement of something coming toward him, smell, or cues from some residual vision. Their assessment convinced them that it was the touch cue only that caused him to open his mouth. They decided to use an instructional procedure called “time delay.” This started by simultaneously pairing the cue that they knew Tom responded to (i.e., touching the lip with a spoon) with the cue they wanted him to respond to (i.e., the verbal instruction “Open up”), followed by giving him a spoon of fruit yogurt. This simultaneous pairing is known as a zero delay because there is no time between the presentations of both cues. This was done numerous times throughout the day when Tom would normally be expected to open his mouth in an effort to help Tom to make the connection between the two cues. After this had been done for a few days, a 1-second time delay was put between the cues. The teacher would say “Open up,” then wait 1 second before touching his lip. Over the next couple of weeks, the time delay between asking Tom to “Open up” and touching his lip was gradually increased in 1-second intervals, always followed by a small bite to eat or sip to drink. When the time delay got to 5 seconds, Tom opened his mouth to accept the food before his lip was ever touched—he had responded to the instruction! Time delay had been successfully used to transfer control from the one cue to another. Some people might think that this didn’t matter much, but it did! For the first time in years, people who worked with Tom were excited and encouraged that he had learned a new skill. People interacted with him differently, more positively, as someone capable of learning. They were anxious to find out what else Tom could learn. Tom will always need substantial support from others, but this small change had a big impact.

Provide Sufficient and Consistent Learning Opportunities

Once instructional methods have been selected, with the individual student’s learning characteristics in mind, the team needs to ensure that sufficient and consistent learning opportunities are provided for the student. A scheduling matrix (Giangreco et al. 1998, p. 161) provides a way for a team to ensure that a student’s IEP goals and additional learning outcomes are incorporated into the daily or weekly schedule. A

scheduling matrix is set up as a simple grid. Listed across the top are regularly occurring class activities (e.g., arrival, language arts, math, science, physical education, lunch, recess). It can be helpful to note the amount of time devoted to each activity. For example, arrival time may be only 10 or 15 minutes at the beginning of the day, whereas a full hour might be devoted to language arts. The time frame is important to know because the number of learning outcomes that can reasonably be addressed will vary accordingly. Since daily schedules often change (e.g., one day math is at 9:00 a.m., a different day it is at 10:30 a.m.), when using a schedule matrix it is not crucial to arrange the general class activities in a specific order according to the schedule. Once a team determines which learning outcomes will be addressed in each class, that match will be the same regardless of what time the class occurs or on which day of the week. In this way, the scheduling matrix can then be used to clarify which of a student’s learning outcomes can be embedded within all classes (e.g., express greetings and farewells, respond to yes/no questions, follow instructions, make choices when presented with options) and which will be targeted to specific classes or activities that make the most sense.

During computer class, Joshua will engage in individual active leisure by activating single-response software on a computer using an adapted microswitch. During language arts, he will identify photos and symbols, summon others, and do classroom jobs.

Providing sufficient and consistent learning opportunities requires persistence and creativity on the part of team members to embed opportunities for learning within class activities. Although the team wants to provide a reasonable level of planned consistency, since students with severe disabilities often present a very unique constellation of learning characteristics, team members need a certain level of instructional flexibility. They need room to explore new approaches, combinations of approaches, and capitalize on unscheduled, teachable moments.

Use Data to Make Instructional Decisions

Along with this flexibility comes accountability in the form of data collection. Just as we collect data and examples of work completed by students who do not have disabilities to monitor and document progress

and to be accountable for our teaching, teams have a responsibility to do the same for students with severe disabilities (see chapter 5). Individualized data provide the essential information for making reasoned instructional decisions (Farlow & Snell, 1994).

As we think about collecting data on student learning, it is important to remember that performance related to specific IEP goals and objectives is only part of what is necessary. Regardless of the extent of student progress, it is important for each priority goal to be evaluated on the basis of its real impact on a person's life. Wolf's (1978) classic article introduced the field of applied behavior analysis to the assessment of *social validity*. Wolf argued that we must augment objective observable measures of behavior with subjective perspectives of consumers if we are to achieve outcomes of social importance. He suggested that we evaluate (a) the social significance of the goals being sought, (b) the social appropriateness of the procedures being used, and (c) the social importance of the effects. The concept of social validity acknowledges that a student's attainment of an established goal is not necessarily synonymous with its importance or meaningful changes in the student's life.

Maria is learning a set of social skills (e.g., responds to the presence of others, greeting, taking turns) with the intention that the attainment of these skills will contribute to establishing or extending friendships with peers. Merely knowing that she has acquired those skills is a good first step, but it is incomplete until we determine whether her relationships with peers have changed for the positive and whether her improved skills contributed to those socially important changes.

Sometimes, socially important outcomes can occur even when target skills are not achieved. There may be circumstances where a student does not progress much in development of the targeted skill but where the nature of the instructional arrangement (e.g., peer involvement in typical class activities) leads to improvement in valued life outcomes because something in the environment has changed (e.g., access to typical settings, attitudes of classmates). Improvements in valued life outcomes for individuals with severe disabilities can be enhanced by a combination of skill acquisition on their part as well as changes in the environment, especially the attitudes and actions of the people in those environments.

Access to Individually Determined Supports

As described earlier, one of the defining characteristics of people with severe disabilities is that they require ongoing supports. A primary mechanism within IDEA to provide support is through the provision of *related services*:

The term "related services" means transportation, and such developmental, corrective, and other supportive services (including speech-language pathology and audiology services, psychological services, physical and occupational therapy, recreation, including therapeutic recreation, social work services, counseling services, including rehabilitation counseling, orientation and mobility services, and medical services, except that such medical services shall be for diagnostic and evaluation purposes only) as may be required to assist a child with a disability to benefit from special education, and includes the early identification and assessment of disabling conditions in children. (20 U.S.C. sec. 1400 [sec. 602][22])

For many students with severe disabilities, special education services alone are not sufficient for them to receive an appropriate education; in such cases, the provision of related services are essential. The availability and array of related services recognizes the reality that no single discipline embodies the varied knowledge and skills necessary to effectively support the education of the full range of students with disabilities. One of the primary challenges of providing related services is ensuring that a student receive appropriate supports yet at the same time being careful that those services do not inadvertently interfere with the student's access to the least restrictive environment, appropriate curriculum, or effective instruction.

Team Decisions About Related Services

All too often, related services for students with severe disabilities are based on separate, discipline-specific goals and perspectives. Such scenarios highlight that merely assigning a group of individuals to the same student does not make them a team. It is the way these individuals interact together that ultimately distinguishes whether they are accurately referred to as a *group of individuals* or a *team*.

At the very outset of making team decisions about related services, it is helpful to understand and

acknowledge that all decision making is based on underlying assumptions and values. Sometimes these are clearly understood and agreed to by team members. It is when they are unclear or conflicting that it becomes problematic because it increases the probability that team members will be working at cross-purposes, sometimes without even realizing why this is happening. Though honest disagreements about values will certainly exist among some team members, it is preferable that disagreements are in the open and that members strive toward identifying shared values that can guide their decisions. Having shared values can assist members in evaluating proposed actions as consistent or inconsistent with the team's approach. Listed in the following sections are three common value systems teams might encounter. The first two are inconsistent with sound educational practices; the third is suggested as a desirable alternative.

More Is Better Some team members are continually advocating for *more* related services. If one session of a particular therapy is recommended, they think two would be better and three better yet. The *more-is-better* approach is misguided because it confuses quantity with value. Often, although it is rooted in benevolent intentions, the more-is-better approach can have unintended, negative consequences for students by interfering with participation in other school activities. What is the student missing when he or she is spending time receiving a service someone has advocated for but that is not necessary? Providing more services than necessary may do the following:

- Decrease time for participation in activities with peers who do not have disabilities
- Disrupt class participation and membership by removal from class activities
- Cause disruption in acquiring, practicing, or generalizing other important skills
- Cause inequities in the distribution of resources when some students requiring services remain unserved or underserved
- Overwhelm families with an unnecessarily large number of professionals
- Result in stigmatization by the provision of special services
- Create unnecessary or unhealthy dependencies
- Unnecessarily complicate communication and coordination among team members

Return on Investment Another misguided value system, called *return on investment*, places a high value on serving students who have a favorable history and prognosis for being “fixed”—those likely to contribute the most, economically, to society. The return-on-investment approach fails to recognize the many noneconomic contributions made by people, including those with the most severe disabilities.

The return-on-investment value orientation is based on a curative mentality that sends negative messages to children with disabilities and their families. Imagine what it might be like to continually get the message, “You are not OK the way you are. In order to be OK, your disability has to be fixed and you need to be more like us (people without disabilities).” Increasingly, self-advocates are asking that their disabilities be viewed as a form of natural human diversity and that others' efforts be less about “fixing” a person's disabilities and more about accepting individuals for who they are and providing necessary and self-determined supports.

In addition, the return-on-investment approach tends to discriminate against individuals with the most severe disabilities. It seeks to justify the differential valuing of people and the services they receive on the basis of the severity of their disability characteristics. Anytime schools sanction practices that imply that some students are more worthy of staff time and resources than other students, there is a serious problem. All children are worthy, although they have differing needs.

Only as Specialized as Necessary An alternative value system is referred to as *only as specialized as necessary*—providing enough but not too much. This value orientation is based on the notion that, like other things people *need* (e.g., food, water, sleep, sunshine, time with others), our aim should be to get what we need in balance with all the other things we need rather than in the most amount possible. This involves both trade-offs and individualization when determining the appropriate type and amount of service for each student. This determination will be a collective best judgment of team members. Although this value system is contemporary, its conceptual basis within special education pre-dates federally protected educational rights for students with a full range of disabilities (Reynolds, 1962) and has a strong legal foundation in a U.S. Supreme Court precedent (*Board of Education of the Hendrick Hudson School District v. Rowley*, 1982).

The only-as-specialized-as-necessary approach seeks to identify and draw on natural supports, including those currently existing and available to students without disabilities (e.g., guidance counselor, teachers, school nurse, peers, educational support teams). In cases where more specialized services are deemed necessary, ongoing data should be collected in an effort to document the impact of the services while the team continues to explore alternatives that would allow students with disabilities to receive needed supports in the most natural and sustainable ways possible. This approach supports the provision of needed services and acknowledges the contributions made by various disciplines but takes precautions to avoid the inherent drawbacks of providing well-intentioned but unnecessary services.

It is important to recognize that the only-as-specialized-as-necessary approach does not necessarily mean that “less is always best” or “only a little is plenty.” Some advocates have voiced concerns that this approach might be misused to justify denial of needed services; this certainly is not its intended use. When used as intended, the only-as-specialized-as-necessary approach results in students receiving needed services. Further, it is meant to be a value orientation agreed to by the team, which includes the family. In summary, it is most important that teams understand the value orientations held by their members and that they work toward a shared value system that will contribute to making educationally sound support service decisions.

Educational Relevance and Necessity

When considering a value orientation such as the only-as-specialized-as-necessary approach within the context of the IDEA definition of related services and putting it into practical use requires that teams ask themselves challenging questions about the educational relevance and necessity of a proposed service. *Educational relevance* exists when a proposed service can be explicitly linked with a component of a student’s educational program (e.g., IEP goals, general education curriculum).

Lisa, an occupational therapist, has made various recommendations to support the handwriting skills of Adam, a student with autism, based on her evaluation of him. If handwriting is included as a goal or objective on Adam’s IEP or is part of the general education for which the student needs special education,

then the recommended occupational therapy supports are educationally relevant.

Educational relevance alone is not sufficient to warrant service provision; services must also be *educationally necessary*. A service is educationally necessary if, after establishing its educational relevance, the team determines that the service is essential. In many cases, IEP teams are asking the wrong questions, such as “Could the proposed related service help?” When this question is posed, the answer is almost always “Yes.” But this is not the question that the IDEA poses in the definition of a related service. The question may be more appropriately posed like this: “If the student does not receive a proposed related service, is there reason to believe that he or she will not (a) have access to an appropriate education or (b) experience educational benefit?” This question requires a higher standard of accountability to answer “Yes” than the one asking whether it could help. If a team does answer “Yes,” it clearly suggests educational necessity.

Consider the following two scenarios: (a) A parent takes her child with a disability to a private clinic for an evaluation and a consultant recommends music therapy once a week as a related service. (b) A therapist recommends therapeutic horseback riding twice a week. First, consider the following question to assist your team in determining whether a proposed related service is educationally necessary. Will the absence of the service interfere with the student’s access to or participation in his or her educational program this year? If the team answers “Yes,” the service under consideration probably *is* educationally necessary. If the team answers “Yes” to any of the following questions, the service under consideration probably *is not* educationally necessary (Giangreco, 2001).

- Could the proposed service be addressed appropriately by the special educator or classroom teacher?
- Could the proposed service be addressed appropriately through core school faculty or staff (e.g., school nurse, guidance counselor, librarian, bus drivers, cafeteria staff, custodians)?
- Has the student been benefiting from his or her educational program without the service?
- Could the student continue to benefit from his or her educational program without the service?
- Could the service appropriately be provided during nonschool hours (as established in the 1984 U.S.

Supreme Court decision, *Irving Independent School District v. Tatro*, 1984)?

- Does the proposed service present any undesirable or unnecessary gaps, overlaps, or contradictions with other proposed services?

If the team asked the question “Could these services help?” it could be quite easy to answer “Yes.” It would be more difficult to answer “Yes” if the question was asked a different way: “If the student does not receive music therapy or therapeutic horseback riding as a related service, is there reason to believe that he or she will not be able to receive an appropriate education?” This aspect of educational relevance is rooted in the *Rowley* decision *Board of Education of the Hendrick Hudson School District v. Rowley* (1982). In that case, the Court established that if a student was receiving educational benefit without the service, it was evidence that the service was not needed, even though providing the service might help. In such cases, schools are not required to provide the proposed service.

This type of scrutiny of service provision presents many gray areas and points of potential conflict among team members, which is why it is so important to continually build a shared understanding as a team. Ultimately, unnecessary services take away from rather than improve a student’s educational program. Conversely, well-conceived and well-carried-out related services can make a substantial contribution to a student’s educational program.

Jamal is a student with multiple disabilities, including deaf-blindness. The related services providers on his team have worked closely with the special educator, his classroom teacher, and his parents to ensure that his related services are both educationally relevant and necessary. The physical and occupational therapists have selected and modified equipment (e.g., specialized seating, arm/hand supports, adapted computer interface) that allows Jamal access to many learning opportunities. The speech-language pathologist has developed an augmentative communication system and corresponding instructional approaches that create opportunities for Jamal to communicate more effectively with teachers and peers. The vision and hearing specialists have adapted materials and learning environments (e.g., tactile labels, individualized amplification) to allow Jamal access to the general education curriculum.

These are only a few of the many ways that educationally relevant and necessary related services can be imperative for some students with disabilities. Making effective team decisions is not always easy but definitely is important.

Summary

Regardless of your role on the team, how you approach the task of educating students with severe disabilities depends quite substantially on the attitudes and dispositions you bring to this important task. One of the best places to look for encouraging and affirming perspectives is to families who have accepted their child with a severe disability unconditionally. That leads me to my colleague and friend, Susan Yuan, who has three children, all of whom are now young adults. Her youngest, Andreas, has severe disabilities. In a recent essay, she wrote about “seeing with new eyes” by using metaphors to help people think about individuals with severe disabilities differently (Yuan, 2003). Susan’s metaphor regarding Andreas was that of a bicycle. She likened her earlier parenting experiences with her two older daughters to riding a basic bike with fat tires, no gears, and a coaster brake. She knew basically what to expect and was able to figure it out. When Andreas was born, one of her first reactions was, “No way I could be a good mother to him!” He wasn’t like the bike she was accustomed to riding.

Sticking with the bicycle metaphor, to many people in our society the constellation of characteristics presented by Andreas would lead them to thinking of him as a bike that was broken or missing some parts. Such a perspective leads to many of the traditional ways our society limits opportunities and provides services for people with disabilities. You don’t take a broken bike out for a ride on the recreation path; first you try to fix it. If it can’t be fixed, some consider discarding it. Others become sentimental or hopeful and put the bike in the garage and tinker with it now and then; but their expectation is that it will never be a bike they can really ride or fully enjoy.

Rather than thinking of Andreas as a broken bike, Susan extended the metaphor by coming to think of him as a fancy Italian racing bike, with many gears, hand brakes, and racing handlebars. This bike wasn’t broken; she just hadn’t learned to ride it yet. She came to see this new bike as more complex, more sensitive, more responsive than a typical bike. On top of it all, it

was a tandem bike that both parents would need to learn to ride together, move together, and get in sync. She closed her essay this way:

Though I may not be ready for the Tour de France, I have become quite comfortable and capable with my own fancy, complex bicycle, known in the metaphorical world as my son, Andreas. Yes, he has his own unique characteristics, idiosyncrasies, peculiarities—don't we all! As I enter the 30th year of an incredible journey, I am still tinkering with the gears, appreciating that this bike has a mind of its own, and enjoying the ride. (p. 210)

As you proceed with your learning and your practice, part of the work is the struggle to find a balance between attending to the undoubtedly special needs of individuals with severe disabilities and their right to live regular lives. As a community of educators, we know quite a lot about what we think makes for effective education, but there is so much we don't know or simply don't do regularly enough. A key aspect of this work is creativity and unwavering persistence. By combining these elements, we have a reasonable chance for making the kinds of individual, collective, and incremental breakthroughs that can make a difference in people's lives.

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