# Effective Literacy Instruction for Learners with Complex Support Needs

# Second Edition

edited by

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and

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with invited contributors



Baltimore • London • Sydney



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# Introduction

The purpose of this book is to provide the most current information on effective literacy instruction for individuals with complex support needs across the life span, based on sound research and respect for the human rights of people with disabilities. Much has been learned about this crucial topic since we last published a text on literacy instruction (Copeland & Keefe, 2007). The number and quality of research studies in this area has grown tremendously, and acknowledgment of the rights of students with complex support needs has become more widespread. This book is intended to provide up-to-date information for preservice and in-service practitioners in schools and community settings (e.g., teachers, speech–language pathologists, educational psychologists, direct support staff, administrators), individuals interested in pursuing more effective literacy instruction for themselves, and families wanting to learn more about effectively supporting their family member with a disability in literacy activities. It is also intended to serve as a resource for scholars in the field. Perhaps most important, this book also intends to address and dispel the numerous myths that many people still hold about literacy and individuals with complex support needs. (See Myths and Facts in the Supplementary Materials at the end of the book.)

Each of the following chapters describes assessment and instructional practices that have a solid research foundation. The authors, each expert practitioners and researchers in this field of study, provide examples of how these practices can be used to develop engaging, effective instruction for students of varying ages and across a range of skill levels. Each chapter includes learning objectives, reflection questions, and suggested resources for readers who want to do further study on their own. There are also detailed case studies included in the Supplementary Materials that instructors can use to create application assignments for students.

These additional resources make the text ideal for teacher preparation courses or for school or adult program-based learning communities of practitioners in schools or adult educational programs who want to improve literacy instruction for their students.

# **SECTION I: CHAPTERS 1–5**

This section presents a foundation for literacy access and instruction as a human right for all people. Chapters address critical issues that affect the opportunities and access to high-quality literacy instruction that students with complex support needs are given. The first chapter lays out the history and legal basis for providing literacy instruction for individuals with complex support needs. The remaining chapters in this section address language as the foundation for literacy, considerations for instruction for students who are culturally or linguistically diverse, and the role of college- and career-ready standards in literacy instruction planning and implementation.

# **SECTION II: CHAPTERS 6–11**

In this section, chapters focus on how to organize and implement high-quality comprehensive literacy instruction for students with complex support needs. Each chapter in this section describes how components of literacy instruction can be appropriately and meaningfully applied with age groups across the life span. Chapters include multiple examples of meaningful instruction for individuals with complex support needs who have a range of knowledge and skills, including older individuals who may be emergent literacy learners. Reflection questions are included in each chapter, as well as a list of print-based and Web-based additional resources for each instructional area.

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# SECTION III: CHAPTERS 12-15

Chapters in this section address literacy instruction beyond the traditional pre-K–12 school curriculum. These chapters provide a broad discussion of the importance of opportunity and access to literacy instruction for individuals of all ages and skill levels. Chapter 12 describes how and why practitioners and parents can adapt books and other reading materials in creative ways to provide access to learners with unique challenges. Chapter 13 explains how to incorporate literacy instruction into the arts as a way of motivating students and enhancing their learning. Chapter 14 describes the importance of continuing literacy education into adulthood.

The final chapter synthesizes the overarching ideas across the book and describes implications for future research and practice.

## REFERENCE

Copeland, S.R., & Keefe, E.B. (2007). *Effective literacy instruction for students with moderate or severe disabilities*. Baltimore, MD: Paul. H. Brookes Publishing Co.

# **SECTION 1**

# The Foundations of Literacy as a Human Right

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# **CHAPTER 1**

# Literacy for All

Susan R. Copeland, Elizabeth B. Keefe, and Ruth Luckasson

# LEARNING OBJECTIVES

By the end of this chapter, readers will

- 1. Understand the basis of literacy instruction as a human right.
- 2. Learn the importance of, and implications for, how literacy is defined.
- 3. Be able to describe the legal mandates undergirding literacy instruction for students with complex support needs.
- 4. Be able to describe and critique the historical models of literacy instruction for students with complex support needs.
- 5. Be able to describe how literacy enhances opportunities for individuals with complex support needs.

The United Nations (U.N.) Convention on the Rights of Persons with Disabilities (CRPD; U.N. General Assembly, 2006) states that education is a human right for everyone, regardless of disability status. The purpose of education is to equip students with knowledge and skills that will lead to increased opportunities, choices, and autonomy, with literacy being a critical part of learning. As a crucial component of education, literacy is valued by and is, in fact, required for full participation in all societies. All individuals have a right to receive high-quality literacy instruction as part of their education.

Teaching literacy skills to any student, regardless of ability levels and support needs, is a complex process. For the student populations described in this book, who need various supports, teaching literacy skills requires particular dedication, expertise, sensitivity, and creativity from all members of the educational team. This book provides research-based information and strategies on how to deliver high-quality literacy instruction to students with complex support needs and equips educators with the skill set they need to bring literacy to all. This first chapter will define literacy, discuss how acquiring literacy skills empowers individuals to live fuller lives, advocate for literacy as a human right, and introduce literacy instruction for learners with complex support needs.

# WHAT IS LITERACY?

Research, conceptual frameworks, and teaching methods related to literacy are often referenced without ever defining what is actually meant by the term *literacy* (Keefe & Copeland, 2011). Think for a minute about how you would define this term. Why is how you define literacy so important? You might think that defining literacy should be simple, but Knoblauch (1990) cautioned that "Literacy is one of those mischievous concepts, like virtuousness and craftsmanship, that appear

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to denote capacities but that actually convey value judgments" (p. 74). According to Knoblauch, we must be aware of the sociocultural aspects of definitions that are based on assumptions, ideological dispositions, and political influences. We agree. We believe the way in which we define literacy specifically communicates assumptions we make regarding the learning potential of students with complex needs for support.

## **Defining Literacy**

Traditional skill-centered, functional, and individually focused definitions of literacy have dominated the educational landscape (Katims, 1994; Kliewer & Biklen, 2007; Mirenda, 2003). As discussed later in this chapter, these definitions have resulted in literacy programs built on readiness models and in functional approaches for students with complex needs for supports. Although some of these students can acquire conventional literacy skills with appropriate intensive instruction, others find themselves unable to reach the first rung of the metaphorical "ladder to literacy" as described by Kliewer et al. (2004, p. 378). Kliewer and Biklen (2007) described the unfortunate circular logic by which many students with complex needs for supports are deemed incapable of developing literacy skills and, often, placed in segregated classroom settings where they are not provided opportunities to develop literacy skills. The fact that these students do not develop literacy skills is then used as evidence that these students are indeed incapable.

It is clear that definitions are powerful and affect the classroom instruction, community services, and literacy opportunities offered to individuals with complex needs for support. Scribner noted the critical impact of definitions on educators: "Definitions of literacy shape our perceptions of individuals who fall on either side of the standard (what a 'literate' or 'nonliterate' is like) and thus in a deep way affect both the substance and style of educational programs" (1984, p. 6). We go further and reject definitions of literacy based on the assumption that only some people can be literate—there is no dichotomy of literate and illiterate individuals (Downing, 2005; Kliewer & Biklen, 2007; Koppenhaver, Pierce, & Yoder, 1995).

Taking all of the prior discussion into account, it is clear that no single definition of literacy will hold true for all times and places (Kliewer et al., 2004) and that literacy exists on a continuum and develops across an individual's lifetime (Koppenhaver et al., 1995). We propose five core definitional principles to broaden the ways we conceptualize literacy:

- 1. All people are capable of acquiring literacy.
- 2. Literacy is a human right and is a fundamental part of the human experience.
- 3. Literacy is not a trait that is isolated in the individual person. It is an ever-developing interactive tool and status for mutual engagement between a person and a community and its people, knowledge, and ideas; literacy requires and creates connections (relationships) with others.
- 4. Literacy includes observation, communication, social contact, internal connection and incorporation, and the expectation for interaction with all individuals and ideas; *literacy leads to enhanced empowerment*.
- 5. Acquiring literacy is an individual responsibility of each member of a community as well as a collective responsibility of the whole community; *that is, ensure that every person develops meaning-making with all human modes of communication* in order to exercise his or her personal and communal responsibilities and opportunities and to transmit and receive information and ideas.

These core literacy definitional principles underlie our discussion of literacy throughout this text and serve as important guidelines for providing quality literacy instruction. For a more in-depth discussion of each principle, we refer you to Keefe and Copeland (2011). We hope you agree that individuals with complex support needs must be welcomed as full and active participants into the literate community.

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### **REFLECTION QUESTION 1**

How do the ways we define literacy and the assumptions we hold affect educational opportunities for individuals with complex support needs?

# Literacy in America: Historical and Legal Landscapes

Over the centuries, American law and legislation have been intimately tied to literacy. These ties between law and literacy illustrate how important literacy is in a society, and the ways in which its power is viewed and used by governments. Literacy's perceived and actual power to increase employability, enhance democratic participation, and limit or enhance human rights can all be seen in different types of laws. For example, law was used to prevent access to literacy, as in the slave laws forbidding the teaching of reading to slaves. Literacy was frequently denied women to "protect" them or limit their public participation. Literacy also serves as a strong legal tool for political purposes, such as excluding immigrants or preventing access to democratic voting.

Lunsford, Moglen, and Slevin stated that for all people, "literacy is a right and not a privilege: A right that has been denied an extraordinary number of our citizens" (1990, p. 2). Unfortunately, in the United States, certain groups have historically been denied access to literacy, including people of color, women, and the poor. Because they were denied literacy, few first-person accounts exist that describe the deprivation. But Asante described his understanding in his moving memoir: "Now I see why reading was illegal for black people during slavery. I discover that I think in words. The more words I know, the more things I can think about. Reading was illegal because if you limit someone's vocab, you limit their thoughts. They can't even think of freedom because they don't have the language to" (2014, p. 229).

Furthermore, attempting to analyze the importance of reading in the lives of women, Acocella explained the meaning of the harsh punishment of the young heroine caught with a book at the beginning of the novel Jane Eyre, "A nineteenth-century reader would have understood, as a twentieth-century reader might not, that Jane's crime was made especially serious by the fact that it involved a book. In the history of women, there is probably no matter, apart from contraception, more important than literacy" (2012, p. 88).

Keefe and Copeland noted, "People with extensive needs for support represent the last group of people routinely denied opportunities for literacy instruction" (2011, p. 92). Furthermore, in their excellent examination of the history of literacy opportunities for students with intellectual disability (ID), Kliewer, Biklen, and Kasa-Hendrickson concluded that much of the history of literacy for people with complex needs for support has been characterized by a "narrative of pessimism" (2006, p. 175). As a consequence, literacy instruction has often either been denied them or provided in ways that did not meet their learning needs.

More recently, law has also been used to attempt to increase access to literacy instruction for students, as in the reading mandates of the Individuals with Disabilities Education Improvement Act (IDEA) of 2004 (PL 108-446) and the No Child Left Behind (NCLB) Act of 2001 (PL 107-110); and to shape certain aspects of public education, such as in the use of students' reading test scores to "evaluate" teachers' suitability for continued employment; or as a requirement for a "real" high school diploma. Most recently, NCLB has been reauthorized as the Every Student Succeeds Act (ESSA) of 2015 (S. 1177), which continues the focus on reading instruction as a critical component of college and career readiness for all students. (See Chapter 4 for more about academic standards related to college and career readiness.)

The historical and routine denial of literacy instruction to students and adults with disabilities is rooted in this conflicted legal history as well as in the ongoing exclusionary practices that keep people with disabilities out of rigorous educational opportunities and literate environments. The push and pull of historically restricting access in order to control certain

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populations, and now mandating access in order to make up for lost opportunities, is currently playing out in educational policy and practices. Future directions in literacy for people with disabilities will be informed by past restrictions, current and future law, and contemporary research and practices. Understanding the context set by this legal history and the current legal landscape can provide a strong foundation for understanding the absolutely critical nature of literacy in the lives of people with disabilities, improving literacy legal policies and practices, ensuring effective advocacy for literacy for all, and enhancing the literacy rights of people with disabilities.

### Literacy Is a Human Right

Luckasson explained that the human right to inclusive educational opportunities for individuals with extensive needs for supports is the same as for individuals without disabilities. She further noted that these rights are non-negotiable and are "aspects of being human that the social contract must respect" (2006, p. 12). At the national level, literacy is a vital part of inclusive education and is essential for full participation in society. Similarly, at the international level, reading and literacy are viewed as critical human rights and development tools for all people. On International Literacy Day in 1997, then U.N. Secretary General Kofi Annan stated:

Literacy is a bridge from misery to hope. It is a tool for daily life in modern society. It is a bulwark against poverty and a building block of development, an essential complement to investments in roads, dams, clinics and factories.

Literacy is a platform for democratization, and a vehicle for the promotion of cultural and national identity. Especially for girls and women, it is an agent of family health and nutrition. For everyone, everywhere, literacy is, along with education in general, a basic human right. (Annan, 1997)

In terms of international law, the U.N. CRPD, Article 24, contains this powerful obligation for education:

- 1. States Parties recognize the right of persons with disabilities to education. With a view to realizing this right without discrimination and on the basis of equal opportunity, States Parties shall ensure an inclusive education system at all levels and lifelong learning directed to:
  - a. The full development of human potential and sense of dignity and self-worth, and the strengthening of respect for human rights, fundamental freedoms and human diversity;
  - b. The development by persons with disabilities of their personality, talents and creativity, as well as their mental and physical abilities, to their fullest potential;
  - c. Enabling persons with disabilities to participate effectively in a free society. (U.N. General Assembly, 2006)

Thus, literacy must be an essential part of CRPD's call for the development of fullest human potential of all people with disabilities.

Twenty years ago, Yoder, Erickson, and Koppenhaver (1997) recognized the critical right of all people to literacy instruction when they wrote the Literacy Bill of Rights (see Figure 1.1). A Literacy Bill of Rights, written by three pioneers in the field of literacy instruction for students with complex support needs, not only proclaims that literacy is a human right regardless of disability, but it explains the nature of this right in detail, describing the specific literacy opportunities that should be afforded each person and emphasizing the importance of high-quality literacy instruction. This document is a strong foundation on which to build literacy instruction for your students.

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All persons, regardless of the extent or severity of their disabilities, have the basic right to use print. Beyond this general right are certain literacy rights that should be assured for all persons. These basic rights are

- 1. The right to an *opportunity to learn* to read and write. Opportunity involves engagement in active participation in tasks performed with high success.
- 2. The right to have *accessible*, clear, meaningful, culturally and linguistically appropriate texts at all time. *Texts*, broadly defined, range from picture books to newspapers, novels, cereal boxes, and electronic documents.
- 3. The right to *interact with others* while reading, writing, or listening to text. *Interaction* involves questions, comments, discussions, and other communications about or related to text.
- 4. The right to *life choices* made available through reading and writing competencies. *Life choices* include but are not limited to employment and employment changes, independence, community participation, and self-advocacy.
- 5. The right to *lifelong educational opportunities* incorporating literacy instruction and use. Literacy *educational opportunities*, regardless of when they are provided, have the potential to provide power that cannot be taken away.
- 6. The right to have teachers and other service providers who are knowledgeable about literacy instruction methods and principles. *Methods* include but are not limited to instruction, assessment, and the technologies required to make literacy accessible to individuals with disabilities. *Principles* include but are not limited to the belief that literacy is learned across places and time and that no person is too disabled to benefit from literacy learning opportunities.
- 7. The right to live and learn in *environments* that provide varied models of print use. Models are demonstrations of purposeful print use such as reading a recipe, paying bills, sharing a joke, or writing a letter.
- 8. The right to live and learn in environments that maintain the *expectations and attitudes* that all *individuals are literacy learners.*

Figure 1.1. A literacy bill of rights. (From Yoder, D.E., Erickson, K.A., and Koppenhaver, D.A. [1997]. A literacy bill of rights. Chapel Hill: University of North Carolina at Chapel Hill, Center for Literacy and Disability Studies.)

### THE POWER OF LITERACY

High-quality literacy instruction makes a real difference in people's lives. Acquiring even basic literacy skills can create opportunities to participate more fully in one's community, be less dependent on others, and make individual choices about what one wants to do or learn. In other words, literacy skills contribute to a more engaged, satisfying life. For instance, literacy facilitates participating as an active citizen in the democratic process and increases opportunities for communicating one's ideas, thoughts, and intentions (e.g., deFur & Runnels, 2014; Reichenberg & Lofgren, 2013). Acquiring literacy skills expands educational and employment opportunities and thereby promotes economic stability (e.g., Vaccarino, Culligan, Comrie, & Sligo, 2006). Improved safety, health, and well-being are also associated with basic literacy skills (Taggart & McKendry, 2009). Literacy skills create access to a greater variety of recreation and leisure activities and can boost self-confidence (van Kraayenoord, 1994) and support enhanced social interaction and relatedness (e.g., Forts & Luckasson, 2011). Take a moment to read about the ways in which literacy affects the lives of two young people with complex support needs, Milagro and Noah, in the "How Literacy Enriches Lives" textbox. Milagro and Noah have different interests, abilities, and backgrounds, yet their literate citizenship (Kliewer, 2008) enriches their lives in a multitude of ways, not the least of which is bringing them joy and personal satisfaction (see Figure 1.2 for an example of Noah's literacy journey).

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# HOW LITERACY ENRICHES LIVES: Milagro and Noah

#### Magdalena, Milagro's mom, says:

Our daughter, born August 7, 1998, was given the name Milagro Tonantzin, which means "miracle of mother Earth" in our native Spanish and Nahuatl language. As parents, we had no idea that our journey from the onset of her arrival would result in a constellation of unique outcomes that would provide a homegrown literacy-based framework. From the moment Milagro was born and suffered severe brain trauma, we were told by medical experts to expect the worst. Her initial medical diagnosis was hypoxic encephalopathy due an insufficiency of oxygen at childbirth, which resulted in a traumatic brain injury. She is now referred to as having cerebral palsy and is unable to swallow, blink, sit, or stand. She has seizures, cardiac hypertrophy, high blood pressure, and severe muscle spasticity with scoliosis. She breathes through a trach and is on oxygen 24/7, with severe intellectual impairment.

Initially, we were in shock because of the unexpected medical crisis. When we first saw Milagro, she was wrapped in wires, probes, and life-sustaining equipment. At that first moment of contact with our daughter, we touched her, looked at each other, and knew we had been presented with an extreme challenge. Creating a home environment for a medically fragile child, one completely predicated on her needs that would adapt and evolve over time, seemed insurmountable. We started to read and research to educate ourselves on children with traumatic brain injuries. The focus of our visits to the neonatal intensive care unit in those early days was talking to Milagro; touching her to stimulate her; and studying her every movement to learn every inch of her and her body responses, what she liked, and what she didn't like. These interactions became the first foundational actions of our parent-based literacy explanatory model. Creating literacy is an action-based process, and this was the first step.

Even when our daughter was at her most vulnerable due to her medical condition, she was still capable of learning through stimulation. As a newly made family, we were all three system outliers; we no longer fit into a "typical family" norm. My husband and I realized that whereas our daughter might be perceived by others as incapable, *we* perceived her as "capable with the potential to learn." It was we, as Milagro's parents, who held the ability to empower our daughter and to change the societal expectations and limitations that would be imposed on her because of her severe medical constraints. We supported her potential to become literate as defined by different norms, and we aided her learning as her capacity to learn was expressed in a series of nonverbal and later semivocal guttural responses and sound intonations. Milagro's form of communication is now the third language in our multicultural household. She challenges to us to understand it at every turn.

Every moment with Milagro became an opportunity to create an environment for learning. Lauro, her dad, excelled at coming up with story after story as he held her—even I became spellbound at his storytelling! Sound was the means of reinforcing Milagro's learning that she was important, that she mattered, and that we expected her to interact. She responded by smiling, cooing, engaging with her eyes, and creating repeated actions—her own self-developed forms of communication, to which we ascribed meaning. Gradually, we have changed her room from looking like a mini acute-care center to a place bright with color and alive with stimulating music, audio books, aromatherapy, and a collection of award-winning bilingual and bicultural books we read to her.

We also use music to create literacy and meaningful stimulation. We dance with her: slow dancing music so she gets a feel for the movement and rhythm of the body; fast dancing music to give her a feel for vibrant body movements. We are rewarded with smiles and eyes alive with joy, interest, and focus. We put her hands on our faces so she can feel and not just see our faces. We put her hands to our lips so she can feel the vibration of sound emanating from our mouths. We repeat her sounds as a way of affirming that what she says is important. Verbal and eye communication, in addition to touch, provide critical seeds of Milagro's literacy and are essential for building the bridge to her developing self-worth and self-esteem. We insist that everyone coming into our home introduce themselves to Milagro and speak *to* her, not *at* her. We strongly recommend that people new to her

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# Noah's Notes

# **Best Bud Brad**

Noah Tatz | Features



Brad and I pose at "the wall".

My bowling buddy Brad Harvey loves to bowl. That is how I met him. I've known him for about two years. I bowl for Special Olympics. Brad cheers for me and helps me bowl better.

Brad is a senior at La Cueva High School. Brad is amazing and awesome because he is friendly to me. He always says hi, and we talk about bowling.

Brad started working at Silva Lanes bowling alley his freshman year. He does everything there! Brad helps with bowling, the front desk, and the snack bar. Basically he helps with anything and everything.

Brad works many hours at Silva Lanes. He gets tired sometimes, but he still has time for some fun. Brad gets to bowl for free when he's at work. That's good! He also likes to hang out with his friends. On August twenty-second Brad and his identical twin brother Zach were born. Zach is older than Brad. His parents are Russ and Bari. Brad and Zach and his dad love to race cars on the asphalt track. At home he has two pets: a dog named Bear and a turtle.

Brad is in orchestra at LCHS. He plays the viola. He is really good at it. At age five he began to play the violin with a private teacher.

About 6 years ago his teacher asked him to try the viola. Brad likes the viola a lot because it is soothing and calming. So Brad has played twelve years! His orchestra has won two state championships. I think he is so happy and proud about it.

After high school Brad is going to do some more bowling and then college. He wants to go to West Texas A&M to become a special education teacher.



Brad plays the viola in orchestra class.

Figure 1.2. Noah's Notes.

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read to her as the primary way of introduction, so she gets exposed to their voices and becomes familiar with them.

In August 2013, Milagro celebrated her 15th birthday. She is a calm, confident, loving child who knows she matters in this world. She watches PBS with her dad and listens to NPR with her mom. She is read to often, and she listens to books as well: bilingual and bicultural audio books that soothe her mind and continue to strengthen her world of literacy. Our assumption is that she can learn, and she does not disappoint. She is always listening and watching out of the corners of her eyes. In our eyes, she is a stellar student, an honor student of home-based literacy, and she fully participates and engages. She is an excellent communicator. Milagro has met our expectations and is an intelligent and literate child whose eyes tell all.

### Jill, Noah's mom, says:

When Noah was in third grade, the teacher told us (bluntly!) that he was never going to learn to read. She was wrong. Noah was already reading, just not the way they were trying to teach him in school. Noah recognized lots of environmental print. He always knew when we passed McDonald's or Toys"R"Us. He loved to listen to the stories read to him every night. He started finishing the sentences and picking out familiar words.

Noah is now 21 and loves to read. He reads at a fifth-grade level, with excellent sight word skills and good comprehension, when he is given time to process. According to Noah, "Reading makes you smart. Reading is very important. Reading makes you effective. I love reading to kids."

Reading has enhanced Noah's quality of life. He loves to read books, magazines, and newspapers. Noah is fulfilled by the world around him. He is able to work on a computer, write for his school newspaper, and read to younger children. He can read a menu and order in a restaurant. Noah will tell you that reading is fun. We believe that Noah's ability to read enhances his life every day and continues to develop his great potential as an important participant in the world around him.

We believe that the need to be able to access and use information across all aspects of our lives is greater now than ever before. Everyone should be given the opportunity to gain these essential skills.

# LITERACY FOR LEARNERS WITH COMPLEX SUPPORT NEEDS

We think it is more useful to consider individuals with disabilities in terms of the supports they need to be active participants in their families, schools, communities, and places of employment rather than considering them simply in terms of an educational label or medical diagnosis. A diagnosis or label is helpful for many purposes (e.g., providing access to resources or services), but this alone does not convey all the information an educator wants and needs—for example, what a student's strengths and interests are—or provide information on how to design instruction to meet individual learning needs. When teaching literacy skills, it is critical also to consider an individual's need for supports, defined as "resources and strategies that aim to promote the development, education, interests, and personal well-being of a person and that enhance individual functioning" (Schalock et al., 2010, p. 224). Supports come in many forms: some formal supports, some generic services that are available to anyone, some specialized paid services, and some natural supports from friends or family.

Using a supports-needs model to consider disability calls our attention to the fit between a given individual's current abilities and skills and the demands of the environments in which that person participates. Supports act as a "bridge between 'what is' (i.e., a state of incongruence due to a mismatch between personal ability and environmental demands) and 'what can be' (a life with meaningful activities and positive personal outcomes)" (Thompson et al., 2009, p. 136). This paradigm is based on the fundamental recognition that all humans require supports, and receiving appropriate supports improves our ability to function. Some may require more intense support or supports in more areas of their lives than others, but everyone needs some level of support at one time or another.

## **Defining Complex Support Needs**

Individuals with complex support needs have varied, often overlapping needs for supports across multiple domains (e.g., academic skills, home living skills) and time. Their need for supports will likely be lifelong, although provision of appropriate supports creates a positive interaction between supports and functioning, improves life functioning, and may change the intensities and types of needed supports across time and circumstances (Schalock et al., 2010). Individuals with diagnoses such as ID, autism spectrum disorder, or multiple disabilities frequently have complex support needs, although individuals with other disability labels might also fit into this category. Although it is beyond the scope of this book to provide detailed information about how best to provide literacy instruction to individuals with every configuration of support needs, the guidelines, teaching methods, and examples provided throughout can be adapted for use with learners with many different types of support needs. Where applicable, we discuss research findings and recommendations pertaining to specific types of complex support needs an individual learner might have.

Using the supports-needs paradigm has the potential to positively affect the way in which education, health care, and other services are provided to individuals with disabilities. It requires that we take into account the demands of a given context and or environment and the individual's strengths and limitations in that context or environment when planning the supports that will allow the individual to be an active participant and acquire new skills to diminish the "gap" between demands and current skill performance (Thompson, Wehmeyer, & Hughes, 2010). This approach makes it far more likely that the instruction and services provided will be individualized, age-appropriate, and aligned with the individual's goals, interests, and preferences, in contrast with a medical model approach of focusing solely on an individual's deficits.

Consider, for example, how this supports-needs conceptualization of disability might affect provision of literacy instruction for Terri, a student with complex support needs. Rather than selecting an instructional program based on Terri's disability label (e.g., selecting a manualized sight word program because she has autism), the educational team-that includes Terriconsiders her current performance level across the multiple components of literacy; her age; the curriculum standards for her grade level; her communication and language skills; and finally, and just as important, her interests (currently Japanese manga). Based on this information, the team selects goals that align with curriculum standards and plans instruction that takes advantage of Terri's strengths and interests while also building new skills in her areas of weakness. The outcomes of considering disability in this way are that Terri attends a world literature class with her general education peers while receiving individualized support and literacy instruction within the class. Her support is sometimes provided by a teacher or paraeducator, and sometimes it is provided more informally by her peers. Terri is engaged and motivated in her classes and has friends she sees in and out of school settings. Meanwhile, she is acquiring skills that will be critical for her success in the postsecondary program she wants to attend in a nearby university, where her older brother also goes to school.

#### **REFLECTION QUESTION 2**

What is the rationale for providing comprehensive literacy instruction for individuals with complex support needs?

### **Core Principles for Literacy Instruction**

The closely related principles of *least dangerous assumption* and *presumed capability* are essential to opening the doors to effective literacy instruction for students with complex needs for support. The criterion of the least dangerous assumption was first proposed by Donnellan (1984) and can be summed up as assuming that all individuals, regardless of label or diagnosis,

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are capable of learning. Jorgensen noted that one outcome of the least dangerous assumption was that "Students are seen as capable of learning; educators do not predict that certain students will never acquire certain knowledge or skills" (2005, p. 4). Closely related to the least dangerous assumption is the presumed capability of students regardless of their label or diagnosis. This presumption of capability could be considered the most basic form of the least dangerous assumption. Low expectations based on an IQ score or label can have a negative impact on educational opportunities and outcomes for students with complex needs for support (Jorgensen, 2005).

This book is based on the least dangerous assumption that all people are presumed capable of acquiring literacy. The remaining sections of this chapter will lay a foundation to support the efforts of educators, policy makers, and individuals with disabilities and their families to support and uphold this assumption and enact the tenets of the Literacy Bill of Rights.

#### **Literacy Instruction Models**

It is particularly important that schools provide literacy instruction for individuals with complex support needs that will enable them to have access to the important benefits associated with literacy. Too often, as noted previously in this chapter, educational systems have either denied literacy instruction to these students, viewed them as incapable of learning, or offered instruction that is inadequate or ineffective (Kliewer et al., 2006). Such lowered expectations have resulted in poorer outcomes for many people with disabilities. For example, students with complex support needs have higher rates of postschool unemployment or employment in lowwage jobs, which results in lowered status and greater social isolation compared to typically developing peers or peers with high-incidence disabilities (Newman et al., 2011). Keeping this in mind, we will briefly examine the history of literacy instruction for students with complex support needs, addressing the implications, limitations, and strengths of different models used.

Readiness Model For many years, educational programs for students with complex support needs used a readiness model. This model required students first to master sequential subskills considered to be prerequisites for more advanced literacy skills. Failing a subskill meant not being allowed to progress or being denied the opportunity to continue literacy instruction (Mirenda, 2003). For example, children might be expected to learn and name all of the letters of the alphabet in order before being taught to read their names. Unfortunately, many of these subskills were taught in a decontextualized, disconnected manner, which made it very difficult for learners with complex support needs to master them or use them in meaningful ways. Skills learned were not connected to authentic purposes, which limited students' generalization of what they learned. This resulted in students not using them outside of school or intervention settings or using them only in limited ways. This instructional model often placed students in the vicious cycle previously mentioned: They frequently failed to master low-level skills taught in a decontextualized manner, which resulted in educators not providing higher-level literacy instruction-such as comprehension-because the students were not considered "ready," which resulted in students not progressing, and so forth. Furthermore, this model frequently resulted in age-inappropriate instruction that had little real value to motivate students or address their interests. In classrooms using this model, for instance, it was not uncommon to see 17-year-olds still singing the alphabet song or being drilled on color words, a situation that engendered further stigma and devaluation by peers and teachers.

**Functional Skills Model** Beginning in the mid- to late 1970s, the curriculum focus for students with complex support needs changed to functional skills (Browder et al., 2004). In terms of literacy instruction, this meant that educators taught students sight words considered necessary for survival in their schools and communities (Conners, 1992; Katims, 2000). Students receiving functional literacy instruction might spend time learning words like *exit* and *poison* or learning to write the words needed to complete job applications. In many ways,

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this instructional approach was an improvement over the readiness model. Students learned to read words that they could use immediately in their schools, job settings, and communities, which decreased their dependence on others. However, although functional literacy instruction has benefits, it also limits the range of literacy skills students can acquire and, therefore, their opportunities for full participation in their families, schools, and communities. This approach does not teach students skills that might allow a broader, richer range of literacy experiences, such as reading for pleasure, learning vocabulary terms that create access to science content, or writing an e-mail to a friend.

**Comprehensive Instructional Model** The National Reading Panel (NRP) identified components of effective reading instruction for typically developing students (Armbruster, Lehr, & Osborn, 2001) (see Figure 1.3). We assert that students with complex support needs benefit from literacy instruction that goes beyond a readiness or a functional skills approach to incorporate all the areas identified by the NRP and more. Functional skills, such as financial literacy, are important and should be a part of every student's educational experience. However, recent research examining literacy instruction for individuals with complex support needs has



*Fluency:* This is the ability to read text accurately and at a reasonably rapid, smooth pace. To be a fluent reader, a child must recognize words automatically without having to slow down to decode each word in a text. Fluent reading allows the child to concentrate on the meaning of what is being read instead of concentrating on each letter sound. Fluent readers can comprehend what they are reading more easily than readers who read slowly or in a choppy manner.

Vocabulary: A child's vocabulary is comprised of the words a child understands and uses in listening, speaking, reading, and writing. *Listening* vocabulary consists of words a child understands when she or he hears them spoken; it includes words that the child understands but may not use in his or her everyday conversation. *Speaking* vocabulary consists of words students understand and routinely use when speaking. *Reading* vocabulary consists of the words a child can read and understand. *Writing* vocabulary consists of words a child understands and can use when composing text. Having a well-developed vocabulary is important for beginning readers because to read a word in print requires having that word in your vocabulary. For example, decoding a word that you have never heard won't be very useful to you because you have no point of reference to understand its meaning.

Text Comprehension: Text comprehension is understanding the meaning of printed text, or, in other words, making sense out of what you read. It is the point of reading! Text comprehension can range from understanding the meaning of a single word ("Stop!") to understanding the nuances of meaning found in a Shakespeare sonnet. Effective comprehension requires several skills including efficient word recognition, a well-developed vocabulary, fluent reading, and adequate background knowledge ("knowledge of the world").

**Figure 1.3.** Components of effective reading instruction. (From Armbruster, B.B., Lehr, F., & Osborn, J. [2001]. *Put reading first: The research building blocks for teaching children to read: Kindergarten through grade 3.* Washington, DC: The Partnership for Reading.)

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shown how important it is not to underestimate these students or inadvertently limit their skill development (Allor, Mathes, Roberts, Cheatham, & Al Otaiba, 2014; Conners, 2003). Although not all students will become conventional readers or writers, educators can no longer come to that conclusion merely by looking at students' disability labels. Instead, practitioners must give students the opportunity to develop a broad range of literacy skills while taking into account their individual needs for supports. This begins by viewing *all* students as readers and writers, having high expectations for what they can learn, and providing appropriate, sustained literacy instruction in meaningful ways that will allow students to develop their skills and interests to the fullest extent possible.

Research conducted within the past 10 years has demonstrated positive student outcomes associated with providing what we term comprehensive literacy instruction (e.g., Allor et al., 2014). We define a comprehensive literacy instructional model as integrated instruction that teaches all the components of reading concurrently: early literacy skills, such as concepts about print; language development and vocabulary skills; word recognition skills that include both sight word and phonics knowledge; listening and reading comprehension skills; fluency; and writing. This model is in contrast to the decontextualized instruction of the past that sought to teach discrete skills (Browder, Ahlgrim-Delzell, Courtade, Gibbs, & Flowers, 2008). Figure 1.4 graphically illustrates how using this approach to literacy assessment and instructional planning looks. This diagram can be a useful tool when planning instruction. Figure 1.5 shows how Laura White, an early intervention therapist, used comprehensive literacy instruction to create an overall literacy instructional plan individualized for a young child with ID who was at the emergent literacy level. The plan addressed all aspects of literacy and served to organize the individual lessons Ms. White provided. (This student is now a conventional reader and writer who uses her literacy skills to enhance her active participation in school, family, and community activities.)

Although we have necessarily addressed various components of literacy in separate chapters within this book, we encourage practitioners to plan lessons that reflect this model of comprehensive literacy instruction and include instruction on multiple components within lessons. (See, for example, the tools and sample lessons in Chapters 5 and 11.) Creating lessons in this manner will help students with complex support needs make meaning, which in turn will support maintenance and transfer of skills beyond the teaching or intervention settings.



Figure 1.4. Components of a comprehensive literacy model.



Figure 1.5. Example of an individualized comprehensive instructional plan for a young emergent literacy learner.

### **Renewed Focus on Literacy Instruction for Individuals With Complex Support Needs**

In recent years in the United States, several legislative mandates, accumulating research findings, and advocacy actions by parents and individuals with complex support needs have contributed to renewed attention to the creation of effective literacy instruction for this population. Increased accountability for the teaching and learning of these students was a by-product of NCLB (recently reauthorized as ESSA) and the most recent reauthorizations of the Individuals with Disabilities Education Act (IDEA) in 1997 (PL 105-17) and 2004 (PL 108-446). IDEA 2004 mandated authentic access to the general curriculum for all students and required that students' progress toward meeting grade-level standards be monitored. These mandates also required educators to implement evidence-based instruction with students with disabilities. Teachers must now prepare students to meet more rigorous curriculum standards that require higher-level literacy skills and focus on standards for college and career readiness. This, in turn, necessitates that schools critically reexamine the models and types of instruction they currently use. A curriculum based solely on learning safety words, for example, will not be sufficient for students to meet more rigorous academic standards.

Another recent development affecting literacy instruction for students with complex support needs is the reauthorization of the Higher Education Opportunity Act of 2008 (PL 100-315). This reauthorization created more opportunities for these individuals to attend postsecondary programs by providing ways for families to secure financial support to pay for these programs. As a result, the number of students attending postsecondary programs has increased. The students in these programs need stronger academic preparation to be successful (Grigal, Hart, & Weir, 2014), further raising the expectations of parents and students themselves that effective literacy instruction be provided.

Still another development affecting practices in literacy instruction is a growing awareness that individuals with complex support needs, like their typically developing peers, have the capability to be lifelong learners (Moni & Jobling, 2014). Much more is known about effective reading instruction for children and adolescents with complex support needs, but increasingly,

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researchers are now examining reading instruction for adults (Copeland, McCord, & Kruger, 2016). The available research with adults shows that learning does not stop when students leave formal school programs. Individuals with complex support needs, like many typically developing adults, may have increased motivation and focus when pursuing learning opportunities of their own choosing and for their own purposes. Thus, literacy instruction should be available for adults who wish to expand their skills.

# **GUIDELINES FOR LITERACY INSTRUCTION**

Our own research and our review of the research and practitioner literature examining literacy instruction for students with complex support needs has resulted in our developing several overarching guidelines to use when planning and implementing literacy instruction for this group of individuals. Keep these in mind as you read each chapter. Each guideline arises from careful consideration of research findings and from the many years of advocacy by individuals with disabilities and their families.

The first of these guidelines is to *begin instruction with, and maintain, high expectations for students with complex support needs.* As you have read in this chapter, the beliefs we hold about our students' abilities and the definition and nature of literacy strongly influence what we choose to teach; how we teach it; and, as a consequence, student outcomes. Research simply does not support the outdated idea that we can know what a given student can learn based solely on a disability label. Second, combine high expectations for students with provision of individual-*ized, systematic, and sustained instruction.* Students with complex support needs benefit from well-planned, consistent instruction across their years of schooling (e.g., Allor et al., 2014). In the past, educators often discontinued instruction when students did not make rapid progress, not recognizing that they continue to learn when given high-quality, sustained instruction.

The third guideline is to provide language and communication interventions and support from the earliest years of a child's life. Language is the foundation on which later literacy develops, so it is crucial to support its development beginning at birth (see Chapter 2). Children use words to develop important conceptual understandings; language "drives cognitive development" (Neuman, n.d.), so we must give every child the opportunity to develop his or her language and communication abilities. We must also pay attention and consider a child's home language when planning language/communication and literacy intervention. (See Chapter 3 for a thorough discussion of the issues related to children whose home language is not English.) Related to this, the fourth guideline is to begin structured, developmentally appropriate literacy instruction during the preschool years and continue instruction across a student's formal schooling. Many individuals with complex support needs also choose to attend postsecondary programs (see Chapter 14 for more information) or adult education programs where they may choose to continue their literacy instruction.

Fifth, create comprehensive literacy instruction that includes concurrent instruction in all the core components of reading; this type of instruction is most effective for individuals with complex support needs (e.g., Allor et al., 2014; Browder et al., 2008; Browder, Ahlgrim-Delzell, Flowers, & Baker, 2012). Practitioner preparation programs have a responsibility to teach their students to move beyond highly scripted intervention programs focused narrowly on only one component of literacy and instead provide instruction across skill areas using engaging materials and activities. This leads to a sixth guideline: *Students with complex support needs learn to read in a manner similar to their typically developing peers and alongside those peers* (e.g., Wise, Sevcik, Romski, & Morris, 2010). Having students receive their instruction alongside typically developing peers utilizes the natural supports, motivation, and incidental learning opportunities this arrangement provides. Researchers and practitioners have documented that the intensive, individualized instruction required for students with complex support needs can be successfully provided within general education contexts (Hudson, Browder, & Wood, 2013; Ryndak, Moore, Orlando, & Delano, 2008/2009; Ryndak, Morrison, & Sommerstein, 1999). Researchers such as de Graaf and van Hove (2015), for example, found that students with ID who received literacy instruction in general

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education classrooms, regardless of their cognitive abilities, acquired higher levels of reading skills than students with similar cognitive abilities educated in segregated classrooms. Findings such as this lead to recognition that preservice practitioners should have coursework and field-work related to planning and implementing high-quality, comprehensive literacy instruction for students with complex support needs within general education settings. Teacher preparation program content must address universal design for learning lesson design, use of technology, and up-to-date literacy instructional practices. We hope that our book will prove useful to all those who want to provide effective literacy instruction to individuals with complex support needs.

## **REFLECTION QUESTION 3**

Think about the importance of literacy in your own life. How can you use the guidelines in this chapter to help individuals with complex support needs become members of the literate community?

## SUMMARY

The potential consequences of not providing effective literacy instruction for individuals with complex support needs are too serious to ignore. Michael Bach's statement on the importance of literacy, as cited by Ewing (2000), illustrates the critical need for appropriate instruction and support:

No longer viewed as a set of particular skills, literacy refers to a status that accords people the opportunities and supports to communicate, given the skills and capacities they have and can develop. To be literate is to have status, respect, and accommodation from others; to have skills in communication (verbal, written, sign, gestural, or other language); and to have access to the information and technologies that make possible self-determined participation in the communication processes of one's communities and broader society (p. 1).

Providing effective, high-quality literacy instruction for individuals with complex support needs is the responsibility of all of us—educators, policy makers, researchers, families, and adult service providers. Society is strengthened when all members have the opportunity for the "literate citizenship" Kliewer (2008) described. However, making these opportunities a reality requires change—specifically, substantial adjustments in how teachers and other practitioners are prepared and in how supports for this group of learners are conceptualized, implemented, and funded across the lifespan. As the remainder of this book demonstrates, considerable knowledge now exists within the field about how to provide effective, comprehensive literacy instruction for students with complex support needs. Although additional research will continue to inform our practice, individuals with complex needs for support cannot afford for us to delay making changes. *Now* is the time to embrace the challenge and ensure that *all* individuals have opportunities for effective, lifelong literacy instruction.

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