NINTH EDITION

Instruction of Students with Severe Disabilities

Meeting the Needs of Children and Youth with Intellectual Disabilities, Multiple Disabilities, and Autism Spectrum Disorders

Fredda Brown | John McDonnell | Martha E. Snell

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Meeting the Needs of Children and Youth with Intellectual Disabilities, Multiple Disabilities, and Autism Spectrum Disorders

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For our children, grandchildren, partners,
and for our friends and colleagues
who have enriched our lives.

And to all the individuals with disabilities and
their families with whom we have worked—we
thank you for allowing us to be
part of your lives.

Fredda, John, and Marti

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PREFACE

In this ninth edition, we have, as a foundation, many of the same principles about teaching students with severe disabilities that were present in earlier editions because these principles have continued relevance:

- Inclusive schools create new opportunities for *all* students to learn relevant skills and to form meaningful and supportive social relationships.
- Inclusive schools enable teachers to become better teachers of *all* of their students.
- Teams of people, not any one individual, are responsible for designing, implementing, and evaluating educational programs.
- The skills identified for each student to learn should be functional (matching the student's current and future needs), suited to the student's chronological age, and respectful of the student's and family's preferences.
- Teams should maximize students' access to the general education curriculum.
- To be appropriate, instruction must be planned to suit the individual student.
- If special education is merged with general education instead of viewed as a separate educational structure, the diverse talents of both special and general educators will be preserved and instruction for all students will be improved.
- The teaching methods that we use need to be solidly based on research and demonstrated to be effective and appropriate for a variety of students in inclusive settings.
- All supports, both educational and behavioral, should be age-appropriate, respectful, and meet the same standards that are applied to students who have not been identified as having disabilities.

In this ninth edition, as in the eighth, we continue to emphasize that learning is more than increasing specific isolated skills. Learning and supportive efforts should be organized toward the achievement of three outcomes: membership/belonging, self-determination, and skills. To reach these outcomes, schools need to appreciate the relationship among them and focus on supporting students and their families to follow a vision of a satisfying, meaningful, and personally determined quality of life. There is great value in building self-determination in our students, as there is for all students; the challenge is to understand the many individualized ways that this characteristic can be developed. For example, teachers can match job training opportunities to students' preferences, and team members can teach their students to make choices and initiate preferred activities. Furthermore, when teams view their students' problem behaviors as having legitimate motivations, then those motivations can drive the development of positive and respectful behavior support planning.

SUPPORT FOR INSTRUCTORS AND STUDENTS

In addition to these principles and foundations, there are several features that we continue to fine-tune to enhance the reader's experience. One of the most effective ways to learn is through examples. Thus, we begin each chapter with case studies of students and then apply chapter concepts to these individuals. Because heterogeneity is characteristic of those with severe disabilities, our examples are diverse and include individuals across the age range—from kindergarten to adult—and with a variety of abilities and disabilities, including intellectual disabilities, multiple disabilities, and autism spectrum disorders (ASD). As the incidence of individuals with autism spectrum disorders have increased dramatically, each chapter (other than the chapter on physical disabilities) includes a vignette of a student with ASD.

As in prior editions, the instructor supplements include PowerPoint presentations for each chapter created by the chapter authors, and an Instructor's Manual with a variety of useful teaching resources, including a test bank for each chapter. To access these materials, go to **www.pearsonhighered.com** and search the catalog for this title and then click on the "Resources" tab.

NEW TO THIS EDITION

Over the years, this text has gained a reputation for being both comprehensive and current. The aim of earlier editions was to present issues and strategies that were documented as being effective and not to "jump on treatment bandwagons." The ninth edition maintains this reputation. The goal of this revision was to present the latest evidence-based research available with regard to all aspects of educational programs for students with severe intellectual disability, multiple disability, and autism. It has been and continues to be our aim to align the content of this text with evidence-based strategies. As the field continues to evolve, we strive to have this book evolve.

Digital Format. Along with a hard copy of the text, the ninth edition of *Instruction of Students with Severe Disabilities* will continue to be available as a digital book. An eText format benefits you in three ways: It is affordable, it has a search function that allows you to efficiently locate coverage of concepts, and many chapters have links to videos to support its content.

Changes and Additions to the Text. In addition to updating each chapter, the ninth edition includes several changes that expand the content in several key ways and makes the chapters more user friendly.

- *A new introduction*. The introduction describes the experiences, from birth through young adulthood, of Gina and her family as they navigate the challenges faced by individuals with severe disabilities to be accepted and fully included in school and the community. Written by Gina's mother, Niki Mirabella, we are provided with a compelling backdrop for the concepts and strategies addressed in each chapter of the book. We hope readers will keep in mind this wonderful family as they proceed through this book. The messages in this introduction should be a lens through which you read the 16 chapters in this book.
- *Reorganized chapters on instruction*. The ninth edition includes two chapters on teaching and instruction. The first chapter describes the importance of systematically organizing the teaching environment to maximize the efficacy of instruction. The second chapter focuses on the theoretical foundations of effective instruction and provides the reader with a comprehensive description of today's most important evidenced-based instructional strategies.
- *A new chapter on inclusive education*. This chapter provides a definition of inclusive education and how it has evolved over the last several decades. It also describes evidenced-based practices for supporting inclusive education at the school and classroom levels.
- *A new chapter on transition*. In addition to a focus on transitioning from school to employment, this chapter has been expanded to include information on and strategies for supporting students' transition from school to post-secondary education. It describes considerations for preparing for students' transition to college and effective strategies for supporting their success.

- *New pedagogy*. Each chapter begins with learning objectives and ends with summaries based on the objectives. Each chapter also includes suggested activities that are designed to enhance the reader's understanding of the content presented.

ORGANIZATION OF THE TEXT

Following the new introduction to this book, we begin this edition with seven chapters that lay the foundation for the rest of the book. The first two chapters focus on basic concepts that are central to the education of students with severe disabilities—inclusion and families. The discussion by Michael Giangreco, Karrie Shogren, and Stacy Dymond, introduces readers to students with severe disabilities by exploring definitions of severe disabilities and how these definitions and societal perceptions affect the lives of these individuals and their families. These authors offer us a historic retrospective of where we've been, how far we've come, and where we need to be heading. Finally, Giangreco and his colleagues help us to understand what is meant by appropriate education for students with severe disabilities.

Students grow up as members of families, and families are most often the primary advocates for their children throughout life. In Chapter 2, Nina Zuna and Kathleen Kyzar explore the factors that make successful partnerships between home and school. Two such factors are ongoing, reciprocal communication between home and school and interactions that reflect and respect families from diverse cultural backgrounds.

Chapters 3, 4, 5, and 6 are core chapters that set forth the basic strategies and tools that educators use in concert with other team members to plan, teach, and monitor the progress of their students. Chapter 3, (by Jenny Root, Leah Wood, Diane Browder), Chapter 4 (by Deborah Gruber-Wilkinson and Fredda Brown), Chapter 5 (written by the editors with Jessica Bowman and Lyndsey Conradi), and Chapter 6 (written by the editors with Olivia Coleman and Carrie Eichelberger) provide important foundations for the remaining chapters in the book. Four key words sum up the content of this section: assessment, teaching, evaluation, and implementation.

In Chapter 7, a new chapter by Diane Lea Ryndak, Ann-Marie Orlando, and Kristin Krupa Burnette describes effective inclusive education programs. This chapter offers a definition of inclusive education and tracks the evolution of these programs over the last two decades. This chapter identifies evidence-based practices for successfully implementing inclusive education at the school, classroom, and individual student levels.

Chapter 8, by Matthew Jameson, Robert O'Neill, Joanna Ryan, and Jennifer Fletcher, sets forth the principles of positive behavior support. Using comprehensive case examples, these authors describe how the process of functional behavioral assessment is conducted and used to design effective behavioral support plans that are based on the values of self-determination, respect, and inclusion.

In Chapter 9, Donna Lehr and Nancy Harayama describe health care procedures required by some students during the school day. This chapter explains how to incorporate special health care procedures into the school day and how educators can contribute to the prevention of related health problems and conditions.

In Chapter 10, Mary Jane Rapport, Amy Barr, and Maria Jones teach us about the impact of motor disabilities on school participation and learning, and how to successfully address these challenges. Because all team members interact with a student over a range of daily activities, practical knowledge about motor disabilities must be shared. When students with motor disabilities have consistent and conscientious management of their physical needs in their home, school, work, and community environments, they can thrive.

The skills of caring for oneself, toileting, eating, dressing, and grooming are important goals for all individuals regardless of the severity of the disability. In Chapter 11, Monica Delano, Virginia Walker, and Martha Snell provide a comprehensive and current review of effective methods for teaching self-care skills while also showing how these methods apply to specific students.

One of the most important elements that schools can offer students is social relationships with peers. In Chapter 12, Matthew Brock, Erik Carter, and Elizabeth Biggs illustrate strategies that teams can use to promote membership and a sense of belonging and to build a variety of personal relationships among students in classrooms and schools.

In Chapter 13, Susan Johnston and Cheri Blue address functional communication and the importance of socially responsive environments. These authors highlight the pervasive influence of communication in all aspects of life, including education, friendships, well-being, and self-determination.

Basic skills in reading, writing, mathematics, and science are increasingly important as states respond to federal laws and policies. In Chapter 14, Susan Copeland and John McDonnell present methods for identifying what academic skills to teach and evidence-based strategies for teaching those skills in inclusive settings.

Chapter 15 guides teachers on the instruction of skills to increase active participation in home and community life. Linda Bambara, Raquel Burns, Amanda Thomas, and Dolly Singley begin with a series of guiding values and principles that characterize the outcomes of skill instruction referenced to students' homes and communities. These themes are coupled with instructional methods that have been found to be effective with students who have severe disabilities.

Our special education laws require a clear focus on and preparation for the transition to adulthood. Preparing students for real work in the community is a longitudinal process requiring extensive team effort over the teenage years. In the closing chapter of this book, Chapter 16, Valerie Mazzotti and David Test set forth the essential elements of secondary vocational programs that will allow students and their teams to plan the transition from school to adulthood and then to make the transition.

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Many people have assisted in the task of developing this ninth edition. First, we are indebted to the children, adolescents, young adults, and mature adults, who add reality to each chapter and whose abilities and disabilities have challenged and shaped our own skills and those of our contributors. Their families and their educators deserve equal gratitude for providing a vast array of teaching ideas, for granting permission to use their photographs, and for giving us extensive examples and information.

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Fredda Brown, John McDonnell, and Martha E. Snell

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Introduction

From a Mom: Read First!

Niki Mirabella

Meet Gina Mirabella and her family!

February 2018

Mia, Dad, Ralphie, Gina, Toni, Rocky, and Mom, May 2017

Gina and her cousins on family vacation July 2016

In the next few pages you will read a true story about a young lady, Gina Mirabella, who has a diagnosis of Smith-Lemli-Optiz syndrome. This story is narrated by me, her mother. After reading Gina's story, I hope that when you engage with a person who has a severe intellectual disability you will look and talk to him or her just the same as you would anyone else. It is my intention to help you find the strengths in people rather than their weaknesses, to help you find the courage to advocate for people rather than accept preconceived ideas about outcomes, and most importantly, to help you understand that the person is a real person, with feelings, desires, and a whole lot of love.

THE EARLY YEARS

It was at 9:30 a.m. on January 3, 2000, that my life changed in a way I could never have imagined possible. I was 26 years old, and my husband was 36 years old. We had been married for 2 years and had been building a life fairly free from any major concerns or stress. We arrived at the

OBGYN's office for a pregnancy stress test, as Gina was 3 days past her due date. It was then that we learned Gina was breech. A baby is considered breech when she is positioned upside down with her head not facing correctly in order to travel through the birth canal safely.

As we arrived at the hospital, the doctor came to me and explained that Gina would need to be delivered via cesarean section (C-section) and that I "would be making my first maternal sacrifice." My world began spinning. What did all this mean? What did the doctor mean by "sacrifice"? My experience so far with the pregnancy had been perfect. We went to Lamaze classes, we planned financially, we had a plan as to child care for when I returned to work, and we attended to all the big and small details. So, why was this happening? I did not understand why something I was so excited about, prepared well for, and had been waiting 9 months for, was slowly turning into an experience I was feeling unprepared for.

The room became still and quiet on January 3, 2000, at 2:57 p.m. as the doctor delivered Gina. She was not breathing and needed to be rushed to the neonatal intensive care unit (NICU). The nurse began to run out of the room with Gina, not even waiting for the incubator to arrive. She suddenly stopped, backed up, and put Gina in my arms, saying, "Mom needs to hold her first." I held Gina for about 3 seconds and in that short time, holding her tiny head in my hand, my heart immediately filled with love. Looking back on it now, I understand that it was not just love, but strength that filled my heart. And the world continued spinning.

Gina was admitted into the NICU, and a neonatologist came into the delivery room within 10 minutes. He stood by the door and explained, "You have a very sick child; she has low-set ears, upturned nostrils, droopy eyes, and microcephaly." I remember thinking her head was small, but she was a tiny infant. What did this mean? I remembered when I went for my 26-week sonogram the doctor could not measure her head circumference. I remember hearing side chatter among the doctor and the nurse and then being told, "It is okay, we finally got a measurement of 10 inches—that is within normal limits." Now, remembering this and being told Gina had microcephaly, what was happening? He then said, "I have to go work on your baby now" and left the room. More spinning, spinning, spinning. Why did he need to "work" on Gina? What was wrong with her? What did all those words really mean? Was she okay? Was she in pain? Did she need me? Was I allowed to see her? Did she belong to the hospital or to me? I was not sure. Where was she, what was happening to her? My body felt heavy, and numb. I could not move my legs (due to the epidural) but I wanted to jump out of the bed and "save" her, only I was too afraid to speak. I remember the anesthesiologist tapping my shoulder telling me, "It is going to be okay," and my doctor saying, "I have to put you back together and then I will go see what is *wrong* with your baby." Did I even have a baby, or was this a dream? *What* was going to be okay? What was *happening*? Spinning, spinning, spinning.

Gina remained in the NICU for 35 days. She was on a respirator for 2 days, had a feeding tube (orogastric [OG] tube) placed through her mouth to her stomach, received blood transfusions, and was considered as failing to thrive as her body continued to reject all formulas. Gina was tested for multiple syndromes (trisomy 13, 18, 23, Down syndrome, etc.). But it wasn't until the geneticist noticed Gina's syndactyl toes (toes that are fused together) on both feet that he then tested her for Smith-Lemli-Opitz syndrome (SLOS). We were told **NOT** to research the syndrome, that the syndrome was extremely rare. But of course I immediately got my hands on a medical journal and looked up the syndrome. I then understood why he told us not to research the syndrome. It was devastating! I remember feeling that there is no way my little baby has this syndrome. How could it be? I went back to my pregnancy—it was great, we were prepared, we were "normal" people. What was I going to do if the test came back positive for SLOS? Spinning, spinning, spinning.

Three weeks later the test came back positive, and Gina was diagnosed with SLOS. This is a rare genetic, autosomal recessive gene disorder. A person with SLOS lacks an enzyme to convert 7-DHD cholesterol to cholesterol. High levels of 7DHD cholesterol are toxic to the body, while low levels of cholesterol effects the body's ability to produce cell membranes, which are needed to make brain cells in utero and after birth. SLOS is a spectrum disorder in which all, or various parts, of the body and areas of development are affected. A person's initial cholesterol level (at birth) is an indicator of the severity of which the syndrome will affect a person's development. The cholesterol level of a healthy infant is in the 120s. When Gina was 12 weeks old, we learned that her cholesterol level was 12. This meant Gina was severely affected by the syndrome. At that point, Gina was one of five babies at Boston Children's Hospital diagnosed with this extremely low level of cholesterol. Gina was the one out of those five who survived past the age of 9 months.

The doctors explained that the syndrome was a spectrum disorder, but that they were not sure where Gina fell within the spectrum—from mild to severe. My world came crumbling down for about 3 minutes, and then, my response was, "Just tell me what I need to do." The words just came flying out of my mouth. I did not even think about it. My love for Gina was stronger than ever at that moment.

The doctor went on to explain that if Gina was on the mild end of the spectrum, she could have a "normal life with maybe a learning disability. She could probably learn to ride a tricycle and zipper her coat." What in the world was the doctor talking about—how was this even a real conversation? She was 3 weeks old and lying in an incubator hooked up to machines, and being fed by a tube. Why were we talking about her riding a tricycle? I did not understand that he was trying to prepare me for the limitations Gina would have. At that point, I felt that she was just sick and was going to get better; that she was going to develop like my nieces and nephews and all the other children I knew.

It was suggested we consider looking for an institution to place Gina in once she was discharged. It was explained that life would be too difficult for Gina, and it would be "too difficult to care for Gina at home." The hospital's social worker explained that we were "young and needed to continue on with our life. In this type of situation, you hope for the worst." Her passing? These words did not scare me; on the contrary, they helped me to develop a strength I could never have dreamed of, and an overwhelming feeling of love, dedication, and a responsibility to fight for this little baby—my baby! The "strength" I said I felt the second I held Gina and looked into her eyes, had returned. There was only one place Gina was going, and that was home with us—her parents! She was ours, and we would care for her always.

The doctors and social workers emphasized, "Gina has microcephaly. Do you know what that means? She is going to be *mentally retarded."* My world had a different type of spin this time. I felt empowered, motivated, and ready to take Gina home. Those 35 days in the NICU taught me to stand tall, speak up, ask questions, and not to blindly and passively accept statistics or any type of information that was presented to me. I learned that Gina was not a statistic, she was not a burden, she was not someone to pity. She was just a baby, she was our daughter, and she deserved a chance at life—just like everyone else. I also understand now that because the syndrome is so rare, the doctors also lacked confidence in predicting outcomes for Gina's life.

Looking back, I am grateful today that I was so innocent then. What I understand now, that I did not then, is that the "professionals" looked at Gina as "a person with limited brain function that would be a burden to her parents and society." They could not find any positives in Gina's life. They could not see past her limitations. We could and we did.

Gina and friends enjoying winter fun at the bowling alley. Winter 2018

Getting ready for the holidays with her sisters Mia and Toni December 2017

GINA COMES HOME

It was 2000, and my sister had been using the then emerging and popular tool for information, the "World Wide Web" and Internet. In spite of the warnings to stay away, she accessed it to research Gina's syndrome. She learned that there was a group of doctors at Boston's Children's Hospital studying the syndrome; 2 weeks after Gina was discharged (she was now 6 weeks old) my husband and I traveled to Boston to meet with a group of doctors studying this rare syndrome. When we arrived Gina had a fever and the doctors said that they could not accept her if she was sick. I begged, pleaded, cried, and asked them to reconsider accepting her.

We stayed in hotel for a few days, went back when she was fever free and she was accepted into their study as the "weakest, least likely to survive baby with Smith-Lemli-Opitz syndrome." Remember, her cholesterol level was 12 when a typically developing baby's cholesterol is in the 120s. We were told she was the most "severe baby" they had ever seen. I felt relieved, thankful, and happy (if you could imagine) because it meant Gina was going to be given a chance—finally. My husband and I were going to be given a chance to be her parents. It was the most hope we were given since she was born.

Back at home, and 6 months into the study, Gina's cholesterol level dropped even more, down to 9, and doctors were not very hopeful. Gina was sick and in/out of the local emergency room. She was admitted often due to high fevers. She had problems with her heart, kidneys, and gastrointestinal (GI) system. Gina needed surgery at 3 months old to place a permanent feeding tube in her stomach, heart surgery at a year old to plug an opened patent ductus arteriosus, and multiple x-rays, CT scans, MRIs, swallow studies, and upper GI series throughout her first 2 years of life. Life became *scheduled, as we began living by appointments*. First thing in the morning was speech therapy, followed by physical therapy, occupational therapy, and special education. It was then into the car to get to aquatic therapy, and acupuncture. There is nothing we would not try. To add some normalcy to my life, we went to a mommy and me playgroup once a week; everyone stared at us—all but one mom, Kim, with her son Sal. Kim asked about Gina's differences, she asked because she cared. She felt compassion toward our situation. She was aware that life as a new mom was very different for her than it was for me. She recognized how fortunate she was and was grateful for that. She wasn't like the other new moms, complaining about sleepless nights, complaining that their children kept waking to eat, that their baby wanted to be held all the time (all the things I wished I had). Kim made us feel welcomed. I knew then that life was going to be different than what I had planned. I tried to keep a balance between "special" and "typical," but it was getting more difficult as the months went by.

We remained hopeful, and I continued to learn everything I could by talking to other families all over the world via email and parent-directed Internet support groups. I read all I could find about SLOS research.

Gina was nearing the end of early intervention, and she would be going to a special preschool program in Queens, New York, not far from our home. I was no longer going to be with her every second of every day. I needed to educate myself on the next step—the Committee on Preschool Education. I tried to always be a step ahead of Gina's progress to be able to advocate to the fullest of my ability for her. It was then that holding a BA in education and a MS in Early Childhood was not enough to take on this challenge. I decided (with the help of family, friends, and Gina's therapists) to go back to Queens College and study Special Education. I needed to understand special education law, to know her educational rights, and furthermore, what school life was going to be like for Gina. How does a person who is nonambulatory, nonverbal, and fed by tube get by in a classroom? Who will help her? How will I learn about her day? Will she be safe? How will I really know? Can the school system really help her? Would her teachers see her as a beautiful little girl? Would her teachers know when she was uncomfortable, or when she wanted attention? Would they know what made her happy? Would they know what is important for her to learn? Would they know how to teach her?

GINA'S TIME AT SCHOOL

In reflecting on Gina's school career I would like to share with you some significant experiences in Gina's life that have helped to shape how people define Gina. I needed for people to see that Gina is not just a child with SLOS. She is an individual with purpose and meaning, an individual with feelings and desires, *and* an individual with SLOS—which requires accommodations and modifications.

Preschool

When it was time for Gina to end home services at the age of 3, and begin preschool, we had decided on a special preschool—a BOCES program. (BOCES, the Boards of Cooperative Educational Services, is a New York State program that provides educational programs and services to individuals with disabilities as a partnership with the home school.) As I toured the school, asking to see all the preschool classrooms, I was devastated. I could not place Gina in such an environment that lacked stimulation, participation, and rich language opportunities! As the tour came to an end, I stumbled upon an interaction between a teacher and student. The teacher had stopped in the hallway to assist her student with a reading device (a device attached to a storybook that provided auditory output). I was very impressed with the teacher's loving way while helping this youngster (who was nonverbal, and hearing and vision impaired). I immediately asked her name, and what grade she taught. I was surprised to learn that she, in fact, taught preschool (why hadn't we visited her classroom?). The social worker who was giving me the tour said, "Gina is not appropriate for that class." How could she possibly know this—she never met Gina; obviously she was making this statement based on the packet that she received of Gina's educational evaluations. Upon my request, we visited Ms. Kathy's classroom. Two months later, and after much needed advocacy, Gina was placed in Ms. Kathy's class for the next 3 years and flourished! By the end of the 3 years, the assistant principal said, "Well Mrs. Mirabella, we took a chance and made a stretch by putting Gina in a 'high functioning class,' but Gina did very well in spite of it all, and made great progress in Ms. Kathy's class." I had hoped to change the mindset of the administration at the school, but unfortunately did not. Likely the next family will have to go through the same efforts and persistence, but only if they had the vision of reaching and stretching!

K–12 Years

As Gina continued at this school for the next 10 years, little was done to promote socialization, peer interaction, and communication through assistive technology. We continued to listen to reports on "what Gina was not doing," and how "she was not meeting goals" (which were unrealistic most times), and no information was given on how to modify and change programs to help Gina reach goals—goals that were functional and meaningful to her.

Through endless meetings, my suggestions to the school, and rich video documentation of Gina interacting with peers outside of school and at home with her family, no real change occurred. At the age of 13 we found a program outside of our county that focused on socialization, peer interaction, and communication. It was then that we requested the school district consider new placement for Gina. Through many meetings, advocacy by our family and the school district, the school board agreed to the change. Starting over was not easy, but the new school was open to our suggestions, input, and saw positives rather than negatives in Gina's abilities.

In Gina's new placement she began not only to participate in school programs, but she also helped to develop new school programs. The antibullying Peer Buddy program was designed with Gina's needs in mind. When Gina was 15, I talked with the school about the need to have Gina socialize more with peers who were verbal and social. As Gina's mom I understood that Gina had a desire to socialize, although it was not as obvious to all the people working with her. I asked if they could have her experience different classes during the day and target socialization skills, such as eye contact and initiating peer interaction with the other children. Just like in her other school, this school reluctantly agreed. To their surprise, although not my surprise, the feedback was so remarkable that the school decided to pilot a program under the antibullying club, the Peer Buddy program. The program has been running ever since, and the data show positive outcomes in socialization and peer interactions. This is one of many programs that Gina both directly and indirectly has helped to develop. All would agree that Gina is an important part of the school community.

Gina as a Young Adult

Gina turned 18 this year. I think about the "what ifs." If she wasn't born with SLOS, what college would she be going to? Would she be going away to college or staying at home? Instead, I am preparing for what life will be like for Gina once she graduates from school at the age of 21, in 2021. We have different questions concerning Gina—different than what we thought we would be asking 18 years ago. What program(s) will Gina will be part of as an adult with a disability? Are there post–high school opportunities for Gina? What are they? How will I advocate for these? Will those educators be willing to take a chance and stretch their imaginations? How can I learn about adult benefits and services, navigating the Medicaid system, and continuing to support Gina's medical and social needs? Through it all though, I continue to be shaped by that smile she gives me each morning—that smile that got me through the beginning of our journey—that smile that said a million words. "Go tell the world about me, mom!"

From 2000 until now, I have spent my life loving Gina, and advocating for her—to help her meaningfully participate in all that life has to offer—to all that life offers to other children. My husband and I now have four children—Gina has two loving sisters who are 13 and 8 years old, and a brother (from Alfred's first marriage) who is 27 years old. Between my children, my husband, my mother, my in-laws, our siblings, our nieces and nephews, our friends, and neighbors, Gina has a rich family life. She is not a burden to her family, or society; she never has been, and never will be! She is an active participant in her community and her participation is unique. She attends a public school in Suffolk County, New York, where she is a member of her class, the choir, Girl Scouts, the GEM club (a girls only club), and the antibullying Peer Buddy program. Gina has a one-to-one assistant on the school bus, in the classroom, and at home. She attends a variety of community-based programs—some are designed for all children in the community, and some are focused on children with disabilities. She is well known in our neighborhood, and she is greeted by our neighbors as she rides her "tricycle" and uses her gait trainer up and down the streets of our neighborhood.

Gina has also brought couples together! It was through Gina that Danielle and John, and then Lisa and Dave met and were married in 2017. Danielle was one of Gina's personal assistants at our home for several years; she met Gina's cousin at family gatherings and a connection was made! And then there was Lisa who attended camp with Gina one summer as her assistant, and Dave (Gina's former counselor). Yet another connection! Gina has also helped many in higher education decide what career to pursue. Through working with Gina, several first-year college students decided to pursue nursing or education careers, and are very successful in their careers today. They will often say, "It is because of Gina." Actually, this is a phrase we have gotten used to hearing. Whether it is because of a marriage, career, or the successful job interview—"It is because of Gina." Gina has clearly made a difference in so many people's lives. She is admired by many, and the most significant part of it all, the most purest part, is that she has no idea how much of an impact her life has on the world. I am so proud to call her my daughter and I am so grateful for the wonderful people I have met through this journey. I share my story to help educate people to never give up no matter how trying something may be. Believe with your heart that YOU can make a difference!

Gina as a bridesmaid at John and Danielle's wedding May 2017

I know this book is filled with so much information—from the philosophical foundations of educating students with severe disabilities, to trends and issues in the field, through the most recent research and evidence-based strategies. There is a lot here—I know, as I too used this book when I was in my MS in Special Education program. There is a lot to learn, but please keep Gina and her mom, and her family, and all those who love her, in your thoughts as you journey through this book.

Hippo-therapy 2014

Underwater at aquatic-therapy April 2015

Danielle and Gina jumping on the family trampoline

Gina and her sisters at the beach

Gina cruising the neighborhood on her adaptive tricycle

Gina enjoying the swing in her community Playground for All Children

Gina and mom riding the roller coaster at the amusement park

Photos: Niki Mirabella

1

Educating Students with Severe Disabilities

Foundational Concepts and Practices

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> *"Learn from yesterday, live for today, hope for tomorrow.*
> *The important thing is not to stop questioning."*
>
> —ALBERT EINSTEIN

1.01 **Who are Students with Severe Disabilities?**

Learning Outcome

Identify definitions of severe disabilities, the role of the supports model in understanding students with severe disabilities, and the influence of societal perceptions and social interactions.

1.02 **Reasons for Optimism and Concern**

Learning Outcome

Identify areas where progress has been made in providing individualized supports for people with severe disabilities in inclusive communities, and areas where work is still needed.

1.03 **Access to Quality Education**

Learning Outcome

Discuss the foundational principles of providing supports to students with severe disabilities that promote access to (a) inclusive environments, (b) individualized curriculum, (c) purposeful instruction, and (d) necessary supports.

Providing quality education for students with severe disabilities requires that we learn from our past practices, both the mistakes and the successes, by drawing on the historical bank of foundational concepts and practices available to us. Our contemporary challenge is to apply what we have learned within today's context and to do so with a sense of urgency, because as we ponder, debate, and research the merits of our practices, the children who enter our schools are quickly growing up—they and their families do not have the luxury of waiting. Providing students with severe disabilities quality education requires that we adopt conceptually sound, evidence-based practices in our schools and confront assumptions about ability that continually threaten current and future opportunities.

People identified as having severe disabilities are the epitome of why the challenge in Einstein's quote at the start of this chapter, "not to stop questioning," is so important. Only 45 years ago, students with severe disabilities had no legal right to attend public schools and many did not—expectations for their educational progress were minimal. Today because of people with disabilities, their family members, and professionals who never stopped questioning, people with severe disabilities are doing things that many would have thought to be unimaginable just a few short decades ago: They are (a) attending general education classes with their peers who do not have disabilities, (b) learning general education curricular content, (c) participating in general education co-curricular activities, (d) engaging in supported employment, (e) transitioning to community-based supported living options, and (f) accessing inclusive postsecondary educational opportunities. Since only some students with severe disabilities have access to these opportunities, we must continually reflect upon and question our practices to pursue better outcomes for more students.

WHO ARE STUDENTS WITH SEVERE DISABILITIES?

Definitions

Although the term *severe disabilities* is used extensively in the professional literature, no single authoritative definition exists. Amendments to the Individuals with Disabilities Education Act (IDEA) (2004), a common source of special education terminology, do not define the term specifically. However, IDEA and its corresponding Code of Federal Regulations (CFR) (2006) define 13 distinct disability classifications (34 CFR 300.8), several of which reasonably include a subset of students considered to have severe disabilities (e.g., autism spectrum disorders, deaf-blindness, intellectual disability, multiple disabilities, traumatic brain injury) and which sometimes occur in combination. IDEA's definitions of these disability classifications are provided in Table 1–1. Students with severe disabilities are often described as having *low-incidence* disabilities. This term refers to the fact that severe disabilities occur infrequently relative to other types of disabilities. IDEA (2004) section 662(c)(3) defines a low-incidence disability as (a) a visual or hearing impairment, or simultaneous visual and hearing impairments; (b) a significant cognitive impairment; or (c) any impairment for which a small number of personnel with highly specialized skills and knowledge are needed in order for children with that impairment to receive early intervention services or a free appropriate public education.

Watch the video "Classification and Intellectual Disability" at www.youtube.com/watch?v=80rc4ZAtQ0I.

Students with severe disabilities may also be described as having *extensive support needs* or *high intensity needs*. The Office of Special Education Programs (OSEP) (2017) in the U.S. Department of Education coined the term *high intensity needs* to shift the focus of the definition of low-incidence disabilities from disability labels to the level and intensity of supports required. OSEP describes students with high intensity needs as "children with low incidence disabilities, including those with persistent and severe learning or behavioral problems that need the most intensive individualized supports" (OSEP, 2017) for students with severe disabilities.

The first two principles of IDEA (Box 1–1)—*zero reject* and *free appropriate public education*—establish in law the notion that *all* students are capable of learning and entitled to appropriate education. IDEA used the zero-reject principle to establish that *all* school-aged children, regardless of the severity of their disability, are entitled to a free appropriate public education (Turnbull, Stowe, & Huerta, 2007). This principle was tested in the case of *Timothy W. v. Rochester School District* (1989) when a student with severe, multiple disabilities was denied admission to his local public school because school officials deemed him unable to benefit from education due to the severity of his disability. Although the trial court sided with Rochester School District, the U.S. Court

TABLE 1–1
Definitions of Disability Classifications in IDEA that May Include Students with Severe Disabilities

Disability Classification in IDEA	IDEA Definition of Disability Classifications (34 CFR 300.8)
Autism Spectrum Disorders	Autism means a developmental disability significantly affecting verbal and nonverbal communication and social interaction, generally evident before age 3, that adversely affects a child's educational performance. Other characteristics often associated with autism are engagement in repetitive activities and stereotyped movements, resistance to environmental change or change in daily routines, and unusual responses to sensory experiences.
Deaf-Blindness	Deaf-blindness means concomitant hearing and visual impairments, the combination of which causes such severe communication and other developmental and educational needs that they cannot be accommodated in special education programs solely for children with deafness or children with blindness.
Intellectual Disability	Intellectual disability means significantly subaverage general intellectual functioning, existing concurrently with deficits in adaptive behavior and manifested during the developmental period, that adversely affects a child's educational performance.
Multiple Disability	Multiple disability means concomitant impairments (such as intellectual disability–blindness or intellectual disability–orthopedic impairment), the combination of which causes such severe educational needs that they cannot be accommodated in special education programs solely for one of the impairments. Multiple disability does not include deaf-blindness.
Traumatic Brain Injury	Traumatic brain injury means an acquired injury to the brain caused by an external physical force, resulting in total or partial functional disability or psychosocial impairment, or both, that adversely affects a child's educational performance. Traumatic brain injury applies to open or closed head injuries resulting in impairments in one or more areas, such as cognition, language, memory, attention, reasoning, abstract thinking, judgment, problem solving, sensory/perceptual/motor abilities, psychosocial behavior, physical functions, information processing, and speech. Traumatic brain injury does not apply to brain injuries that are congenital or degenerative, or to brain injuries induced by birth trauma.

of Appeals for the First Circuit overturned this ruling, and strongly reaffirmed the zero-reject principle as a core component of IDEA, stating that

> *. . . educational methodologies in these areas are not static, but are constantly evolving and improving. It is the school district's responsibility to avail itself of these new approaches in providing an educational program geared toward each child's individual needs. The only question for the school district to determine, in conjunction with the child's parents, is what constitutes an appropriate individualized education program (IEP).* (p. 973)

Box 1–1

Principles of IDEA

1. Zero reject
2. Free appropriate public education
3. Nondiscriminatory identification and evaluation
4. Least restrictive environment
5. Due process safeguards
6. Parent and student participation.

A more recent Supreme Court case, *Endrew F. v. Douglas County School District* (2017), further affirmed the right of students with severe disabilities to a free appropriate public education that enables children with severe disabilities to achieve "appropriately ambitious" goals. In this case, Douglas County School District argued that Endrew, a young man with autism, had a right to only *de minimis* (minimal) benefit from his IEP. The Supreme Court rejected this argument, stating:

> *The IDEA demands more. It requires an educational program reasonably calculated to enable a child to make progress appropriate in light of the child's circumstances . . . . his educational program must be appropriately ambitious in light of his circumstances, just as advancement from grade to grade is appropriately ambitious for most children in the regular classroom. The goals may differ, but every child should have the chance to meet challenging objectives.*

These decisions, and all reauthorizations of IDEA, leave little doubt that the intent of the law is to ensure *all* students receive a free appropriate public education that focuses on setting and achieving challenging and ambitious goals and objectives, and promotes learning and postschool outcomes valued by students and their families. To achieve these goals set by IDEA, schools must continuously question their assumptions about supports for learning and participation, and ensure that teachers have access to state-of-the-art practices for meeting *all* students' individualized needs and learning goals.

Building on the first two principles, IDEA established other principles to guide the provision of a free appropriate public education. These remaining principles are listed in Box 1–1 and are further described in later sections of this chapter and text, but focus on ensuring that (a) there is a clear, equitable, and nonbiased process for identifying and evaluating students as in need of special education services and supports, (b) parents and students are a part of this process and are partners in the identification of learning needs and individualized goals through the IEP, and (c) there are due process safeguards, meaning that the rights of students with disabilities must be protected and that parents have the right to question the identification, evaluation, educational placement, or goals identified for a student with a disability if they have concerns. Additionally, and importantly for students with severe disabilities, IDEA established the right to education in the least restrictive environment (LRE).

The *least restrictive environment* principle establishes that students with disabilities have the right to be educated with their peers without disabilities. The federal government has expressed a strong preference for placement in general education classes for students with disabilities, including those with severe disabilities (Rebhorn & Smith, 2008). As the U.S. Department of Education wrote in the regulation's "Analysis of Comments and Changes," the IDEA

> *. . . presumes that the first placement option considered for each child with a disability is the regular classroom in the school that the child would attend if not disabled, with appropriate supplementary aids and services to facilitate such placement. Thus, before a child with a disability can be placed outside of the regular educational environment, the full range of supplementary aids and services that could be provided to facilitate the child's placement in the regular classroom setting must be considered.* (CFR, 2006, p. 46588)

The Code of Federal Regulations corresponding to IDEA goes on to state:

> *In all cases, placement decisions must be individually determined on the basis of each child's abilities and needs and each child's IEP, and not solely on factors such as category of disability, severity of disability, availability of special education and related services, configuration of the service delivery system, availability of space, or administrative convenience.* (CFR, 2006, p. 46588)

Further evidence of federal support for educating students with severe disabilities in the LRE is found in a jointly submitted *amicus curiae* (friend of the court) brief that the U.S. Department of Justice (Office of Civil Rights) and the U.S. Department of Education wrote in support of a student with severe disabilities (named Spike who attended Valley Grove School District) to be educated in the general education classroom with supplemental supports and aids.

> *. . . The IDEA does not require that Spike be able to perform at or near the grade level of non-disabled students before placement in the regular class can be considered the LRE for him. Congress expressed a strong preference in favor of educating children with disabilities in an inclusive manner and an integrated environment and requires States accepting IDEA funds to educate children with disabilities in the least restrictive environment (i.e., with their non-disabled peers in the regular classroom) to the maximum extent appropriate. States and school districts are not asked to determine whether LRE is an appropriate policy but rather to determine how a child can be educated in the LRE. Thus, school districts must determine how a child can be educated in the regular class with the use of supplementary aids and services. Valley Grove did not even attempt to make the necessary determination of how Spike could be educated in the LRE. Indeed, Valley Grove argues instead that, directly contrary to IDEA regulations, Spike must be removed from his age-appropriate regular classroom solely because his educational level is below that of the class.* (U.S. Department of Justice, 2002, pp. 13–14)

Together, these six principles establish a strong foundation for the right of students with severe disabilities to a quality education, in inclusive environments that are appropriately designed to meet the learning needs of the child, enabling the achievement of appropriately ambitious goals.

Societal Perceptions and Expectations

TASH (n.d.), an international advocacy and professional organization focused on promoting the full inclusion and participation of people with severe disabilities, states that people with severe disabilities are

> *. . . most at risk for being excluded from society; perceived by traditional services systems as most challenging; most likely to have their rights abridged; most likely to be at risk for living, working, playing, and learning in segregated environments; [and] least likely to have the tools necessary to advocate on their behalf.*

Because people with severe disabilities require ongoing supports to mitigate the abovementioned risks, the ways in which they are perceived and subsequently treated by others can have a major impact on their quality of life. When coupled with the historical emphasis on deficits in functioning experienced by people with disabilities, social perceptions and expectations have tended to be low. This can lead to *disability spread*, defined as the tendency to make broad inferences, assumptions, and generalizations about a person on the basis of disability stereotypes within the society (Dembo, Leviton, & Wright, 1975; Liesener & Mills, 1999). Some common stereotypes portray persons with disabilities as sick, subhuman, a menace, an object of pity, an object of charity, or a holy innocent (Smith & Wehmeyer, 2012; Wolfensberger, 1975).

Opportunities for Interaction and Reciprocal Benefit

As noted by TASH, stereotypes and disability spread have a significant negative impact on the quality of life of people with severe disabilities. However, it is not just people with severe disabilities who are negatively impacted. 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 as it limits relationships between people with and without disabilities (Bogdan & Taylor, 1989).

As you continue to read this chapter and the rest of this book about people who have the label *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 we *all* are human beings—someone's child, someone's sibling, someone's classmate, someone's neighbor, or someone's friend. It is true that some people are born with or acquire disability characteristics that require lifelong systems of supports. Remember, though, that we all need supports, we just differ in the type and intensity of those support needs at different times. Our collective attitudes and responses to differences in support needs can influence how much of a barrier those support needs are (or are not) to living a full, engaged, and self-determined life.

REASONS FOR OPTIMISM AND CONCERN

From an historical perspective, our current times are among the best for people with severe disabilities, at least thus far. We write this with the full recognition that our current *best* is relative and is quite a long way from *good* for far too many people labeled as having severe disabilities. This section highlights a set of key reasons for optimism about the education of students with disabilities followed by a set of continuing concerns.

Reasons for Optimism

Table 1–2 lists five areas for optimism about our 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 these important challenges.

Karrie Shogren discusses self-determination at www.youtube.com/watchv=ZdArcPCH8FQ&src_vid=SOdHpLvpVH&feature=iv&annotation_id=annotation_2241971059.

First, nowhere is progress more evident or reason for optimism more warranted than with regard to *inclusive educational opportunities* (see Table 1–3 for key elements of inclusive education). Across the country, students with severe disabilities are increasingly accessing general education classrooms and other inclusive settings with their same-age peers without disabilities (Giangreco, 2017; Kurth, Morningstar, & Kozleski, 2014; Morningstar, Kurth, & Johnson, 2017); such options were rare or nonexistent just two or three decades ago. Inclusive schools promote equity, opportunity, and social justice for all their students (McCart, Sailor, Bezdek, & Satter, 2014; Shogren, McCart, Lyon, & Sailor, 2015). These outcomes are relevant for any student across a range of diverse characteristics (e.g., race/ethnicity, culture, primary language, socioeconomic level), as well as any student who simply is having difficulty becoming part of a classroom's learning community. The tenets of inclusive schooling are increasingly being linked with broader *school reform and restructuring* efforts designed to improve educational opportunities for *all* students. The Schoolwide Applications Model (SAM) (Sailor & Roger, 2005), Whole Schooling (Peterson, 2004; Peterson & Hittie, 2010), Schools of Promise (Causton-Theoharis, Theoharis, Bull, Cosier, & Dempf-Aldrich, 2011), and Schoolwide Integrated Framework for Transformation (SWIFT, **www.swiftschools.org/**; McCart et al., 2014) offer examples of successful efforts to bridge general and special education, and transform schools into inclusive communities that meet the needs of the diverse array of students in our schools (Giangreco & Suter, 2015).

TABLE 1–2
Areas for Optimism

1. Inclusive education and schoolwide reform
2. Access to the general education curriculum
3. Positive behavior interventions and supports
4. Peer supports
5. Self-determination and transition to adult life

TABLE 1–3
Elements of Inclusive Education

Inclusive education exists when each of the following six characteristics occurs on an ongoing, daily basis.

1. *All* students are welcomed in general education. The first placement options considered are the general education classes in the school that the students would attend if they did not have a disability.
2. Disability is recognized as a form of human diversity. Hence, students with disabilities are accepted as individuals and are not denied access because of their disabilities.
3. Appropriate supports are available, regardless of disability label or the level and/or type of supports needed. Given their portability, supports are provided in typical environments instead of sending students to specialized settings to receive supports.
4. The composition of the classrooms in which students are educated reflects the naturally occurring proportion of students with and without disabilities or other identified needs (referred to as *natural proportions*). Therefore, the percentage of students without disabilities in each class is substantially higher than the percentage of students with disabilities or other special needs.
5. Students, irrespective of their performance levels and/or support needs, are educated with peers in the same age groupings available to those without disability labels instead of with younger students. Students with disabilities need not function at or near the same academic level as their classmates (although some do) to benefit from a chronologically age-appropriate, inclusive placement.
6. Students with and without disabilities participate in shared educational experiences while pursuing individually appropriate learning outcomes with the necessary supports. Educational experiences are designed to enhance valued life outcomes that seek an individualized balance between both the academic-functional and the social-personal aspects of schooling.

(From *Choosing Outcomes and Accommodations for Children (COACH): A Guide to Educational Planning for Students with Disabilities, Third Edition* (2011) by M. F. Giangreco, C. J. Cloninger, & V. S. Iverson. Baltimore, Paul H. Brookes Publishing Co, Inc. Adapted with permission.)

Second, curricular options for students with severe disabilities have extended beyond functional life skills to include greater alignment and *access to the general education curriculum*. Promising approaches have emerged that demonstrate positive learning outcomes for students with severe disabilities in literacy, math, and science (Spooner, Knight, Browder, & Smith, 2012; Spooner, Root, Saunders, Browder, in press). In inclusive settings, the principle of universal design for learning (i.e., designing the curriculum with the needs of *all* learners in mind right from the start) has enabled teachers to create learning environments that accommodate the range of learners in their classrooms (Coyne, Pisha, Dalton, Zeph, & Smith, 2012; Lowrey, Hollingshead, Howery, & Bishop, 2017; Root, Knight, & Mims, 2017). Furthermore, students with severe disabilities are now included in statewide accountability systems through alternate assessments that are aligned with state academic standards (IDEA, 2004; Every Student Succeeds Act [ESSA], 2015). This increased emphasis on academic instruction has presented new opportunities for students with severe disabilities to access challenging curriculum and for school personnel to be held accountable for their learning.

Third, the rapidly developing technology of *positive behavior interventions and supports (PBIS)* has resulted in effective, nonaversive interventions for students with severe disabilities who exhibit problem behavior (Brown & Michaels, 2006; Dunlap et al., 2010; Freeman et al., 2016; Gage, Leite, Childs, & Kincaid, 2017; Goh & Bambara, 2012; Horner et al., 2009; Sailor, Dunlap, Sugai, & Horner, 2008) (see Chapter 7). PBIS is based on the premise that all behavior serves a function (or purpose) and interventions must be designed to teach alternative behaviors that serve the same functions. Since the reauthorization of IDEA in 1997, schools have been required to consider the use of PBIS for students with problem behavior. Schools are increasingly implementing PBIS strategies schoolwide, which has resulted in the creation of more positive learning environments for all students, including students with severe disabilities. Culturally responsive practices have also been embedded in PBIS, to enable culturally responsive behavior support delivery in schools (Vincent, Randall, Cartledge, Tobin, & Swain-Bradway, 2011).

Fourth, drawing upon *peers* to lend support to students with severe disabilities has emerged as a prominent area of research because it is central to social and academic classroom success (Biggs, Carter, & Gustafson, 2017; Brock, Biggs, Carter, Cattey, & Raley, 2016; Carter, Cushing, & Kennedy, 2009; Janney & Snell, 2006). Peers without disabilities can effectively provide an array of supports to their classmates with disabilities in ways that enhance educational experiences. Increasingly, school personnel are recognizing the benefits of peer supports instead of the common response of relying too heavily or unnecessarily on extra adult supports (e.g., one-to-one teacher assistants) (Giangreco, 2013; Giangreco, Doyle, & Suter, 2012) (see Chapter 11).

Finally, the focus on family involvement has expanded to include student involvement and *self-determination*. Self-determined young people have skills and attitudes that allow them to act as causal agents, to make things happen in their own lives. Self-determination emerges as students learn the skills needed to make choices and decisions about their own lives, have opportunities to make decisions, and then have those decisions honored (Shogren et al., 2015). As succinctly summarized in self-advocacy circles, "Nothing about me without me!" Self-determination is critically important as it pertains to *transition to adult life* (Shogren, 2013; Shogren & Wehmeyer, 2017; Thoma, Bartholomew, & Scott, 2009). Self-determination skills facilitate successful transitions into supported employment (Shogren et al., 2015; Wehman, Inge, Revell, & Brooke, 2007), supported community living (Jameson & McDonnell, 2010; Shogren et al., 2015; Taylor, 2006), and postsecondary education (Feldman, Fialka, & Rossen, 2006; Grigal & Hart, 2009; Shogren et al., in press).

Reasons for Concern

Although the five areas for 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, inclusive educational opportunities have remained relatively static, and *inconsistent access to inclusive classrooms* continues to plague public school systems, especially for students with severe disabilities. Primary placement in general education means that a student with a disability receives 80% or more of his or her instruction in a general education classroom with appropriate supports. The U.S. Department of Education (2017) indicates that for all students with disabilities (ages 6–21) in U.S. states, including the Bureau of Indian Education (BIE) and outlying areas, 62.7% spend 80% or more of their day in the general education classroom. A closer look at categories most likely to include students with severe disabilities (e.g., autism, deaf-blindness, intellectual disability, multiple disabilities, and traumatic brain injury) depicts a more stark reality. For example, only 16.5% of students with intellectual disability nationally are included in general education classrooms for 80% or more of their school day as are only 13.3% of students with multiple disabilities. Currently, 15 states (i.e., AZ, CA, HI, IL, ME, MN, MO, NV, NJ, NM, NY, SC, UT, WA, WY) and the District of Columbia include less than 10% of their students with intellectual disability for 80% or more of

TABLE 1–4
Areas for Continuing Concern

1. 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

the school day. In contrast, only four states (i.e., AL, IA, KY, VT) include over 35% of their students with intellectual disability in general education classes for 80% or more of their school day (U.S. Department of Education, 2017). Unfortunately, placement in general education classrooms depends, in large part, on where a student lives and what disability category they have been assigned. Although placement does not equal inclusion, it is a telling indicator of access to general education environments and a first step toward inclusive opportunities.

Second, even in situations where access to inclusive environments is better, the *questionable quality of the curriculum and instruction* for students with severe disabilities in general education classrooms continues to be a serious and ongoing issue (Halle & Dymond, 2008/2009; Hunt, McDonnell, & Crockett, 2012; Morningstar, Shogren, Lee, & Born, 2015; Ryndak, Jackson, & White, 2013). Being physically present in settings with same-age peers who do not have disabilities is necessary, but not sufficient, to be included. Too many students with severe disabilities who are 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 apart from classmates), (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 abilities or learning and communication characteristics. 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). While public debates continue to be waged regarding the *least restrictive environment* provision of the IDEA and the curriculum focus for students with severe disabilities, 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 (Haines, Gross, Blue-Banning, Francis, & Turnbull, 2015; Jegatheesan, 2009; Soodak & Erwin, 2000). While some educators 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* (Turnbull, Turnbull, Erwin, Soodak, & Shogren, 2015). Families from culturally diverse backgrounds experience further frustration when school personnel fail to understand or respect the values inherent in their culture (Jegatheesan, 2009; Rossetti, Sauer, Bui, & Ou, 2017; Shogren, 2013). Family members, friends, and persons with disabilities themselves also have expertise and knowledge concerning issues such as an individual's likes and dislikes, understanding of behavioral challenges, rest/sleep patterns, idiosyncratic communication, personal history, and other important information that may contribute to educational and support 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 (Harry & Fenton, 2017) (see Chapter 2).

Fourth, concern exists about the *continued use of aversive procedures* to manage problem behaviors (Agran et al., in press; Brown & Traniello, 2010; Westling, Trader, Smith, & Marshall, 2010). Sadly and unnecessarily, some students with severe disabilities continue to be subjected to an arsenal of aversive procedures and punishments (e.g., contingent electric shock, restraints, seclusion, noxious smells, white noise, physical assaults) in the name of "treatment," resulting in lost learning opportunities, degradation, psychological trauma, physical injury, and, in a small number of cases, even death (Gonnerman, 2007; National Disability Rights Network, 2009; U.S. Government Accountability Office, 2009). This problem persists despite the availability of effective, positive alternatives (Baker & Blumberg, 2011; Goh & Bambara, 2012; Sailor et al., 2008) and a national campaign to end the use of restraint and seclusion (**www.stophurtingkids.com**).

Fifth, *challenging working conditions for special educators* contribute to the concerns about the education of students with severe disabilities. Of particular alarm is the national shortage of qualified special educators, as well as the need to train and retain more of them. Sutcher, Darling-Hammond, and Carver-Thomas (2016) report that 48 states plus the District of Columbia have special education teacher shortages. Boe, Cook, and Sunderland (2008) report that annual turnover in special education has increased to one in four teachers in recent years. Some of the key factors contributing to special educators leaving the field include excessive paperwork, large caseloads, and lack of administrative support (Hagaman & Casey, in press). Teacher shortages and high turnover rates interfere with students receiving an appropriate, high-quality education. This is particularly true for students with severe disabilities, who constitute a small proportion of the overall population of students with disabilities and require teachers with specialized expertise and skills.

Finally, *limited postschool options* adversely affect young adults with severe disabilities. While some students with severe disabilities are accessing meaningful postschool opportunities, many are not. All too often youth with severe disabilities exit school unemployed, without basic skills, lonely, and unnecessarily isolated. At a time when the lives of their same-age peers are growing more interesting with expanding opportunities, the lives of too many young adults with severe disabilities is becoming smaller and more restricted.

If you are interested in improving the lives of people with severe disabilities through education, there is plenty to motivate you to act. A continually growing set of examples and body of literature documenting steady progress may be what encourages your continuing contributions. Or maybe it is the slow pace of progress or ongoing injustices facing people with severe disabilities that makes your blood boil. Whether it is a "glass half full or half empty" perspective that fuels your fire, or some of both, either way there is plenty of motivation to act and lots of work to do together!

ACCESS TO QUALITY EDUCATION

The remainder of this chapter offers foundational information and ideas about access to quality education for students with severe disabilities in four main areas, including access to (a) inclusive environments, (b) individualized curriculum, (c) purposeful instruction, and (d) necessary supports. All of these components of quality education are given in-depth attention in the subsequent chapters and embedded throughout the book.

Watch "IDEA and Special Education Best Practices" at www.youtube.com/watch?v=lQE4zEGXOGE.

Access to Inclusive Environments

As mentioned, since its passage in 1975, IDEA has mandated that students with disabilities be educated in the least restrictive environment (Rebhorn & Smith, 2008; Turnbull et al., 2007). The LRE provisions state that "to the maximum extent appropriate, children with disabilities . . . are educated with children who are non-disabled. . . . 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" (34 CFR 300.114).

Ironically, it has been this second part of the LRE mandate 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 have severe disabilities continue to be placed in self-contained special education classes or schools, and thus are denied opportunities to build relationships with their peers without disabilities as well as access to general education classrooms and curricula from highly qualified general education teachers who are collaborating with special educators.

IDEA is clear that the default placement—in other words, the starting point each year—for *all* students with disabilities is the general education classroom with appropriate supports. IDEA *does not* say that students with disabilities should be denied access to general education classes

- if they have a particular label (e.g., autism, intellectual disability, multiple disabilities)
- if they require supports or accommodations (even if potentially extensive)
- if they function at a substantially different level 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 the adults in the school are unaccustomed to the characteristics presented by the students and/or their support needs.

Despite trends toward greater access to general education classrooms, students with severe disabilities remain most at risk for segregated placements. Yet, for every student with a severe disability who remains educationally segregated there are other students with similar characteristics, attributes, abilities, and needs who are successfully included in age-appropriate general education classes and are learning relevant skills. This suggests that whether a student with a severe disability is meaningfully included may have less to do with his or her characteristics and more to do with the attitudes, skills, structure, and practices of the adults responsible for providing education (Giangreco, 2017; Giangreco, Carter, Doyle, & Suter, 2010). Imagine how placement options might change if teams shifted from asking whether a student fits in a regular class to asking themselves how they can change their practices so that more students with the full range of disabilities can be successfully educated while being included in the rich general educational environments they would typically access if they were not disabled.

Access to Individualized Curriculum

IDEA provides a potent framework to enhance the lives of students with disabilities through *special education* and the development of an *individualized education program (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. § 1400 [2004]; IDEA, sec. 602[29]). 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 300.39[3]).

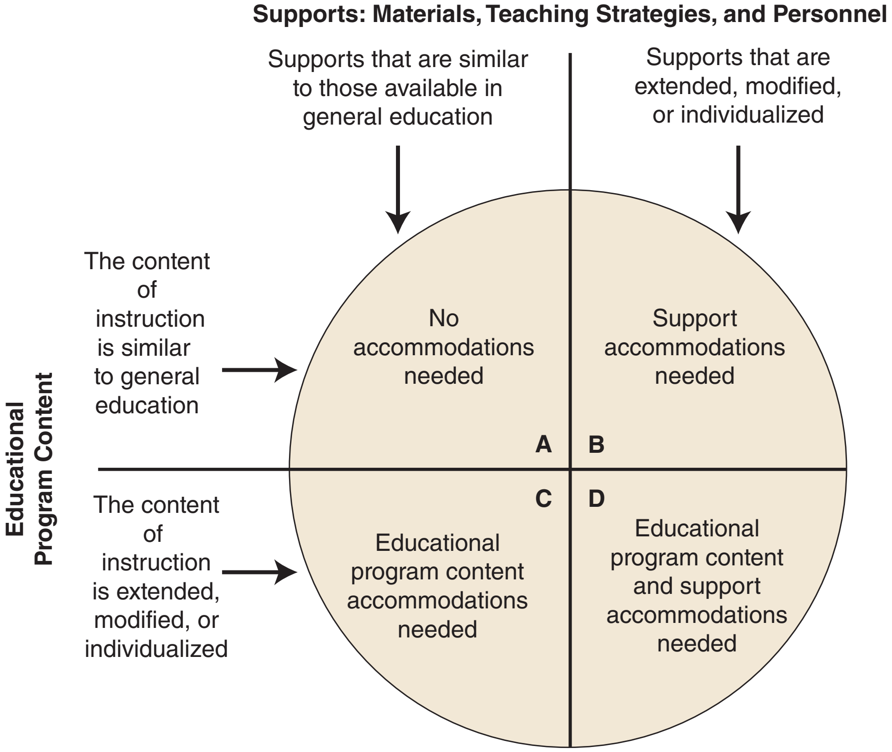
As described in the IDEA, special education is a service, not a place (Taylor, 1988). At its heart, special education refers to the *individualized* ways in which we provide instruction to students in an effort to respond to their unique learning characteristics resulting from their disability. Sometimes individualization means (a) *changes in curriculum* to account for a student's present level of performance or support 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

The participation of students with severe disabilities within general education classes and activities can be broadly characterized along two dimensions: (1) their *educational program content* (i.e., individualized curriculum, IEP annual goals with corresponding benchmarks or short-term objectives, and designated learning outcomes from the general education curriculum) and (2) their *supports*, namely, what is provided to assist the students in accessing and pursuing achievement of their educational goals (e.g., assistive technology, materials, adaptations, learning strategies, related services).

FIGURE 1–1

Inclusion Options Within General Education Environments and Activities



(From Giangreco, M. F., & Putnam, J. [1991]. Supporting the education of students with severe disabilities in regular education environments. In L. H. Meyer, C. Peck, & L. Brown [Eds.], *Critical issues in the lives of people with severe disabilities* [p. 247]. Baltimore: Paul H. Brookes Publishing Co.; adapted by permission. As it appears in *Choosing Outcomes and Accommodations for Children (COACH): A Guide to Educational Planning for Students with Disabilities, Third Edition* (2011) by M. F. Giangreco, C. J. Cloninger, & V. S. Iverson.)

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 sections that follow. During the course of a school day—even sometimes within a single activity—an individual student will move among these different options, depending on the nature of the activity and his or her needs. This approach requires deliberate collaboration among teachers, special educators, and related services providers (see Chapter 6).

Option A: No Accommodations Needed

Option A exists when a student is participating in the same activity with students without disabilities in the same way, and is pursuing the same content at the same level of difficulty. However, supports (e.g., teacher, classmates, classroom equipment) that are typically available can and do vary widely from class to class or school to school.

The participation of students with severe disabilities may be characterized as option A during certain parts of the day. If option A existed all of the time, the student would not be in need of special education nor would he or she be characterized as having severe disabilities. For example, in a primary classroom, when the teacher is reading a story to the class, the student with severe disabilities may not require specialized instruction or specialized supports. The teacher may position the child close by so that the teacher can show each page and respond if the student's attention wanders, or the teacher may have a peer sit nearby in case the student starts to lose his or her balance while seated on the floor with the rest of the class. However, these types of simple supports are not so specialized that they are considered "special education."

It is important to recognize times when a student with a severe disability can participate within option A because (a) it provides opportunities for the teacher to interact with a student who has disabilities in typical (nonspecialized) ways, (b) it allows classmates to see that the student doesn't always need extraordinary 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 one-to-one paraprofessional support while they are in general education class activities (Giangreco, Suter, & Hurley, 2013; Suter & Giangreco, 2009); 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 such as stigmatization, unnecessary dependency, interference with peer interactions, and interference with teacher engagement (Giangreco, 2010). Therefore, teams should continually look for option A opportunities by considering how naturally available supports can be utilized (Biggs et al., 2017; Downing, 2010; Giangreco, Broer, & Suter, 2011; Quirk, Ryndak, & Taub, 2017).

Option B: Support Accommodations Needed

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

Option C: Educational Program Content Accommodations Needed

Option C exists when a student requires extension, modification, or individualization of the content of the general education program but *does not* require specialized supports. For example, the teacher might adjust the content with regard to (a) the 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—although, like option A, natural supports might be provided.

Option D: Educational Program Content and Support Accommodations Needed

Option D exists at times when a student needs extension, modification, or individualization of both the general education curriculum content *and specialized supports* to participate. In addition to adjusting the content of the curriculum with regard to the amount, level, and/or type, individualized supports are provided to assist the student with learning and participation. Some examples of individualized supports that a student with severe disabilities might receive include a visual picture schedule that identifies the steps for completing an activity, individualized prompting from a peer or adult, or an adapted keyboard for use with the computer. These supports allow students to actively engage in educational activities by removing barriers that interfere with learning.

Within both options C and D, teams may employ the *principle of partial participation* (Baumgart et al., 1982; Ferguson & Baumgart, 1991). This principle is based on the premise that students with severe disabilities "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). For example, a student with severe disabilities might have a job in the school library that involves taking returned books from the book drop and placing them on a cart. A peer may then assist the student with severe disabilities to find the correct shelf and position for the book. In this manner, the student performs some, but not all, of the skills that are typically performed by students at school who serve as library assistants.

Partial participation is designed to foster socially valued roles for people with disabilities that have a positive influence on their image and personal competencies. Rather than excluding students from activities because they may never be able to perform independently or in the same way as most students, partial participation focuses on engaging students to the maximum extent possible. Consider Kendra, a middle school student with multiple disabilities who has extensive support needs related to oral–motor skills (e.g., chewing, swallowing).

> *Many foods that Kendra is supported to eat fall out of her mouth. When in the bustling cafeteria, she seems particularly distracted. Her parents identified eating in busy environments as a priority because the family often eats in busy restaurants.*
>
> *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 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 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 fatigued and her eating skills deteriorated as time went on, they decided that instead of having Kendra eat her entire lunch in one 20-minute sitting, she ate two 10-minute mini-meals spread out over 40 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. The remaining 15 minutes was spent in the cafeteria with her peers, eating only foods that she could better manage and hanging out just like everyone else in the middle school cafeteria. After a couple of weeks, the amount of time that she spent in the cafeteria was gradually increased. 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 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 foods in private. The team recorded data on both her eating goals and social interactions—they met regularly to discuss Kendra's progress. Gradually her eating shifted to the cafeteria completely, although 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.*

It is often the case that option D will be necessary, at least part of the time, for students with severe disabilities because of their extensive or pervasive support needs. Teams are encouraged to consider when options A, B, or C are possibilities and to be conscious of not overusing option D if less-intrusive options are appropriate. When options C and D are warranted, care must be taken to structure the learning environment in a manner that promotes access to individualized curricular content as well as access to learning with peers. Unfortunately, options C and D are frequently and unnecessarily operationalized by assigning a paraprofessional to teach individualized curricular content (i.e., 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 and has been linked to a host of unintended detrimental effects (Giangreco, 2010). Delegating primary instructional responsibilities to a paraprofessional also relegates students with the most significant learning challenges to receiving their instruction from the least qualified personnel, who tend to be undertrained and inadequately supervised (Giangreco, Doyle, & Suter, 2014). Two alternatives include *multilevel curriculum/instruction* and *curriculum overlapping* (Giangreco, 2007). See Table 1–5 and Figure 1–2 for shared and distinct components of these two related approaches.

TABLE 1–5
Components of Multilevel Curriculum/Instruction and Curriculum Overlapping

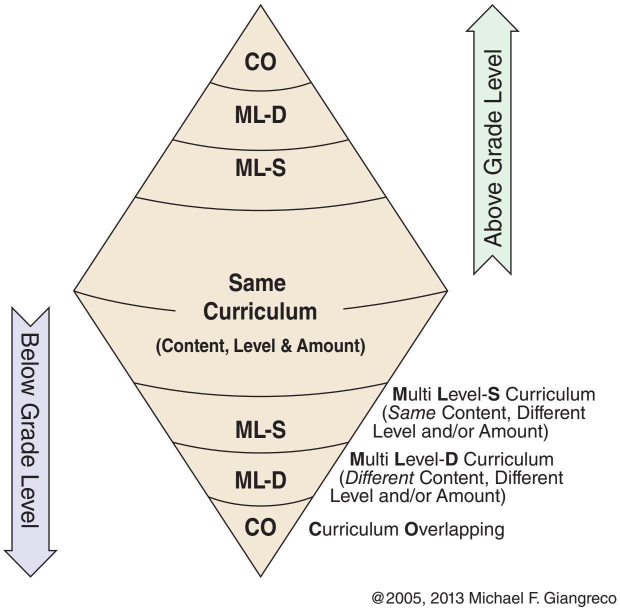
Shared Components	
1. Lessons include a diverse group of same-age learners (e.g., advanced, those with disabilities, at grade level, at risk). 2. Learning occurs within a shared activity or experience within a regular class activity. 3. Each learner has individually appropriate learning outcomes at an appropriate level of difficulty.	
Distinct Components	
Multilevel Curriculum/Instruction	**Curriculum Overlapping**
4. Targeted learning outcomes are within the same curricular area (e.g., science or math or social studies) and students are responsible for more or less of them in terms of amount and complexity.	4. Targeted learning outcomes for the student with a disability come from a different curricular area (e.g., communication, socialization, or personal management) than those targeted for other classmates (e.g., science, math, history).
Variations: (a) Same topical subject matter in same curricular area (b) Different topical subject matter in same curricular area	

(From Extending inclusive opportunities. *Educational Leadership*, *64*(5), 34–37. Reprinted by permission of the author.)

Multilevel Curriculum/Instruction

There are three requirements of multilevel curriculum/instruction. First, the student with a disability is in a heterogeneous group with peers without disabilities that mirrors natural proportions. This means they are not working individually and that the group is not over-represented by students with disabilities or other nonstandard educational needs. Second, it occurs when a student with disabilities and peers without disabilities participate in a shared activity such as a science lab experiment where students are working together to complete required steps and tasks, sharing responsibilities, expectations, and learning. Third, each student has individually appropriate learning outcomes that may be at multiple levels (i.e., below, at, or above grade level); the topical

FIGURE 1–2
Multilevel Curriculum and Curriculum Overlapping



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content may be the same or different, so long as it is all within the same curricular area for students with and without disabilities in the group (Giangreco, Cloninger, & Iverson, 2011). While one student may be learning at a basic knowledge or comprehension level, another student simultaneously may be working at a more advanced level.

> *Imagine second-grade students playing a teacher-designed, small-group, social studies board game to learn about their neighborhood, town, and state. A set of 10 game cards has been prepared for each student that targets individual learning outcomes. For three students (at grade level), the game cards require applying knowledge about the roles of community helpers (e.g., police, firefighters, store clerks, postal workers) by moving game pieces to respond to scenarios on the 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 student who has autism and has occasionally gotten lost or separated from his family, game cards have the student answer questions about himself and where he lives (e.g., last name, street address, phone number, where his parents work). A third student (who is performing above grade level) 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 of the students have individualized social studies learning outcomes, pertaining to different content/subject matter, within a shared activity.*

By definition, multilevel curriculum/instruction involves individually appropriate learning outcomes that may be provided at any level (i.e., below, at, or above grade level) and can include variations across subject content.

> *In one seventh-grade social studies class focusing on history from the American 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 from that for many of his classmates, focusing on counting and basic computation (e.g., adding is a variation within the subject content). 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 curricular content area as his classmates, just at a different level.*

Curriculum Overlapping

Curriculum overlapping starts in the same way as multilevel curriculum/instruction: (a) A student with disabilities and peers without disabilities are heterogeneously grouped in natural proportions, (b) they participate together in a shared activity, and (c) 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 curricular areas; this is unlike the multilevel curriculum/instruction examples, where they were all within the same curricular area.

> *In a middle school biology class, students are grouped in teams of three for lab activities. They are assembling a model of a human heart. Two students have goals related to the identification, anatomy, and physiology of the human heart. The third student, who has an intellectual disability and extensive support needs, 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 may be appropriate to use when there are large differences between the level of learning outcomes being pursued by most of the students in a class and the student with a severe disability. Before employing curriculum overlapping, the team should consider whether the student could pursue the same learning outcomes as the rest of the class or whether either of the two multilevel curriculum/instruction variations are viable options; this helps to ensure that we do not underestimate students with severe disabilities.

> *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 under his or her thumbs. All of the students have math learning outcomes except for Jesse, a student with an intellectual disability and extensive support needs. Jesse participates in the same activity but has a series of nonmath goals. He is learning to orient himself toward a person who calls his name, react to the tossed ball by moving his arms to attempt a catch, match to a sample by pointing to a photograph of a classmate in the group, and then orient himself toward that person before being assisted to toss the ball.*

At times, both multilevel curriculum/instruction 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 practice skills. Research has demonstrated the effectiveness of embedding individually determined learning outcomes within general class activities (Hudson, Browder, & Wood, 2013; McDonnell, Johnson, Polychronis, & Risen, 2002). Such approaches have become increasingly relevant with the advent of the Common Core State Standards Initiative (**www.corestandards.org**). Occasionally, it may be necessary to plan an alternate activity if a student needs to work on a high-priority goal that does not lend itself to being incorporated into the multilevel curriculum/instruction or curriculum overlapping options. For example, a high school student with severe disabilities may need specific, alternative instruction on a skill that does not readily lend itself to available high school curriculum, such as how to safely cross various types of intersections to travel to a community-based work or recreation site. At other times, students' privacy requirements dictate the need for alternatives, such as when a student is learning to use the toilet or dressing skills.

The Curricular Balancing Act

Ensuring access to a relevant, individualized curriculum for a student with severe disabilities also requires a balancing act *between focus and breadth* (Hunt et al., 2012; Wehmeyer et al., 2016). 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 of the highest educational priorities agreed to by the team; these are documented as IEP goals (Giangreco, Cloninger, et al., 2011).

Historically, curricula for students with severe disabilities have emphasized the identification of *chronologically age-appropriate functional skills* needed to participate in current and future environments (Brown et al., 1979; Brown, Nietupski, & Hamre-Nietupski, 1976). Chronologically age-appropriate skills are ones that are performed by same-age peers without disabilities. For example, when thinking about the use of a coat at school, a 7-year-old may learn to hang his or her coat on a hook in the classroom whereas a 15-year-old would learn to use a locker in the hallway. Selection of age-appropriate skills is particularly important when addressing functional skills. Functional skills are those used across one's lifetime and would need to be performed by someone else if an individual was unable to perform the skills alone. Typical skills identified as functional include self-care (e.g., dressing, bathing, toileting), home living (e.g., cooking, cleaning), leisure (e.g., hobbies, fitness), community (e.g., grocery shopping, traveling in the community), and vocational (e.g., job and job-related skills) (Dymond, 2011).

While the foundational concepts of chronological age appropriateness and functional curriculum remain useful, contemporary 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 (Giangreco, Cloninger, et al., 2011; Halle & Dymond, 2008/2009; Hunt et al., 2012; Wehmeyer et al., 2016). 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, Cloninger, et al., 2011).

> *Juanita Perez is in first grade and has severe disabilities. Her special education teacher worked collaboratively with the team, including Juanita's parents, to identify the highest priorities for Juanita from the family's perspective that would be translated into IEP goals and objectives. These priorities included (a) expressing "more," (b) making a selection 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., digital music player, battery-operated toys). The team cross-referenced each of these priorities to one or more valued life outcomes. For example, being able to activate toys was designed to give Juanita more choices and control and was hoped to be a point of connection that might serve to extend her relationships with other children her age. The team also 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 functional skill categories, to decide which learning outcomes would make the most sense for Juanita. As a result, they selected a series of additional functional skills (in addition to the family's highest priorities), such as imitating skills used in daily life, eating finger foods, drinking through a straw, and increasing the amount of time that she could sustain attention to a task. 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.*

A sound curriculum also *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* on the basis of assessment data. Targeted learning outcomes should be reasonably attainable yet challenging, although not so challenging as to be unattainable or frustrating. Although it is logical to select instructional targets on the basis of the student's current level of performance 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 of 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 using promising or evidence-based interventions. This is consistent with Donnellan's (1984) *criterion of the least dangerous assumption*, which asserts, "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 alternative or augmentative method of 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 a 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 that the concepts were too advanced for her and because they were not able to adequately assess her science learning given her challenges with expressive communication.*

Recognizing that this could be a dangerous assumption given the challenge of knowing how much Juanita understands, they decided to include her in science class and start with curriculum overlapping so that the learning outcomes that she focused on during science class 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 nonscience communication and social skills. Over time, on the basis of the teacher's observations during science class activities, Juanita's additional learning outcomes may be expanded to include science class outcomes.

Access to Purposeful 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, 2017). This set of instructional methods, such as chaining, shaping, prompting, time delay, and error correction (see Chapter 5), 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 curricula. Use of systematic instructional methods played a major role in documenting the wide range of skills and functional routines that people with severe disabilities could learn if offered consistent, quality instruction. In fact, the use of these methods was instrumental in helping to establish the "educability" of students perceived as having the most profound disabilities.

Ironically, as students with severe disabilities have gained greater access to general education classes, 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 evidence-based, systematic instructional approaches in new and contextually viable ways (Koppenhaver & Erickson, 2008; Sailor, 2015; Schnorr, 2011). 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.

As teams pursue quality instruction, it is important to remember that the principles of teaching and learning remain the same regardless of a student's ability or where that student receives his or her education (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. (For more on this topic, see Chapter 6.)

Box 1–2

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 and welcoming learning environment.
5. Select effective teaching methods.
6. Provide sufficient and consistent learning opportunities.
7. Use data to make instructional decisions and evaluate outcomes.

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 label, although 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' support needs allows for *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 (Halle & Dymond, 2008/2009; Hunt et al., 2012; Wehmeyer et al., 2016). Highly effective instruction applied to irrelevant, nonfunctional, or chronologically age-inappropriate learning outcomes is a waste of both the student's and team's time. 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.

In addition to considering curricular aspects related to instruction mentioned earlier in this chapter (e.g., functionality, age appropriateness, balance of breadth and focus), teams should also consider (a) the frequency with which a learned skill will be used both now and in the future, and (b) the extent to which a learned skill will increase independence, including self-determination. Clearly, skills that are used frequently and have current and future utility generally are more important than those that are used infrequently or will not be useful in the future. Selecting meaningful learning outcomes is always a judgment. Sometimes, skills with a lower frequency of use can be extremely important for being safe (e.g., street crossing, evacuating a building in response to an alarm) or for personal preferences (e.g., the leisure skills that one enjoys, predictable environments, unstructured time). For individuals with the most severe or multiple disabilities, another major consideration is the extent to which a learned skill will allow a person to control his or her environment. For example, learning to use an adapted microswitch may allow a person with severe or multiple disabilities to activate a wide variety of electrical or electronic devices across a range of locations and activities (e.g., communication, cooking, leisure, work).

Establish Shared Expectations Among Team Members

Having the perspectives of a variety of team members can be an asset to planning good instruction (Hunt et al., 2012; Ryndak et al., 2013; Wehmeyer et al., 2016). In order for teams to plan effectively, they must share common expectations and be willing to come to consensus about the direction of instruction for each student. Establishing shared expectations means that all members should (a) know the student's learning-related characteristics and support needs, (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, (f) know the student-specific instructional procedures and adaptations, and (g) know what information should be collected on the student's progress (Giangreco, Cloninger, et al., 2011).

Create a Motivating and Welcoming Learning Environment

Although it may seem obvious, the importance of *creating a motivating and welcoming learning environment* for all students cannot be underestimated. Establishing a sense of belonging is considered a key building block for effective learning (Schnorr, 1990, 1997; Shogren et al., 2015; Swedeen, Carter, & Molfenter, 2010). In order for students with disabilities to develop meaningful relationships with peers who do not have disabilities and to have access to a broad range of meaningful learning outcomes, they must share learning experiences with peers on an ongoing basis. This includes experiences not only in the academic classroom but also in typical school routines (e.g., changing classes in the hallways, eating in the cafeteria, hanging out before school), special events (e.g., field trips, job fairs, talent night), school jobs (e.g., office helper, library assistant), and extracurricular activities (e.g., drama club, student council, intramurals).

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 (Giangreco & Cravedi, 2007). Some of these common methods include modeling and demonstration, repeated practice, guided discovery, participatory activities, playing educational games, 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 into smaller components; or use different instructional methods such as task analysis, chaining, shaping, and time delay (see Chapters 4, 5, 6, 10, 12, 13, and 14). Consider how Tom learned a new skill because of the use of a systematic instructional procedure and its impact on his life:

> *Tom had a traumatic brain injury that resulted in severe physical, cognitive, and sensory disabilities, including cortical visual impairment, loss of language, and the inability to walk, sit up independently, or use his arms and hands. Tom was fed primarily through a gastrostomy tube, although 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 from side to side when supported from behind, the ability to open and close his mouth, and some chewing. Tom communicated primarily through vocalizations (e.g., groaning was recognized as discomfort). This usually meant that 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" so that he would open his mouth to receive food, drink, and 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 was started by simultaneously pairing the cue that they knew Tom responded to (i.e., touching his lip with a spoon) with the cue that they wanted him to respond to (i.e., the verbal instruction "Open up"), followed by giving him a spoonful of fruit yogurt. This simultaneous pairing is known as a zero delay because there is no time delay 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 inserted 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 a sip to drink. When the time*

delay was increased to 5 seconds, Tom opened his mouth to accept the food before his lip was ever touched—he had responded to the instruction! He soon was opening his mouth immediately and consistently following the request. 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, but this small change had a big impact. Once it was clear that he could respond to the "Open up" cue, the staff was sensitive to considering that Tom might keep his mouth closed as a way to indicate that he no longer wanted more to eat. Increasingly, the team was more aware of subtle behaviors that might have communicative intent.

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, Cloninger, et al., 2011) provides a way for the team to ensure that the 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). Listed down the left side of the matrix are IEP goals and other targeted learning outcomes (see Chapters 4 and 6 examples). It can be helpful to note the amount of time devoted to each activity. For example, arrival may be only 10 to 15 minutes at the beginning of the day, whereas a full hour may 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. Because daily schedules often change (e.g., on one day math is at 9:00 a.m., and on a different day it is at 10:30 a.m.), when using a scheduling matrix it is not crucial to arrange the general class activities in a specific order according to the schedule. The team examines the matrix, determines which learning outcomes will be addressed in each class, and marks those locations on the matrix. The match between the learning outcomes and the class where they will be taught 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.

Providing sufficient and consistent learning opportunities requires persistence and creativity on the part of team members to embed opportunities for learning within class activities. 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 and combinations of approaches and to capitalize on unscheduled, teachable moments.

Use Data to Make Instructional Decisions and Evaluate Outcomes

Along with instructional 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 in order to monitor and document progress and be accountable for our teaching, teams have a responsibility to do the same for students with severe disabilities (see Chapter 5). Individualized data provide essential information for making reasoned instructional decisions (Alberto & Troutman, 2017; Farlow & Snell, 2005; Kingston, Karvonen, Thompson, Wehmeyer, & Shogren, 2017).

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 the 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 with meaningful changes in the student's life.

> *Maria is learning a set of social skills (e.g., responding to the presence of others, greeting, taking turns) with the intent that the attainment of these skills will contribute to establishing or extending friendships with her 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 better 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 the 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 and changes in the environment, especially the attitudes and actions of the people in those environments.

Access to the Necessary Related Services and Supports

As described earlier, one of the defining characteristics of people with severe disabilities is their need for supports in multiple domains to meet the demands of inclusive environments. Systems of supports for students with severe disabilities typically include supports for learning and participation (such as those described in the previous sections) as well as related services and supports. Related services and supports, according to IDEA, include

> *transportation, and such developmental, corrective, and other supportive services (including speech-language pathology and audiology services; interpreting services; psychological services; physical and occupational therapy; recreation, including therapeutic recreation; social work services; school nurse services designed to enable a child with a disability to receive a free appropriate public education as described in the individualized education program of the child; 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. § 1400 [2004]; IDEA, sec. 602[26][A])

Team Decisions About Related Services

The goal of related services is to support students with severe disabilities to receive an appropriate education in the least restrictive environment. For this reason, related service providers, education professionals, and family members must work together as a *team* to identify the best ways to build a system of support that meets the individualized needs of each student.

When considering how to build a system of support for an individual student, different stakeholders may bring different value systems to the decision-making process. Some related service disciplines are rooted outside of education, such as allied health fields (e.g., speech/language pathology, physical therapy, occupational therapy) that may have discipline-specific values and perspectives. Coming to an agreement on shared values can enable teams to work together more effectively. In the sections that follow, three common value systems that teams might encounter are described. The first two are inconsistent with sound educational practices; the third is suggested as a desirable alternative.

More Is Not Necessarily Better. Some team members advocate for *more* related services. If one session of a therapy is recommended, they think that two would be better, and three better yet. The *more-is-better* approach is misguided because it confuses quantity with value. Although rooted in benevolent intentions, the more-is-better approach can have unintended, negative consequences for students by interfering with participation in other school activities by

- decreasing the time available for participation in the general education curriculum with peers who do not have disabilities, particularly when a student is removed from the classroom to receive related services
- stigmatizing students if the provision of special services violates contextual norms
- fostering unnecessary or unhealthy dependencies
- unnecessarily complicating communication and coordination among team members
- causing inequities in the distribution of resources, with some students remaining unserved or underserved.

The Fallacy of Return on Investment. Another misguided value system, called *return on investment*, places a high value on "fixing" student's deficits; and it gives higher priority for supports and services to those students most likely to be "fixed." This approach fails to recognize that disability is not something to "fix," and instead, as IDEA states, is "a natural part of the human experience." It can lead to devaluing and discrimination based on the intensity of a person's support needs. Any time that schools sanction practices that imply that some students are more worthy of staff time and resources than other students, there is a serious problem. And, imagine what it might be like to continually get the message, "You are not okay the way you are. In order to be okay, your disability has to be fixed and you need to be more like us (people without disabilities)."

Only as Specialized as Necessary. An alternative value system is referred to as *only as specialized as necessary*—providing enough but not too much support. Remember, the goal of providing individualized supports to people with severe disabilities is to address the mismatch between a person's capacities and the demands of inclusive environments. This requires an individualized system of support that balances the capacities of the individual with the demands of the environment.

Systems of supports for students with severe disabilities should include multiple sources of supports, including both natural supports (e.g., peers, family members, community members) and specialized supports (e.g., educators, related service professionals). When specialized services and supports are used, ongoing data should be collected to document the impact of the services and supports and to explore ways for the services to be provided in the most natural and sustainable way, which may involve natural supports.

It is important to recognize that the only-as-specialized-as-necessary approach does not automatically mean "less is always best" or "only a little is plenty." The recent *Endrew F. v. Douglas County School District* (2017) decision emphasized that students with severe disabilities had the right to appropriately ambitious goals and more than a "minimal" benefit from IEP goals and objectives. When used as intended, the only-as-specialized-as-necessary approach results in students getting the supports they need to receive an appropriate education and achieve appropriately ambitious goals. Further, it provides a values orientation for members of a student's team that can lead to educationally sound decision making. (See Chapter 6 for further discussion of the only-as-specialized-as-necessary approach.)

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, teams must ask themselves challenging questions about the educational relevance and necessity of a proposed service. A related service has *educational relevance* when it can be explicitly linked with a component of a student's educational program (e.g., IEP goals, general education curriculum).

> *Ms. Burns, an occupational therapist, based on an individualized evaluation has made recommendations for supports to enable Adam, a student with autism, to develop his handwriting skills. If handwriting skills are a goal or objective on Adam's IEP or part of the general education curriculum, then the recommended occupational therapy supports are educationally relevant.*

Educational relevance alone, however, is not sufficient to warrant the provision of services; 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. Many teams may start by asking themselves, "Could the proposed related service help?" and the answer is almost always, "Yes." But, a way to ask the question that is more consistent with the IDEA and to promote educationally sound decision making is, "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?"

To understand how this applies to a specific student, think about Jana, a student with multiple disabilities, and her team. Ms. Reeve, Jana's mother, takes Jana to a private clinic for an evaluation, and a clinic consultant recommends that Jana receive music therapy once a week as a related service at school. Ms. Reeve brings this recommendation to the school team. The clinic consultant, in making this recommendation, was asking the question, "Could Jana benefit from this service?" But, remember, the question the team must start with is, "If the student does not receive music therapy as a related service, is there reason to believe that he or she will not be able to receive an appropriate education?" It can be particularly challenging for external clinics and consultants to make appropriate decisions about necessary related services when they are unfamiliar with the student's educational program, which is why inviting outside consultants to be a part of the educational team can be helpful.

Some questions the team will have to ask themselves as they determine if music therapy (or any related service) is necessary for an appropriate education include the following (Giangreco, 2001):

- Could the benefit provided by the proposed related service be addressed appropriately by the special educator or classroom teacher or by other core school faculty or staff (e.g., school nurse, guidance counselor, librarian, physical education teacher, 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*)?
- Does the proposed service present any undesirable or unnecessary gaps, overlaps, or contradictions with other proposed services?

The answers to these questions will guide the team in making decisions about the educational relevance consistent with the Supreme Court's decision in *Endrew F. v.*

Douglas County School District (2017) requiring appropriately ambitious goals and more than a "minimal" benefit from IEP goals and objectives.

In the example of Jana, the school might not agree to provide music therapy as related services if (a) Jana was receiving educational benefit without the service, (b) the service wasn't deemed necessary for Jana to receive more than a minimal educational benefit, or (c) the service could be appropriately provided during nonschool hours. Jana's team might, however, work to provide opportunities to experience music as part of a general education music class with support from peers and the general education teacher. Ultimately, by staying focused on the supports students need to meet the demands of inclusive environments, given their personal capacities, IEP teams can consider the full range of related services, then select and implement those that are educationally relevant and only as specialized as necessary. Well-conceived and well-executed related services can make a substantial contribution to a student's educational program and system of support, as Jamal's case illustrates.

> *Jamal is a student with multiple disabilities, including deaf-blindness. The related service 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) to provide supports for participation and learning. 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 to access 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 team decisions is not always easy, but it is important.

Ultimately, all of the foundational information provided in this section and elaborated on throughtout the rest of the text about promoting access to quality education for students with severe disabilities provides a framework for, as we stated at the start of the chapter, educators to continually reflect and to never stop questioning how to provide the most effective supports for learning and participation. This has the potential to promote greater optimism and enhance the opportunities for valued outcomes for all students with severe disabilities.

LEARNING OUTCOME SUMMARIES

1.01 Who are students with severe disabilities?

Learning Outcome

Identify definitions of severe disabilities, the role of the supports model in understanding students with severe disabilities, and the influence of societal perceptions and social interactions.

There is no single authoritative definition of severe disabilities in the field. IDEA defines 13 distinct disability classifications, several of which reasonably include a subset of students considered to have severe disabilities (e.g., autism spectrum disorders, deaf-blindness, intellectual disability, multiple disabilities, traumatic brain injury). And, students with severe disabilities are increasingly being described based on the intensity of their support needs. This reflects the shift away from defining students based on their deficits and the growing focus on the interaction between personal capacities and the demands of inclusive environments. This focus brings attention to support needs and building systems of supports, with the underlying assumption that people with severe disabilities have a fundamental capacity to learn and a right to supports that enhance learning and participation. This assumption has been codified in IDEA in the zero-reject principle, and upheld in multiple court decisions. In society, negative assumptions about people with severe disabilities still exist, and disability spread, which is the tendency to make broad interferences about people with disabilities because of stereotypes, can still create low expectations. But by creating opportunities for social interaction and participation in inclusive communities, disability spread can be limited and people with severe disabilities can lead full, engaged, and self-determined lives.

1.02 Reasons for optimism and concern

Learning Outcome

Identify areas where progress has been made in providing individualized supports for people with severe disabilities in inclusive communities, and areas where work is still needed.

Substantial advancements have been made to improve the education of students with severe disabilities. These advancements include increased opportunities for inclusion in educational settings with same-age peers, access to a broader array of curricular options that includes the general education curriculum, the use of positive behavior supports and peer supports, and emphasis on teaching individuals to be self-determined as they transition into adult life. Despite these areas for optimism, many concerns continue to exist. These concerns include inconsistent access to inclusive classrooms, the questionable quality of curriculum and instruction, family frustrations with professional responsiveness, the continued use of aversives, challenging working conditions for special educators, and limited postschool options for individuals with severe disabilities.

1.03 Access to quality education

Learning Outcome

Discuss the foundational principles of providing supports to students with severe disabilities that promote access to (a) inclusive environments, (b) individualized curriculum, (c) purposeful instruction, and (d) necessary supports.

Broadly conceptualized, quality education for students with severe disabilities must include access to (a) inclusive environments alongside peers without disabilities, (b) individualized curriculum, (c) purposeful instruction, and (d) necessary supports. Options for including students with severe disabilities in general education environments can be conceptualized across individualized combinations of educational program and supports; these can fluctuate over time and even within a school day. When students require educational program accommodations, multilevel curriculum/instruction and curriculum overlapping can be implemented to meet students' support needs within shared educational experiences with their classmates without disabilities. In order to achieve meaningful outcomes, careful decisions must be made by educational teams about the curriculum a student receives and how instruction is provided. The determination of individualized supports should be guided by educational necessity, educational relevance, and an "only-as-specialized-as-necessary" approach. When conceived in this manner, individualized supports enable students with severe disabilities to pursue meaningful learning outcomes and self-determination through participation in inclusive contexts.

2

Fostering Family–Professional Partnerships

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2.01 **Parent Rights and Responsibilities**
Learning Outcome
Identify the connections between the six principles of the Individuals with Disabilities Education Act of 2004 and the rights and responsibilities of parents of students with disabilities, including parent and child implications.

2.02 **Parent and Professional Advocacy**
Learning Outcome
Explain the importance of advocacy resources for parents and describe professionals' role in advocating on behalf of their students and their students' families.

2.03 **Family Systems**
Learning Outcome
Articulate the major elements of the family systems framework, and the implication of childhood/youth disability on each of these major elements.

Introducing the Campbells: An African American Family

Please note: Both families presented in this chapter are fictional; any similarity to one real family's circumstances is purely coincidental.

Loretta Campbell is determined that her son Jeremy, 13, will be included in all school activities with his classmates who do not have disabilities. Her determination, however, encounters obstacles. "It has not always been easy to make inclusion happen." Hard going? Yes. Late-night emails and frequent telephone calls to Jeremy's teachers prove how hard it is.

Transition exacerbates the challenge. Jeremy has just entered middle school. At a time when nearly all students are acutely self-conscious and socially sensitive, Jeremy's autism and intellectual disability inhibit his ability to establish friendships easily. But this has not stopped him from being curious about the many subjects that interest his peers, such as the nearby Dallas Cowboys football team.

Has Loretta's insistence on inclusion been worth the effort? Yes. Jeremy enjoys the routine of going to school, and, with the support of his peers, he has just mastered finding his own way to all six of his classes in his middle school. He spends 80% of his day in general education classrooms and the remaining 20% in a