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Creating Authentic Inclusion for Students with Complex Support Needs

by

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Excerpted from *It's More Than "Just Being In": Creating Authentic Inclusion for Students with Complex Support Needs* by Cheryl M. Jorgensen, Ph.D.

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Paul H. Brookes Publishing Co.
Post Office Box 10624
Baltimore, Maryland 21285-0624
USA

www.brookespublishing.com

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Typeset by Progressive Publishing Services, York, Pennsylvania.
Manufactured in the United States of America by
Sheridan Books, Inc., Chelsea, Michigan.

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Library of Congress Cataloging-in-Publication Data

Names: Jorgensen, Cheryl M., author.

Title: *It's more than "just being in" : creating authentic inclusion for students with complex support needs* / by Cheryl M. Jorgensen.

Description: Baltimore, Maryland : Paul H. Brookes Publishing Co., 2018. | Includes bibliographical references and index.

Identifiers: LCCN 2017051005 (print) | LCCN 2018005221 (ebook) | ISBN 9781681251738 (epub) | ISBN 9781681251752 (pdf) | ISBN 9781681250786 (paperback)

Subjects: LCSH: Inclusive education. | Children with disabilities—Education. | Classroom environment. | BISAC: EDUCATION / Special Education / General.

Classification: LCC LC1201 (ebook) | LCC LC1201 .J6699 2018 (print) | DDC 371.9/046—dc23
LC record available at <https://lcn.loc.gov/2017051005>

British Library Cataloguing in Publication data are available from the British Library.

2022 2021 2020 2019 2018

10 9 8 7 6 5 4 3 2 1

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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. 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.

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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.

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.

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.

- 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)

Needs	Action steps	Person(s) responsible	Time line
Give back to community	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.	Gramma	Beginning next Sunday
Play Minecraft on iPad	Purchase and install app.	Parents	Tonight
	Consult state ADAPT Center to learn how to set up switch access.	Occupational therapist (OT)	Within 2 weeks
Play soccer at recess	Build adaptation to James's wheelchair that will allow him to kick the ball during a soccer game or practice.	Physical therapist (PT), OT, and physical education teacher	Next Monday for meeting One month to build and fine tune adaptation
Improve reading skills	Assess James's current reading skills.	Reading specialist and speech-language pathologist (SLP)	A week from Thursday
	Fully include James in guided reading group.	Second-grade teacher	Starting tomorrow
	Create adapted Power-Point or BookCreator books that read aloud and enable James to turn pages with switch.	SLP and OT	One month to create five adapted books
	Order trial version of <i>MEville to WEville</i> literacy curriculum.	Special education teacher	Team, including parents, will review the curriculum in 1 month or as soon as the trial version arrives
Establish planning time for team	Review all providers' schedules and identify 45 minutes each week when all can meet to plan upcoming units.	Special education teacher and principal	Beginning in 3 weeks
Give James more control over his environment	Identify 10 times a day when James can make a choice or control his environment.	OT	OT will bring list to team meeting 3 weeks from today, and the team will select the top three to implement right away

(continued)

Table 2.1. *(continued)*

Needs	Action steps	Person(s) responsible	Time line
Allow James more down time	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.	Special education teacher and paraprofessional	By next week
Increase interactions with peers in class	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.	Paraprofessional Second-grade teacher SLP	By next week
Ride bus with Sam	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.	OT and PT Principal and special education director District transportation director Parents Bus monitor Bus driver Paraprofessional	Next administrative team meeting Two weeks before start of school in the fall
Assign some homework	Give James one modified reading and one modified math homework assignment per week that will take no longer than 15 minutes to complete.	Second-grade teacher, special education teacher, parents	Next week

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

- 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.

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 at 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

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 minibreaks 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

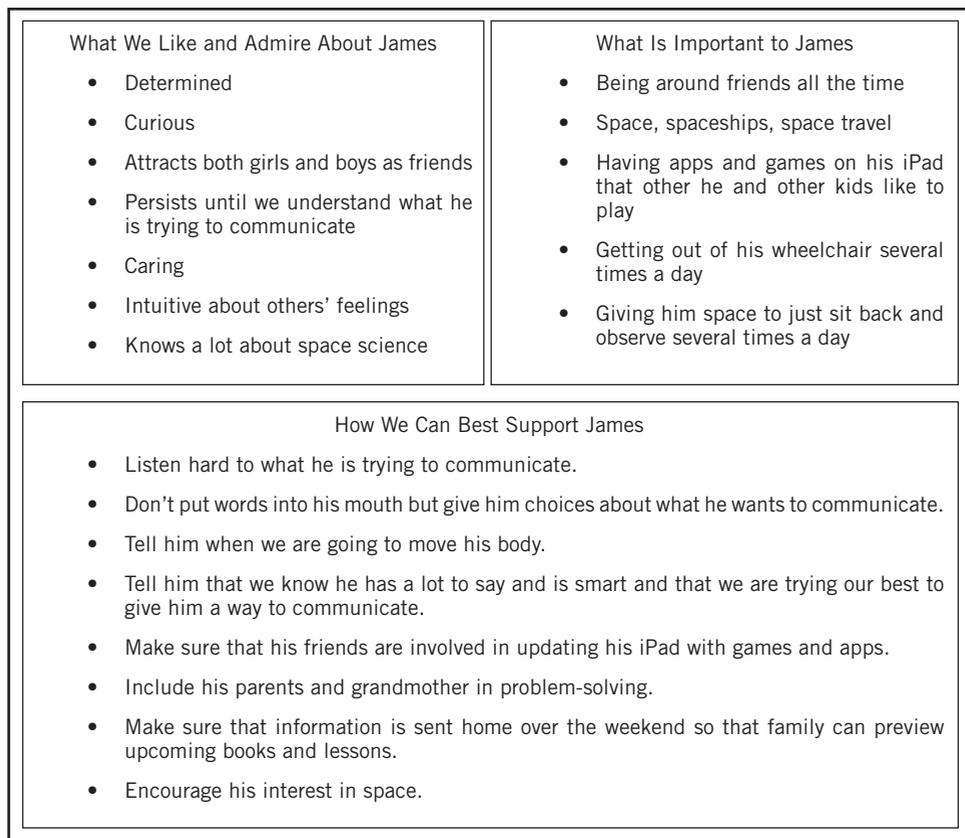


Figure 2.2. James's one-page profile.

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.