IT’S MORE THAN “Just Being In”

Creating Authentic Inclusion for Students with Complex Support Needs

Cheryl M. Jorgensen
Forewords by Paula Kluth & Dan Habib
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by

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Excerpted from It’s More Than "Just Being In" by Cheryl Jorgensen, Ph.D.
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Cheryl M. Jorgensen, Ph.D., is an inclusive education consultant in private practice after being a project director with the Institute on Disability at the University of New Hampshire (UNH) and an assistant research professor in UNH’s Education Department from 1985 to 2011. During her tenure with the Institute on Disability, she was the director or coordinator of state and federally funded research, personnel preparation, model demonstration, alternate assessment, and in-service training grants totaling more than $12 million. She is a cofounder of the National Center on Inclusive Education and collaborated with the U.S. Department of Education’s Schoolwide Integrated Framework for Transformation (SWIFT) Project.

Dr. Jorgensen works with parents, teachers, and administrators as part of the Vermont I-Team and in her private consultant role to increase their commitment to and capacity for including students with complex support needs in general education classes and to implement and sustain broad-based inclusive school reform.

Dr. Jorgensen has authored several books (including *The Inclusion Facilitator’s Guide* and *The Beyond Access Model*) and research articles; presents at state, national, and international conferences; and provides student-specific consultation throughout the United States.

Dr. Jorgensen received an award from the National Down Syndrome Congress in 2008 for her contributions to inclusive education research.
I was recently giving a presentation to a large group of educators. The talk went well, and the audience seemed receptive. A young teacher approached me as I was packing up to leave and asked a question I hear a lot. It seems like a simple question, but it is far from simple: “I really want to do this. I want to get students included in my school. How do I begin?”

I absolutely love this question, but I am often at a loss to answer it. It is hard to know what to share in this moment. I know enthusiastic educators do not want to hear all they need to learn, know, and do to successfully support students in inclusive environments. They want to know what step to take first and how to follow that successful step with another. I typically provide the people in these situations with a laundry list of recommended reading, web sites, and clips on YouTube because I am not sure how to give a pithy answer to such a big question. Unfortunately, this response can cause an interested advocate, teacher, or parent to feel totally overwhelmed and possibly to give up before they have even started.

I am so grateful that I can now provide a more helpful response to that teacher and others like her. My new response is, “You need to get a copy of It’s More Than ‘Just Being In’ and read it cover to cover! This book will guide you on where to start, where to go next, and how to create big and small changes in your school and your district.”

Believe me. There is not another book on the market like It’s More Than “Just Being In” I have been a public school teacher and inclusion facilitator in both elementary and secondary schools. I have spent time planning with teachers in the role of inclusive education consultant. I have also worked as a university professor and teacher educator in inclusive schooling. Therefore, my sagging bookshelf is overflowing with books on this topic. I have books on universal design for instruction, teaching strategies, students with specific disabilities, positive behavior supports, collaboration and co-teaching, and school restructuring. So many of these resources are top-notch; so many are critical to my work; and so many are useful for broad audiences, but none will take you step-by-step through the process of supporting and including one, a few, or many students with identified needs in quite the way this book does.

The process I refer to begins with setting a vision. In this book, Cheryl Jorgensen examines the “why” and “how” of doing so and provides a pathway to realizing that vision via chapters that highlight positive practices that are critical to a high-quality inclusive experience today. Nothing is left to chance. No stone is left unturned. Every necessary detail is provided. Certainly, the book is filled with Cheryl’s progressive values and ideology and it is—without question—centered
on a broader agenda of social justice and democratic education. At the same time, however, the book is no nonsense and filled with the tips, reminders, and practical advice that busy educators, advocates, and families need. For example, she highlights the importance of focusing (and refocusing) on communication needs as a tool for support, connection, and learning; she examines the broad range of supplementary aids and services that learners might require in any inclusive environment; and she emphasizes the critical need to facilitate and honor authentic reciprocal social relationships.

Critically, these information-packed chapters are not filled with mere steps to follow and practices to put into place. You will find steps and practices, no doubt, but the pages of this book are also chockful of classroom stories and examples of how to implement the many ideas provided; these stories and examples are as real as they are varied, and readers will appreciate that they focus on students with a range of needs, abilities, skills, challenges, characteristics, and strengths. Research is also a centerpiece of these chapters. Studies relevant to each topic are explored to help readers understand every aspect of inclusive education and support the many practical recommendations offered throughout the book.

And if all of that is not enough reason to buy, read, and absorb the wisdom in this book, let me share one more point. The book you hold in your hands (or see on your screen) is written by a researcher, scholar, educator, and advocate who is, quite honestly and without exaggeration, second to none. No author is in a better position to share the most relevant research, offer guidance for change, highlight necessary values and practices, or provide tips and ideas that are both teacher and administrator tested. Cheryl has worked intimately with both families and educators and has served as a critical friend to both elementary and secondary schools. She has worked in teacher education for years and has inspired thousands of new K–12 educators to teach inclusively in her work at the university level. Furthermore, she not only knows the research on this topic inside and out, but she has also written several of the studies that matter the most to those of us seeking answers and guidance in this field.

For all these reasons, I hope that this book is used in your pursuit and study of inclusive education. I also hope that you pass it on to a teacher, parent, advocate, therapist, school board member, or student who needs some information, insight, or inspiration. I know I will be purchasing several copies. I definitely need one for my bulging bookshelf filled with inclusion-related titles, but I also need several others for those who will undoubtedly say, “I really want to do this! Where do I begin?”

Paula Kluth, Ph.D.
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Excerpted from It's More Than *Just Being In* by Cheryl Jorgensen, Ph.D.
Our son Samuel was diagnosed with a complex, lifelong disability when he was about a year old. My wife Betsy and I reacted with a web of emotions. Fear. Grief. Confusion. Uncertainty. We were overwhelmed, and we craved reassurance that Samuel could still have the fulfilling, happy life that we had envisioned for him and his older brother, Isaiah.

We were seeking a vision for Samuel’s life. In that vision, Samuel would feel like he belonged—in our extended family, our neighborhood, our community and, most certainly, in our local schools.

Cheryl Jorgensen helped us find that vision.

One of Cheryl’s many hats back in the early 2000s was serving as a facilitator for the New Hampshire Leadership Series, organized by the University of New Hampshire Institute on Disability (part of a national Partners in Policymaking model).

My wife and I participated in the Leadership Series before Samuel made it past preschool. At every juncture of this yearlong “boot camp for disability advocacy” as I called it, Cheryl assured us that Samuel could be fully included in general education with the proper supports and instruction. She backed up that assurance with extensive supporting research and practical strategies for schools and families.

When I graduated from the Leadership Series in 2003, I was inspired to begin work on a personal documentary project that would eventually become my 2008 film Including Samuel. Of course, Cheryl was among the very first people I turned to for guidance and interviews. One of my favorite lines in the film comes from Cheryl, who states plainly, “All kids, with the right support and the right technology and the right teaching, can learn the general education curriculum. And that’s a pretty dramatic statement.” It is a dramatic statement, and Cheryl lays out a compelling, practical case for support in this book.

It’s More Than “Just Being In” is an essential and accessible tool for families and schools to develop a shared commitment to working in partnership for inclusion. The book is a blueprint for best educational practices, including

- Presuming competence
- Collaborative planning, teaching, and learning
- Administrative leadership
- Person-centered planning
- Communication strategies
- Self-advocacy and self-determination

Excerpted from It’s More Than "Just Being In" by Cheryl Jorgensen, Ph.D.
Standards-based individualized education programs
Implementing adaptations, accommodations, and modifications with fidelity
Facilitating social relationships
Effective postsecondary transition

And much, much more.

It is important to understand that Cheryl is not an outlier. She is just outstanding at presenting comprehensive and cutting-edge information in an accessible, empowering manner.

As a national leader in inclusive education, Cheryl is plugged into the most current knowledge base for inclusive education, such as the Schoolwide Integrated Framework for Transformation (SWIFT). I have been involved as a filmmaker for the SWIFT technical assistance center throughout the life of this $25 million federally funded effort (based at the University of Kansas).

SWIFT is the best chance we have ever had to scale up inclusive education nationally. Research from SWIFT and other studies is persuasive—when students with different support needs learn together, they experience better academic and behavioral outcomes, social relationships, high school graduation rates, and post-school success.

Although we all want large-scale systems change such as SWIFT, Cheryl also recognizes that most parents need a road map to advocate for inclusion at every juncture. It’s More Than “Just Being In” is that road map.

Oh, and I should mention that as I write this, Samuel is a high school senior, included in general education, on a track toward a regular diploma with an eye toward college, and surrounded by a wide circle of friends.

He belongs.
Thank you, Cheryl.

Dan Habib
Filmmaker and Project Director
University of New Hampshire Institute on Disability

Excerpted from It’s More Than “Just Being In” by Cheryl Jorgensen, Ph.D.
Preface

Are you a general education teacher who will have a student with autism spectrum disorder (ASD) in your class next year and just do not know where to begin? Do you wonder how you will communicate with him or her? Have you heard rumors about his or her challenging behavior? Are you concerned that your teacher evaluation will be affected if you spend a disproportionate amount of time with this student and fall behind in your syllabus?

Perhaps you are a special education teacher who is responsible for facilitating the inclusion of several students with multiple disabilities but cannot imagine how you will manage this with all your other responsibilities. Are you concerned about meeting your students’ individualized education program (IEP) goals within the general education curriculum and classroom?

Maybe you are a parent or guardian who desperately wants your child who has Down syndrome included with his or her classmates without disabilities, but you have not yet been able to convince the school that this is appropriate. Perhaps you have already tried the bit-by-bit approach suggested by the school but worry that at this rate your child will graduate before he or she gets the opportunity to be fully included. You want to be a collaborative team player and do not want to alienate those who are responsible for your child’s safety and emotional well-being.

Are you a secondary school administrator who is getting more requests for inclusion from parents whose children were in general education in the lower grades? You have been to conferences and read a lot of articles about inclusive education, but few seem to address the unique needs of secondary school students and staff. Maybe you wish that there were a step-by-step guide so there is some consistency in students’ educational programs and a shared understanding by staff about the purpose of inclusion.

This book was written to address these concerns and, more broadly, to help families and educators of students with intellectual and other developmental disabilities (IDD) to fully include those students in general education instruction within a general education classroom. Strategies are included for enhancing the participation of students who are already “in,” as well as strategies for moving students from a self-contained or life skills class into general education.

This preface presents a little bit about my history in the field of inclusive education, provides alarming statistics about inclusion in the United States, introduces three students whose stories are featured in this book, and shows how this book can be used in your unique situation.
MY HISTORY

I was hired by the University of New Hampshire’s (UNH) School of Health and Human Services in 1985 to coordinate a small in-service training project for teachers of “severely and profoundly handicapped” students. I spent the first couple of months of the project visiting the various programs in which these students were enrolled because I was new to the state and knew nothing about special education (I am a general educator by training and experience); some were in self-contained classrooms in public schools, some attended regional cooperative programs, and others attended classes housed in large residential facilities such as the now-closed Laconia State School. Two encounters during my tour of Laconia made a lasting impact on me.

I met Ronnie, who was lying naked on a gurney in the middle of a stark room that had no desks, books, or computers. The woman who was giving him a sponge bath said with a jolly laugh, “Don’t worry about Ronnie. He doesn’t mind. Come on in!” I was mortified, but I managed to say, “Oh, that’s no problem. I’ll just wait out here until you are finished.” Ronnie had cerebral palsy, could not talk, and had no way to communicate. Neither he nor the other five students in the room appeared to be engaged in anything that could remotely be considered educational. Although the facility was clean and there appeared to be as many staff people as residents, there were vestiges of the institutional life that had existed there for almost 100 years. It was chilling to see, embedded in the concrete walls, the heavy iron rings used to restrain people while they were bathed with cold water sprayed from common garden hoses. I did not know what Laconia had been like in the past, but the attitude toward and treatment of Ronnie still seemed inhuman.

The second encounter I had was with a program director at Laconia. He proudly showed me the facility’s “store.” There were racks of clothing, and the residents could use tokens to “buy” one of the hundreds of identical navy blue T-shirts or khaki-colored pants.

I naively asked, “Why don’t you just take people to K-Mart?”

The director said, “Well, we just don’t have enough staff for that, and, besides, the residents don’t have any money and all these clothes have been donated at no cost. It just wouldn’t be fiscally possible.”

I knew nothing about the disability rights movement at this point in my career. I had never heard of person-centered planning, community integration, or inclusive education. But I just felt in my gut that there was something drastically wrong with these situations, and I decided that I would do my best to ensure that no child was ever sent to a place like this again. I worked for the Institute on Disability at UNH for the next 26 years, supporting the inclusion of students with IDD through professional development, model demonstration projects, research, large-scale systems change efforts, reform of teacher certification and preparation, and dissemination of best practices. I retired from the university in 2011 and continue my work as an independent consultant and professional development trainer.

AND MILES TO GO

Much has changed since 1985, but much remains to be done.

• New Hampshire became the first state to close its public institution for people with IDD in 1991, and 11 additional states have since closed all of their
state-run large institutional facilities. Although that is good news for people living in those states, more than 26,000 people in other states still live in developmental disability-specific institutional settings, and more than 29,000 live in nursing homes (National Council on Disability, n.d.).

- Most students with IDD are still largely segregated from their classmates without disabilities, despite the fact they are educated in public schools. For example, from 2002 to 2011, the percent of all students ages 6–21 served in special education who were educated in public schools. For example, from 2002 to 2011, the percent of all students ages 6–21 served in special education who were educated inside the regular class 80% or more of the day increased from 48.2% to 61.1%. Yet, the 2012 average of all states’ placement of students with intellectual disability (ID) at least 80% of the day in general education was only 17.1% (U.S. Department of Education, 2014).

- The average of all states’ placement rates hides large state-to-state variation. According to the 36th Annual Report to Congress on the Implementation of IDEA (U.S. Department of Education, 2014), the percent of students with ID educated at least 80% of the day in general education classes ranged from lows of 4.4% in Washington, 4.8% in New Jersey, and 5.5% in Nevada, to highs of 64% in Iowa, 48.6% in Puerto Rico, and 45.5% in Alabama.

- Approximately 62% of students with ID in the United States do not leave school with a regular high school diploma (Institute on Disability, 2015).

- The U.S. employment rate for people with ID (ages 21–64) is 26.1%, compared with 41.1% for people with disabilities overall and 79.1% for people without disabilities (Siperstein, Parker, & Drascher, 2013).

There are some good reasons to be hopeful that these statistics will change. More schools are adopting a multi-tiered system of supports (MTSS) instructional framework, which is a whole-school, data-driven, prevention-based framework for improving learning outcomes for every student through a layered continuum of evidence-based practices and systems. One principle of MTSS is that all students, including those with IDD, have access to high-quality core instruction based on the principles of universal design for learning (UDL).

The Schoolwide Integrated Framework for Transformation (SWIFT), another initiative funded by the U.S. Department of Education, was a kindergarten through eighth-grade technical assistance center that helped schools create academic and behavioral supports that promote inclusive learning and academic achievement of all students, including students with IDD (University of Kansas, 2016). Although the project ended in 2017, staff continue contracted work with school districts throughout the United States. SWIFT classrooms represent diverse learning communities in which all students are learning together and have the supports they need to fully participate in the general education curriculum. General educators, special educators, Title I tutors, other support staff, and family and community members work in tandem to differentiate instruction. For example, you may witness a parent volunteer practicing sight words with a student, a general educator and a special educator leading differentiated small reading groups, a speech-language pathologist working on reading vocabulary with another group of students, and classmates collaborating on a reading comprehension activity. Students are valued for their unique contributions to the learning community, and educators have the support they need to successfully teach all students.
A majority of schools are still at the very beginning stages of including students with IDD in general education classrooms, despite these promising initiatives. I typically see one of three common situations when I consult at a school.

1. A student is primarily a member of a self-contained classroom and is mainstreamed for morning meeting, lunch, music, and perhaps another nonacademic subject.

2. A student is primarily a member of a general education classroom but is pulled out of language arts and math lessons to receive instruction in a setting with other students with disabilities.

3. A student is a member of a general education classroom for most of the day but is not really participating with his or her classmates in the same general education instruction and is an “island in the mainstream” (Biklen, 1985, p. 18).

Even if your situation is slightly different from these, this book was written to enable you to use whichever chapters meet your needs.

THE PURPOSE OF THIS BOOK

The purpose of this book is to provide a step-by-step approach to the inclusion of students with IDD, such as Down syndrome, ASD, and multiple physical disabilities—all students with complex support needs. It is written for families, the school-based members of students’ education teams, and administrators leading inclusion efforts in their schools. Although I am fully supportive of wholesale school restructuring to break down the barriers between general education, special education, Title I, and other categorical services, I know firsthand that most schools are not engaged in those efforts. And as my colleagues Barb McKenzie and Janet Sauer, parents of students with disabilities, say, “My child can’t wait for systems change!”

The Students

This book describes a step-by-step approach to inclusion for students with IDD. Although these deficit-based definitions will not be used anywhere else in this book, nor do they reflect my own beliefs about students’ capacity for learning, I share them here to let readers know that the strategies in this book are appropriate for students with the most complex support needs. A developmental disability

- Is attributable to a mental or physical impairment or a combination of those impairments
- Occurs before the individual reaches age 22
- Is likely to continue indefinitely
- Results in substantial functional limitations in three or more of the following areas of major life activity: 1) self-care, 2) receptive and expressive language, 3) learning, 4) mobility, 5) self-direction, 6) capacity for independent living, and 7) economic self-sufficiency
- Reflects the individual’s need for a combination and sequence of special, interdisciplinary, or generic services, individualized supports, or other forms of assistance that are of lifelong or extended duration and are individually planned and coordinated

Excerpted from It’s More Than "Just Being In" by Cheryl Jorgensen, Ph.D.
Some people with developmental disabilities are also diagnosed with an *intellectual disability*, which is defined (in the medical model of disability) as a significant limitation in both intellectual functioning and in adaptive behavior, which covers many everyday social and practical skills. Full disclosure here: I do not put any stock in the label of intellectual disability. All people have a variety of strengths and limitations and categories such as these are, in the opinion of many, wholly socially constructed (Biklen & Duchan, 1994).

The medical model definition of ASD includes deficits in social communication and social interaction across multiple contexts resulting in restricted, repetitive patterns of behavior, interests, or activities. In contrast to this deficit-based description, many people with ASD are constructing their own identities based on the idea of neurodiversity.

The disability rights perspective within the Autistic community is represented in the neurodiversity movement, which promotes social acceptance of neurological difference as part of the broad landscape of human diversity and seeks to bring about a world in which Autistic people enjoy the same access, rights, and opportunities as all other citizens. Acceptance of difference is essential to understanding, accepting, and benefiting from the contributions of everyone in our society, thus allowing all people to live up to their potential. (Autistic Self Advocacy Network, 2018)

**Composite Case Studies: Three Students**

Examples from the educational programs of three students who represent composites of many students whom I have known since the late 1980s will be shared throughout the book. James is a second-grade student with multiple physical disabilities due to cerebral palsy and cortical visual impairment (CVI). I met him when I was asked to consult to his small elementary school in a rural school district. On the day that I first visited James I learned that his parents wanted him to be a member of a general education classroom, but his school believed that his disabilities were too significant for him to gain much benefit from either the general education curriculum or being around his typical classmates. James used a wheelchair and did not have any means of communication other than certain voice inflections or changes in his body posture. His forehead was supported by a strap attached to the back of his wheelchair so that he would not slump when his neck muscles got tired. He needed assistance moving his hands meaningfully, using the bathroom, and eating. I spent a little time reading to him and noticed that he perked up when there was dialogue or during an exciting part of the story. James spent his whole day in a self-contained classroom with three other students with multiple physical disabilities and was engaged primarily in hand-over-hand activities of daily living and various therapies. He had a seizure disorder that was well controlled by medication. He wore glasses and hearing aids, and orthotics on his lower legs. Students like James are often described as having profound disabilities, and they usually participate in their state’s alternate assessment based on alternate achievement standards. I knew that there was much more to discover about James and was anxious to get to know his likes and dislikes, his personality, activities that aroused his attention, and, most important, what kind of communication supports would match his strengths and accommodate for his movement difficulties. James eventually became a fully participating member of a general education classroom through the advocacy of his parents and commitment of the other members of his education team. James now uses an iPad with the Compass app for communication.
Anna, a sixth-grade student with ASD, is the second student who is profiled in this book. I first met Anna at her home where she was the oldest child in a family of eight who were always on the go. She had just begun using an iPad, was a whiz at playing games, and could navigate through many different apps and web sites to find music and videos of her favorite singers. Anna’s parents told me that they were certain that Anna knew more than she could demonstrate, and they wanted her to be enrolled in the full range of general education academic classes when she moved up to the middle school the following year. She participated in art, physical education, and science with her typical classmates when I met her, and she spent the rest of the time in a classroom with five other students with ASD. I spoke to Anna’s case manager who was very concerned that Anna’s behavior presented a barrier to her greater inclusion. She noted that Anna had only recently returned to the school district from an autism-only residential school, and she was unsure how the strict applied behavior analysis program currently being used in the self-contained classroom would work in a general education class. Anna was highly dependent on tangible rewards, and staff frequently used the promise of those rewards (or the threat that she would not receive them) as incentives. Anna spoke some very short phrases in a meaningful way but did not have the technology to enable her to meet the same communication needs as her typical classmates. She had mastered the pre-primer and primer level Dolch words in isolation but did not currently make sense of connected text (Dolch, 1936). Anna’s eighth-grade year was fully inclusive of all core academic classes and electives after many professional development workshops and support from the districtwide inclusion facilitator. Anna currently uses an iPad with the TouchChat app for communication, and she participates in her state’s general assessment with accommodations.

Selena is a tenth-grade student with Down syndrome. I learned that her educational program was comprised of half a day in a life skills classroom with 10 other students with disabilities and the other half of the day in three general education elective classes (e.g., culinary arts, early childhood development, pottery). Selena and her parents wanted her to go on to postsecondary education in the field of tourism or computer technology and wanted her to take a typical course load of classes to broaden her knowledge of literature, science, history, and mathematics. Selena’s case manager expressed concern that her current academic skills were so far below those of the students in the high school’s general education classes that she would be lost and could never meet the academic expectations. I found Selena’s decoding skills to be quite good, but she struggled to demonstrate her comprehension when I spent a day observing her and working with her on some homework. Selena was often accompanied from class to class by a paraprofessional and would frequently glance behind her to see if the paraprofessional was still there. Through some restructuring of Selena’s education team to include a special education resource teacher instead of the life skills teacher (who was already overwhelmed with the other students in her classroom), Selena added general education core academic classes to her schedule and joined a school club that was focused on civil rights and social justice and another club focused on technology.

**HOW TO USE THIS BOOK**

Unlike other books that present a variety of inclusive education topics in somewhat random order, this book is structured so that it can be used in a sequential,
step-by-step manner. The titles of Chapters 2–10 begin with a verb—imagine, construct, write, identify, describe, establish, facilitate, and develop. This is quite intentional because I hope that you will be prepared to take action after reading each chapter. Each chapter begins with some background information about the topic, describes in detail the underlying rationale and detailed processes associated with the chapter topic, presents examples for one or more of the profiled students via the “student case study” boxes, and includes checklists that summarize the steps necessary to implement the suggested strategies. The book also features “best practices for inclusion” boxes to emphasize successful inclusion strategies.

Chapter 1 is titled “The Fundamentals of Inclusive Education.” Even if you are knowledgeable about inclusive education, I recommend that you read it because it sets the stage for each of the following chapters. It begins with the values- and research-based rationale for inclusive education. The core elements of inclusion are then described, including presuming competence, welcome membership in general education, full participation in general education instruction, learning of general education academics and inclusive functional skills, collaborative teaming, and administrative leadership.

Chapter 2 is titled “Imagine an Inclusive Vision for Education and Adult Life.” This chapter describes Making Action Plans (MAPS), a person-centered planning process that helps parents and schools establish inclusive visions for students’ education and life after high school. I suggest that MAPS be used just prior to a student’s very first day of public school (i.e., preschool, kindergarten) and then periodically until the student reaches about 10th grade. The best times to do revisions to the first plan are when there is a significant change in the student, in the composition of the student’s IEP team, and prior to transition to a new school or school district (e.g., elementary to middle, middle to high school).

Chapter 3 is titled “Construct Learning and Communicative Competence.” The fundamentals of presuming competence are taken to the next step—translating a belief in the student’s competence to creating the conditions under which that competence is demonstrated. Specific strategies are described related to providing students with a way to communicate about all academic and social topics as well as strategies for promoting self-advocacy and self-determination, which are skills needed by self-actualized and competent people.

Chapter 4 is titled “Write an Inclusive Standards-Based Individualized Education Program.” Sections from three inclusive standards-based IEPs are shared along with a step-by-step process for writing IEPs. Supplementary aids and services is addressed in a separate chapter because the topic is so extensive.

Chapter 5 is titled “Identify Supplementary Aids and Services as Part of an Inclusive Standards-Based IEP” and describes many possible supports, including adaptations, accommodations, and modifications, that a student might need for participation and learning. It also addresses a little-known aspect of supplementary aids and services, which are the supports needed by the team on behalf of the student, to enable him or her to make progress in the general education curriculum.

Chapter 6 is titled “Describe Inclusive Team Member Roles and Establish Collaborative Teaming Processes” and provides a guide for examining the current roles of all team members and restructuring those roles so that everyone is working toward the same goal—authentic inclusive education.

Chapter 7 is titled “Establish Valued Membership in General Education” and is based on the fundamentals of membership and belonging described in Chapter 1.
It presents a step-by-step guide to establishing a student’s membership in a general education classroom, with specific examples from the profiled students’ elementary, middle, and high school years.

Chapter 8 is titled “Facilitate Reciprocal Social Relationships” and describes what teams need to do and not do to make real friendships happen (Tashie, Shapiro-Barnard, & Rossetti, 2006). The importance of reducing barriers to authentic social relationships is presented along with strategies that parents and educators can use when more intentional facilitation is needed.

Chapter 9 is titled “Develop Learning and Participation Plans and Assess Their Fidelity of Implementation” and describes a collaborative planning process that identifies a student’s priority learning objectives within a unit of instruction and the specific supports that are needed in the domains that are affected by the student’s disability. A process for checking the fidelity of implementation of supports is also provided. Teams have greater confidence that the student’s measured performance is reflective of his or her potential and not a lack of opportunity to learn or poor instruction when the fidelity of implementation of supports is highly rated. Sample learning and participation plans for each of the three profiled students are shared.

Moving from high school to adult life is one of the most important transitions that all students will experience. Person-centered planning is described in Chapter 10, which is titled “Plan and Prepare for an Inclusive Life After High School,” as a strategy for planning and realizing students’ postsecondary education, employment, and community living goals.

Chapter 11 is titled “Solutions to Common Problems and Challenges in Achieving Inclusive Education” and provides solutions to the most commonly asked questions about inclusive education posed by parents, administrators, educators, and related services providers.

Although you can pick up this book and read the chapter or chapters that address the topics that interest you the most, there are a few situations in which reading the book cover to cover and following all the implementation steps might make sense, including the following.

- A child is making the transition from preschool to kindergarten and his or her team is planning for his or her inclusion right from the start.
- A student is making the transition from one grade level and building to an entirely new situation (e.g., elementary to middle school, middle school to high school).
- A student is moving from being largely self-contained to being a full-time member of a general education class.
- A student is moving from one school district to another and the new team has no experience with inclusive education.
- A student has been partially integrated in some general education classes, but there is disagreement within the team concerning the rationale for and “doability” of fully including the student in an age-appropriate general education classroom.
REFERENCES


With love to Byll, Katherine, Anne, Steve, Keith, Jason, Jordan, and Hugo
Imagine an Inclusive Vision for Education and Adult Life

He is a biter.” “She is a runner.” “He is nonverbal.” “She is off in her own world.” “There is nothing really there.” “He is difficult to be friends with because all he talks about is train schedules.” These statements are often used to describe students who have ASD and other developmental disabilities. They represent a belief that disability is a disease or disorder that needs to be cured and ultimately eradicated; that people with disabilities are abnormal and the rest of society is normal. The difficulties or challenges people with disabilities experience are placed within them when they are viewed this way, and, thus, they are required to change to be eligible to participate in the full range of inclusive school and community activities and environments. How often is it said, “She could never be included in a general education class because of her sensory issues?” or “He cannot hold a real job because of his challenging behavior issues?”

RATIONALE FOR CHANGING
THE FUNDAMENTAL VIEW OF STUDENTS WITH DISABILITIES

What if the fundamental way that students with disabilities are viewed could change so that their disability was viewed as a natural part of human diversity instead of a problem? What if people intentionally looked for their strengths and viewed their challenges as problems with their environment instead of trying to make people with disabilities like the rest of society?
What if the unique talents of students with disabilities were appreciated and the contributions that they might make to schools and communities were recognized? How would the lives of children and adults with disabilities be different? How would schools need to change? How would the role of professionals in education be different?

Completing a person-centered plan, such as Making Action Plans (MAPS; O’Brien & Forest, 1989), can help parents and professionals articulate a new view of a student with complex support needs based on a vision of an inclusive life in the community and open the door to an inclusive education that draws on students’ strengths rather than their perceived impairments.

**Best Practices for Inclusion**

Here is a strengths-based way of introducing Erin McKenzie, a student with Down syndrome, in the student profile section of the IEP.

- Erin will have a life in a community that values diversity and accentuates strengths, and she will share her gifts and talents with that community.

- Erin will have reciprocal relationships with friends. She will communicate and advocate for herself.

- Erin will have the same opportunities to learn and participate in typical classroom, extracurricular, and community activities when they would typically happen. Erin will graduate from high school in 2004 with her class and have continued postsecondary educational opportunities and a career that interests her.

Erin’s mother, Barbara McKenzie, shared Erin’s vision statements with parents and educators attending a workshop at the 2014 TASH conference. She told the audience that her vision had evolved over the years since Erin was a preschooler, and they were what kept her and Erin’s educators focused on the kind of life that Erin and her parents wanted for Erin someday in the future. It was this future vision—of living and working in an inclusive adult community—that provided the rationale for what Erin’s educational program needed to look like until she graduated.

Writing a vision statement that goes on a student’s IEP and articulating that vision in team meetings can help ensure that the myriad of small decisions made on behalf of a student with IDD are leading to, not interfering with, the ultimate goals he or she and his or her family have for the future.

This chapter provides several examples of vision statements and describes in detail a person-centered planning process that can help students and their families define their vision and make it operational for each year's IEP team.

Excerpted from It’s More Than "Just Being In" by Cheryl Jorgensen, Ph.D.
ELEMENTS OF A VISION STATEMENT

A vision statement should come from the heart but be specific enough so that an unfamiliar person knows exactly what is important to the student and his or her family. There is not a template for a vision statement but most contain a brief description of what the student’s education and future life after high school will look like with respect to living arrangements, health and safety, postsecondary education, employment, relationships, and how he or she will spend his or her leisure time. Adult life may be far in the future in the case of a 3-year-old or next year in the case of a 20-year-old. The second element of a vision statement describes what the student’s and family’s hopes are for the current school year.

Selena and Anna

Selena, a 10th-grade student with Down syndrome who is one of this book’s profiled students, had this vision statement on her IEP.

Selena wants to work in the tourism industry when she graduates from high school. She needs to be comfortable working in a fast-paced and inclusive environment, have a good command of spoken and written English, maintain her conversational French skills, understand the history of our country and continent, responsibly manage her money, and increase her understanding of other cultures to be successful in that career. Although travel is her most passionate interest, her best subject has always been computers, and we want to encourage her interest in that area too. Therefore, our vision for Selena’s 10th-grade education is that she be fully included in English, French, history, biology, computer technology, and math; and that she joins the social justice and technology clubs.

Selena was involved in writing this vision statement and advocated for her enrollment in the computer class. She read the statement to the school staff at the beginning of her 10th-grade IEP meeting. When school personnel raised some concerns about Selena’s ability to master the rigorous academic curriculum, her parents told them that they would be happy if Selena learned some of the most important concepts from her academic classes, and they were not concerned whether she passed the New York State Regents examination.

Anna’s vision statement had many of the same elements as Selena’s, although it contained a greater focus on social relationships.

The most important thing for us is for Anna to have friends, not special buddies. Anna loves her friends, and she thrives when she is with them outside of school. She communicates more, learns more, and feels a real sense of belonging. Yes, academics are very important, but Anna’s school experience and her adult life will be filled with loneliness without friends. We want Anna to be involved in the same classes and extracurricular activities as other sixth-grade students.

Excerpted from It's More Than "Just Being In" by Cheryl Jorgensen, Ph.D.
THE PROCESS OF DEVELOPING A VISION STATEMENT

Parents and school teams sometimes develop a vision statement together after they talk about the student’s interests, strengths, personality, challenges, and family values. Other parents and school team members benefit from using a person-centered planning process such as MAPS (O’Brien & Forest, 1989), which was first developed as the McGill Action Planning System.

Initial Preparation

The preparation involved in conducting a MAPS meeting includes identifying a facilitator and a chart-paper recorder; inviting the student’s family, friends, and education team members; asking all participants to read a short description of what the process is and is not designed to accomplish; and finding a comfortable location and convenient time for everyone to attend. Schedule about 2 hours for the meeting and send a reminder a day or so ahead of time. Some students write and deliver their own invitations. In other situations, a parent, guardian, or the student’s educational program case manager or inclusion facilitator can issue the invitation. A MAPS facilitator needs to be a strong advocate for the student and believe that he or she has gifts and talents that are more important than his or her disability and so-called impairments. The facilitator should understand the MAPS process, and if he or she has not been formally trained, then conduct a practice session with a small group of people who provide feedback on effective facilitation techniques.

Making Action Plans

Families and education teams use MAPS to help students plan for their futures and guide their education team in making decisions about the focus of the current school year. The process uses a person-centered approach in which future plans are built on the family’s and student’s dreams, fears, interests, and needs. It is directed and guided by the student and family and facilitated by someone skilled in using the MAPS process.

The MAPS process provides a structured format that helps gather information that supports decisions during the current school year, develop an IEP, or prepare for making the transition from grade to grade or school to adult life. It is a new way of thinking about assessment, providing a much broader view of the student’s life than the traditional perspective of outlining impairments in specific skill areas. The MAPS process can help build trust, a common purpose, and positive relationships among team members.
Participants
The following people are usually invited to a MAPS meeting, although this can be customized to ensure that the people who are the most emotionally connected to the student attend as well as people who may have a role in helping the student achieve his or her dreams and goals.

- Student
- Parent(s) or guardians, siblings, extended family
- The student’s friends
- IEP team members, the school principal, the special education administrator
- If appropriate, members of the community who may be involved in supporting the student’s postsecondary education, living situation, employment, social relationships, and leisure activities.
- Other people as requested by family (advocates, faith or community leaders)

Making Action Plans Agenda
Six questions are asked by the meeting facilitator during the MAPS meeting.

1. What is the student’s history?
2. What is the family’s and student’s dream?
3. What is the nightmare? What are the fears?
4. Who is this student? What are his or her interests, talents, strengths, and personality?
5. What does the student need in this school year to put him or her on the path to achieving the dream?
6. What steps need to be taken, and who will put the plan into action? What is the time frame for completing the action steps? How will the team know that the action plan has been successful?

Making Action Plans Norms and Processes
MAPS meetings have established norms that the facilitator describes at the beginning of the gathering.

- At each step, the facilitator asks the student to respond first. Then family members and other team members are free to respond in random order.

Excerpted from It’s More Than “Just Being In” by Cheryl Jorgensen, Ph.D.
• All ideas will be recorded, using actual wording if possible. Information or ideas can be revised or deleted at any time.

• Team members have the right to pass.

• Ideas are expressed in a positive way. The facilitator will ask that any negative information be restated in a more positive way.

• Team members will wait until the final step of MAPS to begin to evaluate the merits of specific ideas. It is acceptable to record ideas that appear to conflict with one another. To have a lengthy discussion of the pros and cons of each idea when it is initially expressed will rob the MAPS of its forward momentum and student focus.

What Happens After the Making Action Plans Meeting?
The chart paper—usually a combination of words and graphics—is given to the student and his or her family and the notes on the chart paper are transcribed and distributed to all participants. Individuals assigned to complete action steps do so in the time frame indicated. The group reconvenes within approximately 3 months to assess progress on the plan and revise any action steps as needed.

Using the Making Action Plans Vision Statement
First, a vision statement should be included on the student’s current IEP and at the beginning of the transition section of the IEP for a student who is 16 or older. The IEP form in some school districts has a placeholder titled Vision for the Student’s Education, Parent and/or Student Concerns, or Parent’s Input for the Student’s Education. Even if such a placeholder does not appear on an IEP form, the vision statement can be added as an attachment or recorded in the student profile section. The team should read this statement aloud at the beginning of every IEP meeting, and the statement should be updated on a yearly basis or when important changes occur in the student or in the family’s expectations regarding the future.

Sample Making Action Plans
The MAPS created for James, a second-grade student with multiple disabilities, is summarized in the following case study, and the action plan that resulted from the MAPS is depicted in Table 2.1. A checklist for developing an inclusive vision is depicted in Figure 2.1.
Table 2.1. Action plan for James's Making Action Plans (MAPS)

<table>
<thead>
<tr>
<th>Needs</th>
<th>Action steps</th>
<th>Person(s) responsible</th>
<th>Time line</th>
</tr>
</thead>
<tbody>
<tr>
<td>Give back to community</td>
<td>Support James every Sunday afternoon after church services to participate in the parish beautification program along with the other children from his Sunday school class.</td>
<td>Gramma</td>
<td>Beginning next Sunday</td>
</tr>
<tr>
<td>Play Minecraft on iPad</td>
<td>Purchase and install app. Consult state ADAPT Center to learn how to set up switch access.</td>
<td>Parents</td>
<td>Tonight</td>
</tr>
<tr>
<td>Play soccer at recess</td>
<td>Build adaptation to James's wheelchair that will allow him to kick the ball during a soccer game or practice.</td>
<td>Physical therapist (PT), OT, and physical education teacher</td>
<td>Next Monday for meeting One month to build and fine tune adaptation</td>
</tr>
<tr>
<td>Improve reading skills</td>
<td>Assess James's current reading skills. Fully include James in guided reading group. Create adapted PowerPoint or BookCreator books that read aloud and enable James to turn pages with switch. Order trial version of MEville to WEville literacy curriculum.</td>
<td>Reading specialist and speech-language pathologist (SLP) Second-grade teacher SLP and OT Special education teacher</td>
<td>A week from Thursday Starting tomorrow One month to create five adapted books Team, including parents, will review the curriculum in 1 month or as soon as the trial version arrives</td>
</tr>
<tr>
<td>Establish planning time for team</td>
<td>Review all providers' schedules and identify 45 minutes each week when all can meet to plan upcoming units.</td>
<td>Special education teacher and principal</td>
<td>Beginning in 3 weeks</td>
</tr>
<tr>
<td>Give James more control over his environment</td>
<td>Identify 10 times a day when James can make a choice or control his environment.</td>
<td>OT</td>
<td>OT will bring list to team meeting 3 weeks from today, and the team will select the top three to implement right away</td>
</tr>
</tbody>
</table>

(continued)
### Table 2.1. (continued)

<table>
<thead>
<tr>
<th>Needs</th>
<th>Action steps</th>
<th>Person(s) responsible</th>
<th>Time line</th>
</tr>
</thead>
<tbody>
<tr>
<td>Allow James more down</td>
<td>Observe other students to identify two times per day when they have unscheduled or choice time and allow James to choose a leisure activity to do with a friend during these times.</td>
<td>Special education teacher and paraprofessional</td>
<td>By next week</td>
</tr>
<tr>
<td>time</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Increase interactions</td>
<td>Make sure that James is working with his table mates when they are doing a cooperative activity. Program key phrases on his AAC device related to cooperative group work.</td>
<td>Paraprofessional</td>
<td>By next week</td>
</tr>
<tr>
<td>with peers in class</td>
<td></td>
<td>Second-grade teacher</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>SLP</td>
<td></td>
</tr>
<tr>
<td>Ride bus with Sam</td>
<td>Meet to discuss assigning an accessible bus to James’s neighborhood. Do a trial run to plan who James will sit next to, who will strap down his wheelchair, emergency procedures, and who will get him off the bus at school.</td>
<td>OT and PT Principal and special education director</td>
<td>Next administrative</td>
</tr>
<tr>
<td></td>
<td></td>
<td>District transportation director</td>
<td>team meeting</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Parents</td>
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</tr>
<tr>
<td></td>
<td></td>
<td>Bus monitor</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Bus driver</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Paraprofessional</td>
<td></td>
</tr>
<tr>
<td>Assign some homework</td>
<td>Give James one modified reading and one modified math homework assignment per week that will take no longer than 15 minutes to complete.</td>
<td>Second-grade teacher, special education teacher, parents</td>
<td>Next week</td>
</tr>
</tbody>
</table>

### JAMES’S MAKING ACTION PLANS

1. **What Is the Student’s History?**

**Mom:** We thought James was just perfect when he was born. You know, 10 fingers, 10 toes. About 5 minutes later we found out that his Apgar score was only 4, and they rushed him to the intensive care unit because his color did not pick up like they thought it should. Our pediatrician came to see us about an hour later and told us that he suspected that James might have suffered from a lack of oxygen, either sometime when I was carrying him or during the birth process. We were devastated, even though the doctor tried to reassure us. Over the...
Imagine an Inclusive Vision

- Ask the student if he or she wants to participate in a Making Action Plans (MAPS; O'Brien & Forest, 1989) meeting.

- Ask the student’s family if they want to participate in a MAPS meeting.

- Identify a facilitator and chart-paper recorder for the meeting and have an initial meeting with the student and family to discuss the process and identify participants.

- Schedule the meeting in a welcoming space.

- Be sure that the meeting space is accessible for all participants.

- Schedule at least 90 minutes for the meeting.

- Invite meeting participants.

- Provide snacks and drinks.

- Set up chairs around the focus student, with family and close friends in the front row and other participants behind.

- Post flip chart pages at the front of the room.

- Use markers with no scent.

- Conduct the meeting.

- Describe the student using person-first (e.g., student with Down syndrome) or identity-first (e.g., autistic student) language, depending on the student’s and parent’s wishes.

- Develop an action plan to implement the recommendations that arise from the meeting.

- Give the flip chart paper to the student and his or her family and a typed version to all participants.

- Follow up on the action steps on a regular basis.

- Write a vision statement and include it in the IEP.

Figure 2.1. Checklist for developing an inclusive vision.

It’s More Than “Just Being In” by Cheryl M. Jorgensen.
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Excerpted from It’s More Than "Just Being In" by Cheryl Jorgensen, Ph.D.
next few months, during his well-baby visits, we learned that James had cerebral palsy. This started a whole round of visits to specialists at the children’s hospital, and they found that James had some hearing and vision problems as well. He had to have a special enriched formula because he did not nurse well. Our worst fears were realized when he did not reach some of the important early milestones, such as holding his head up at 5 months or crawling at 9 months. His doctor referred us to the early intervention network, and our days were filled with visits from nurses, nutritionists, SLPs, and physical therapists (PTs).

Dad: All of these folks tried to be encouraging, but I lost a lot of sleep because every day my wife would have a new problem to talk to me about when I came home from work.

Mom: We had to admit to ourselves that our little boy was not just going to catch up if he had enough therapy, but our son would have a disability that would likely stay with him his whole life.

Gramma: I know that Gina and Don have gone through an awful lot since James was born, but I have always just looked at him as my precious grandson. He is cuddly, he smiles a lot, and he just seems to be a happy boy. I do not want to dismiss their concerns, but I have always thought that James’s parents can handle just about anything that comes their way and that James can have a great life.

Early intervention OT: I have known James since he was about 6 months old, and, even though I do not provide services to him anymore, I do occasionally babysit him so that his mom and dad can have a night out. You know how some kids just tug at your heart strings? That is James. He has a lot of determination and has made some really good progress over the years with his AT, and I hope that people continue to see all of his strengths and not only the scores on his assessments.

2. What Is the Student’s Dream?

James (using his AAC device): Pilot!

Dad: Yeah, my son wants to fly airplanes! You know when your kids are young and you do not want to discourage them from being whatever they want to be? I do not know if we should kind of tell him the reality of what he will be able to do and not do.

Mom: I want us to keep an open mind for as long as we can. We decorated James’s room with posters of airplanes and spaceships. We have every DVD ever made about space, and he is actually able to play them by activating a switch that was hooked up to our DVD player. He plays them repeatedly. We made his wheelchair into a plane this Halloween, and he was the hit of the neighborhood party. It is hard to dream when you see all the challenges that lie ahead, but I guess we have the same dreams for James that other parents have for their kids. We

Excerpted from It’s More Than “Just Being In” by Cheryl Jorgensen, Ph.D.
Imagine an Inclusive Vision

want him to be happy, have a lot of friends, learn all he can in school, and do something he loves when he gets to be an adult. I cannot really think ahead to the specifics of his life when he leaves school, but right now my biggest dream is that he learns to talk or at least communicate with us so that we know what he is thinking. I just know that he knows more than he can tell us, but so far the technology is not that great.

Gramma: I want James to grow up to be a good person and give something back to his community and not always have to have people doing things for him. I guess independence and happiness are my biggest dreams for him.

3. What Is the Nightmare? What Are the Fears?
Gramma: I do not know if I can answer this without crying.
Dad: We have all had our worst case scenario thoughts over the years, and we try not to dwell on them. What good does that do? We just try to stay positive and let James know that we love him and will always be there for him.
Mom: Well, obviously, my biggest fear is about James’s health. Thank God he has been healthy for the last few years except for the occasional cold. But when I listen to the PT, I worry about what will happen if he does not ever walk. Will his bones get brittle? I worry about him developing scoliosis. Other than the medical concerns, which are huge, I guess the fear that I hardly dare to say out loud is that James will be shut away in a segregated classroom and then shut away in a sheltered workshop when he gets older. My biggest fear is that he will be alone and be lonely, regardless of whether he ever learns to tie his shoes or wash his clothes. That would be the worst thing that could happen.
Gramma: Well, that will never happen if I have anything to say about it.

4. Who Is This Student? What Are His or Her Interests, Talents, Strengths, and Personality?
Dad: Like we said before, James loves airplanes, spaceships, anything that flies. I do not really know when it started, but it seems like he has been interested in those things since he was a little guy. Maybe he will design the next space shuttle—stranger things have happened!
Mom: I actually wrote some things down before this meeting so I would not forget anything. It is so easy to look at all the things your kid cannot do. James is really caring and tuned in to other people’s emotions. If somebody in the house is sad or upset, then you can tell that he is concerned for them by his facial expressions and the sounds he makes. He is very curious. Even now, when we put him on the floor,
he wants to roll toward his toys and play with them, even if they are out of reach and it is a struggle for him to get there. He loves using his switches to turn on the DVD player or when he was younger, we had some of those bears that clap or puppies that flip over that he could activate by just hitting a big button. I wish we had more things that he could control in his environment. Although he is usually happy, he can get frustrated, and I want to just make things easier for him.

Gramma: I know he loves books. I do not really know if he can read yet, but he calms right down when I read to him. I can see him looking out of the corner of his eyes to follow along with the pictures.

Third-grade teacher: I would like to jump in here, and do not quote me on this, but I am pretty sure that he has learned to read some words. When we have him read a book that has a predictable or repetitive storyline, I can see him trying to form the words even though he cannot say them. He clearly prefers informational text about planes and spaceships of course!

SLP: I second that. We have just started programming his AAC device with the ending words to familiar poems and repetitive storylines. He will reach out at the right time to hit those buttons when we set up the page for him and give him a little support at his elbow.

Sam (classmate): James is funny. He makes these funny sounds, and we try to figure out what he wants.

Penelope (classmate): James is my second best friend behind Hillary. He has some cool apps on his iPad, and we all like to play with him at recess or snack time. He lets us use the iPad too.

Theo (classmate): I think if I were James I would want to fly right out of that wheelchair. One thing I know is that his favorite food is yogurt.

5. What Does the Student Need in This School Year to Put Him or Her on the Path to Achieving the Dream?

Mom: Communication is the number one priority.

Dad: I agree.

Gramma: Maybe a way for him to tell us when he is not feeling well. I would also like to see him do more reading at home.

Special education teacher: I think he needs more reading instruction. It seems like he is making some connections but not quickly enough for me and for the pace of the curriculum. I feel like we do not have enough hours in the day to give James everything he needs. We need some dedicated planning time every week to plan out how he will be more active in the classroom.

Theo: Can we figure out a way for him to play soccer with us on the playground?
Penelope: He needs Minecraft on his iPad.

Sam: Can James ride on my bus?

OT: More opportunities to control his environment.

SLP: I think we can do a better job helping James interact with his classmates. It is hard when he is just learning how to use his AAC device, but maybe we can set up a communication circle for him and teach his classmates how to be better communication partners.

Mom: Wow, that sounds amazing!

Paraprofessional: Give James some time during the day when we are not all on him. All the other kids get to take minbreaks and we do not even notice, but if James is a little bit off task, then we all think that he must get right back to work. I hope this does not offend anyone.

Dad: I wonder if he should be getting more physical therapy. Should we start letting him control his wheelchair? I know one thing that he, or rather his mother and I, need is some idea of what we should be doing.

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**What We Like and Admire About James**
- Determined
- Curious
- Attracts both girls and boys as friends
- Persists until we understand what he is trying to communicate
- Caring
- Intuitive about others’ feelings
- Knows a lot about space science

**What Is Important to James**
- Being around friends all the time
- Space, spaceships, space travel
- Having apps and games on his iPad that other he and other kids like to play
- Getting out of his wheelchair several times a day
- Giving him space to just sit back and observe several times a day

**How We Can Best Support James**
- Listen hard to what he is trying to communicate.
- Don’t put words into his mouth but give him choices about what he wants to communicate.
- Tell him when we are going to move his body.
- Tell him that we know he has a lot to say and is smart and that we are trying our best to give him a way to communicate.
- Make sure that his friends are involved in updating his iPad with games and apps.
- Include his parents and grandmother in problem-solving.
- Make sure that information is sent home over the weekend so that family can preview upcoming books and lessons.
- Encourage his interest in space.

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Figure 2.2. James’s one-page profile.

Excerpted from *It's More Than "Just Being In"* by Cheryl Jorgensen, Ph.D.
with him at home related to his academics. I feel like we spend a lot of time with our older daughter on her homework, but James is just kind of sitting there.

6. What Steps Need to Be Taken, and Who Will Put the Plan Into Action? What Is the Time Frame for Completing the Action Steps? How Will the Education Team Know That the Action Plan Has Been Successful?

See Table 2.1 for the action plan that was created at the end of James’s MAPS meeting.

CONCLUSIONS

James’s parents crafted this vision statement as a result of participating in the MAPS meeting.

James is a curious and loving boy. He has great strengths as well as some challenges. As parents, we have some practical tools and suggestions for successful inclusion for James, and we hope the team will be supportive of these suggestions. As parents, we hope that the whole team has the right attitude and is fearless, is creative, acknowledges his challenges, is not afraid to make mistakes, and celebrates his success. We would like to see James communicate effectively—to be able to express his novel thoughts and knowledge. We feel it is important for the team to foster social interactions with peers and for James to be in the general education class all day, every day in order for him to achieve the dreams we have for him.

They also created a one-page profile (see Figure 2.2) to share with James's team at every meeting, and as he grew, they updated it with his new interests, talents, and needs for support.
Creating Authentic Inclusion for Students with Complex Support Needs

"Just Being In"

Cheryl M. Jorgensen

IT’S MORE THAN "Just Being In"
Creating Authentic Inclusion for Students with Complex Support Needs

For students with disabilities, including those with complex support needs, inclusion means more than just physical presence in a classroom—it means valued membership and full participation in a general education classroom and the school community. This book is your school team’s practical blueprint for making authentic inclusion happen in K–12 classrooms.

Taking the stress and uncertainty out of inclusion, top expert Cheryl M. Jorgensen guides you step by step through her accessible approach to creating inclusive learning environments for students with autism, Down syndrome, intellectual disability, and multiple disabilities. You’ll get a clear rationale for meaningful inclusion and learn how to use strengths-based, person-centered planning to meet the needs of each individual student. Concrete, research-based examples show you what successful inclusion looks like, and ready-to-use strategies help you
- presume and construct all students’ competence develop supports to promote participation and learning
- write inclusive, standards-based IEPs
- collaborate with all IEP team members
- promote friendships and social connections
- assess academic progress
- help students transition to the next grade
- support students as they plan for life after high school
- overcome common challenges to inclusion

Especially helpful for new teachers—but a great source of real-world ideas for any educator or parent—this essential guidebook will help your school team develop fully inclusive classrooms where every student learns and thrives.

INCLUDES PRACTICAL MATERIALS:
Three in-depth case studies woven throughout the chapters, helpful checklists and tables, sample IEPs, additional online resources, and reproducible forms to help you implement inclusion.

ABOUT THE AUTHOR: Cheryl M. Jorgensen, Ph.D., is an inclusive education consultant in private practice after being a project director with the Institute on Disability at the University of New Hampshire (UNH) and an assistant research professor in UNH’s Education Department from 1985 to 2011. She is a cofounder of the National Center on Inclusive Education. Jorgensen has authored several books (including The Inclusion Facilitator’s Guide and The Beyond Access Model) and research articles; presents at state, national, and international conferences; and provides student-specific consultation throughout the United States.

Cheryl M. Jorgensen

Forewords by Paula Kluth & Dan Habib