

Disability Solutions

A resource for families and others interested in Down syndrome and related disabilities.

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Paraprofessionals in Education

Paraprofessionals in the Classroom: What Role Do They Play?

by Patti McVay

Students with disabilities are successfully included in general education classrooms across the country. Success is a result of scheduled planning, regular meetings, discussions, and openness to new ideas, and taking time to see children as children. In these meetings and discussions the foundation for success is built. For instance, when thinking about including a student with a disability in a general education classroom, the most common first response is to envision all the fears, barriers, and problems that may arise. However, when the team, including parents, takes time to discuss what they know about the student, the picture begins to change. Each member provides a new piece to the puzzle about that student, allowing the

group to see how much is already known and how to make this experience a success. Some of the following ideas may assist parents and professionals to build a team that puts children first through communication, planning together, and finding ways to support each other no matter what difficulties arise.

Role of the Paraprofessional

As the team plans, they may decide that a student needs a paraprofessional to support the classroom teacher and the student. Paraprofessionals, or educational assistants, are important members of the education

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from the editor:

It's I.E.P. Season. . .

Growing up, I thought there were four seasons in a year: fall, winter, spring, and summer. I've decided, however, that for families of kids with special needs there are not four, but five seasons in a year: fall, winter, spring, IEP, and summer. During the late spring, parents and professionals share stories of the myriad of IEP meetings across the nation. Some go pleasantly and others sound like the beginnings of war.

This year, along with the usual mix, I experienced a new twist to IEP season (no, not El Nino). The authors who contributed articles to this issue of *Disability Solutions* shared with me their knowledge regarding paraprofessionals, as well as their dreams of what an inclusive classroom and community look like. They spoke of paraprofessionals working with every student and serving as the "extra set of hands" all teachers need. They described situations where students willingly participate in supporting their classmate with special needs by adapting activities or providing prompts to guide their friend. "But," I thought, "if the students take on those tasks, won't the classroom lose the paraprofessional?" Maybe, but probably not. If classmates begin to provide "natural prompts," it allows the paraprofessional to focus on other tasks such as creating the materials needed for an upcoming lesson the teacher has designed. One success (reducing the prompt needed from adults) leads to another (more time for creative planning).

Most importantly, both authors (Mary Beth Doyle and Patti McVay) feel clear communication and brainstorming by the team is essential to the success of students in inclusive settings—and any other setting. Regular team meetings, clear expectations of each other, and mutual respect promote creative planning and success for all students. As schools implement IDEA 97, parents will become a more frequent addition to the planning team. We will, however, be among the newest to this experience. It is imperative that we foster open communication and avoid confrontational situations when meeting to plan and brainstorm for our children. To prepare yourself and the rest of the team for this, I challenge you to complete the *Create-A-Team!* and *Dream Your Team Meeting* exercises provided by Mary Beth Doyle. I think you will find it an enlightening process. One that will dissolve any barriers that exist between members of the team.

Now that I think about it, there are six seasons: fall, winter, spring, IEP, summer, and implementing the IEP, which never ends. Parents have asked to be a part of the team for a long time. Now that the opportunity is built into IDEA 97 for us, will we live up to the responsibility? I hope so!

Warmest regards,



Paraprofessionals in the Classroom: What Role Do They Play?

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team. When a paraprofessional is assigned to a teacher or classroom to assist students with special needs, it is crucial that they are viewed as a support for all students. This encourages and allows the teacher to take ownership for every student in the class. It also provides the teacher and all students an opportunity for extra instruction and support. Paraprofessionals commonly assist with tasks such as:

- ✓ leading small group instruction designed by the teacher,
- ✓ gathering materials,
- ✓ providing assistance for personal care and other physical needs,
- ✓ assisting students to complete directions given by the teacher,
- ✓ facilitating interactions between students,
- ✓ adapting lessons under the teacher's guidance, and
- ✓ executing other, often unseen, but very important tasks for the classroom community.

As the complexity of classrooms change, the role of the paraprofessional also changes. With increased information and research, we can draw from established best practices for paraprofessionals to ensure quality instruction for students. These best practices include all the activities listed above as well as an increasing role in the student-centered team.

Paraprofessionals are a great asset to the educational team, but there are some constraints on the responsibilities they can and should have. By law, a paraprofessional or education assistant cannot:

- ✓ write programs without supervision of certified personnel,
- ✓ create new, alternative instruction without direction from the teacher or other certified personnel,
- ✓ implement "behavior" ideas without direction of the teacher or other certified personnel, or
- ✓ take complete responsibility for any students.

Sometimes when the role of the paraprofessional is unclear, they may actually be a barrier to student learning (see *My Child Has A New Shadow... And It Doesn't Resemble Her!* page 5). It is helpful if the paraprofessional continually asks the following question while assisting a student: "Is this something a classmate, buddy, or peer tutor could be doing rather than me? Can this student be successful with less assistance overall?"

Often parents will advocate for the presence of a full-time paraprofessional out of concern for their child's success. It is important to discuss the role of the paraprofessional several times each year. If a student can be successful in the classroom once peer supports are developed, the role of the paraprofessional changes. For some students the paraprofessional will continue to be a necessity. However, their direct interaction with the student should lessen over time as natural supports and accommodations are developed and the student learns the classroom routines.

Teacher-Paraprofessional Relationship

The relationship between the classroom teacher and the paraprofessional, along with their interaction with the rest of the team, is the key to success for students in any learning environment. It is working together that builds success. Here are some characteristics of a successful, growing team, particularly the teacher and paraprofessional relationship within that team:

- ✓ Time together in planned regular meetings. Initially these meetings will focus on learning to work together with the student(s). Later, the discussions will focus on problem-solving, brainstorming, and, most of all, celebrating the successes. When building the student's success is the focus of the team, there is a lot to celebrate.

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Paraprofessionals in the Classroom: What Role Do They Play?

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- ✓ Teachers take ownership for all the students in their classroom by interacting, teaching, talking, and having fun with every student.
- ✓ Teachers and assistants share the different responsibilities for supporting all the students in the class. For instance, the teacher and paraprofessional may occasionally switch small groups providing a chance to implement new strategies and measure student growth.
- ✓ Paraprofessionals are careful not to take too much ownership of a student or activity. Sometimes this means waiting for the teacher to see a student has a concern instead of stepping in to meet the student's need immediately.
- ✓ Paraprofessionals and teachers constantly ask, "Could a friend be doing this? Am I a barrier or preventing friends from interacting with this student by being too close or available?"
- ✓ Paraprofessionals look for opportunities to encourage and coach classmates or others on how to say something and when to say it rather than playing "interpreter."
- ✓ Paraprofessionals move throughout the classroom to help all the students rather than hover over the student with an IEP.
- ✓ Teachers, paraprofessionals, support staff, and other school staff make an effort to provide a high ratio of reinforcement to directive. Studies suggest that a ratio of four-to-one (four reinforcing comments to every one directive) is ideal. This isn't easy. "Catching" specific students and classmates being good can make a big difference in classroom management.
- ✓ Teams consider other kids as team members too. Students often come up with ideas and solutions adults wouldn't even consider.
- ✓ Teachers and paraprofessionals look for ways to facilitate and encourage independence. This often means stepping back to prevent over helping or hovering.
- ✓ Staff help kids understand what is expected and how to do something correctly rather than tell them what not to do. For instance, saying "Please walk in the hall" instead of "don't run!" Or saying, "use your words (or communication device) to tell him how you feel when your mad" instead of, "Don't hit!"

These are some ideal characteristics found in teams working together to build successful and positive classrooms for everyone. What is important is to be committed to working things out together.

Conclusion

Building and maintaining a team is not easy. It helps to clarify the roles and responsibilities of each team member at the beginning of the year (see *Create-A-Team!* on page 10). When there is confusion about who is to do something, it is important for the team to discuss the answer together. For this process to be effective, however, it requires commitment by each team member to on-going problem solving rather than giving up when things get tough. This commitment is what helps the team get through difficult times as well. It works in life outside the school, and in building teams for successful students as well.



Patti McVay is the team leader for the Multnomah Education Service District Supported Education Team and Director of the Outreach Center for Inclusive Education in Portland Oregon. Through the combined efforts of the Outreach Center and Supported Education Team, Patti, her team consultants and paraprofessionals assist school teams including students with disabilities in general education classes. Through the Outreach Center, over 40 teams are supported in Oregon, Washington, California, Kansas, Florida, and Massachusetts. Patti is also an adjunct professor at Portland State University and is a nationally recognized educator, working with teams to create learning environments that support all children, families, and educators.

My Child Has a New Shadow... And It Doesn't Resemble Her!

by Mary Beth Doyle, Ph.D.


It is February. You realize the classroom assistant, whom *you* requested, has become your child's new shadow. You've received school projects that you suspect the paraprofessional had more fun creating than your child. The paraprofessional has been invited to team meetings, but the classroom teacher has not. You've even received phone calls requesting your child and the assistant go over to play at a classmate's house!

Are you aware that paraprofessionals make up one of the fastest growing, yet least understood positions in public schools today? In fact, in the early 1960's there were approximately 10,000 paraprofessionals working in public schools, while current estimates range from 300,000 to 500,000. Along with this significant increase in numbers of paraprofessionals in schools, their roles and responsibilities have expanded markedly. Instead of performing tasks that are primarily non-instructional in nature, such as clerical work or housekeeping, paraprofessionals are now involved in activities that are more instructional, such as implementing instruction designed by a certified teacher or carrying through with therapy activities designed by certified therapists. One reason for these changes is the increasing numbers of children with disabilities receiving part or all of their education in general education classrooms.¹

As more students with disabilities are welcomed into the same schools and classrooms as their siblings and neighbors, schools are responding by hiring paraprofessionals to assist classroom teachers in meeting the needs of this new mix of students. Generally, para-

professionals do not have a teaching certificate. Although some have college degrees, they are not certified as a teacher. Until recently, little attention has been directed toward clarifying the roles and responsibilities of paraprofessionals who are working in general education classrooms. School personnel are beginning to focus on identifying roles and responsibilities of paraprofessionals and distinguishing the different responsibilities of noncertified (paraprofessionals) and certified personnel (teachers and therapists). Clearly these are important conversations within the educational arena. It is critical that parents of children with and without disabilities join into the conversations that will shape the ways adults work together to support the learning and growth of all children.

Parents can influence and support the development of the roles and responsibilities of paraprofessionals in several ways. First, and perhaps most importantly, parents must establish a primary relationship with the classroom teacher, not with the paraprofessional. Second, parents should ask two questions that are simple, yet often overlooked: "What are the responsibilities of the paraprofessional on *our* team?" and "How are they different from other team members?" Third, parents must establish clear lines of communication with the classroom teacher. While these are simple acts, discussing all of them will have a significant impact on the manner in which the paraprofessional interacts with all the children in the classroom. Each of these areas is discussed in further detail in the remainder of the article.

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Establish a Positive Home-to-School Relationship with the Classroom Teacher

It is important for every parent to meet and develop a relationship with their child's classroom teacher. As a parent of a child with a disability, this holds true for you as well. One of your primary goals is to become *just another parent*. Sign up to participate in classroom activities such as fundraisers, being a reading partner, or snack rotation. Attend class plays and performances. Sign up for parent conferences with the classroom teacher without an entourage of other related professionals. You need to know the classroom teacher's thoughts, perspectives, and insights about your child. Your actions will communicate to the classroom teacher that she is the teacher for all the children in the classroom and your child is one of those children. Be as involved with the class as other parents of children in the classroom. Try not to overdo it or under do it—strike the right balance.

While you are in the classroom for parent meetings or as a volunteer, look and listen carefully. Watch to see if the classroom teacher and the paraprofessional interact directly with your child in a manner similar to children without disabilities. If they do not, this may be important information about their perceptions of their roles and responsibilities to your child. Look to see if your child's work is displayed in the room and hanging on the bulletin board as often as his classmates. Listen for language that might communicate who is responsible for your child. For example, "That's Sarah's aide" or "She helps Sarah" instead of "Mrs. Smith is our classroom assistant" or "Mrs. Smith helps us to do our work." The language chosen by the teacher and paraprofessional communicates assumptions they, and others, hold regarding who is primarily responsible for all of the children in the class, including your child.

If it appears that the paraprofessional is primarily responsible for your child, you need to speak directly with the classroom teacher. Explain your observations and your interpretations in a clear and calm manner. This may be an opportunity to begin a discussion about roles and responsibilities. On the other hand, when you see and hear things that increase your comfort level regarding your child's participation in classroom activities, tell the teacher. Use descriptive language such as, "When I see you touching Sarah's shoulder, it tells me that you care about her" or "Although my child's work is at a very different level than the other children, seeing it displayed with everyone else's tells me her contributions are valued and respected." Be specific and descriptive.

Remember to thank and encourage the teacher throughout the year. Teachers need to know that parents and other members of the community appreciate their hard work. Building a strong foundation to the relationship between you and your child's classroom teacher is critical. It should be your primary relationship in the school.

Role Clarification

When paraprofessionals work in general education classrooms, it is not uncommon for classroom teachers to be unclear about the specific responsibilities of the paraprofessional who is working in their own classroom. In many cases, the responsibilities of the paraprofessional are not understood by any member of the educational team. This is often because no one has taken the time to discuss what he is supposed to do. Often there is a general sense that the paraprofessional is simply supposed to "know" what to do and how to do it.² In order to maximize the instructional benefits associated with having a paraprofessional in the class-

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And It Doesn't Resemble Her!

room, parents must address the issue of role clarification with classroom teams. Every member of the team will benefit from these discussions.

The first step is to suggest that your child's core team – general education teacher, paraprofessional, special educator, and parent – come together to clarify the role and responsibilities of the paraprofessional. This can be done at any time during the school year. In fact, this conversation would be helpful to have two or three times during the year as dynamics within every classroom change throughout the school year. Keep in mind that as the team begins to clarify the role and responsibilities of the paraprofessional, an interesting and exciting phenomena will occur: other members of the team will begin to understand their respective roles and responsibilities more clearly. Why? Because classroom personnel are interdependent. As one person's roles and responsibilities shift there is a ripple effect on others.

Begin the examination of the role and responsibilities of the paraprofessional by reviewing a widely accepted definition of paraprofessionals:

Paraprofessionals are those:

1. whose positions are either instructive in nature or who deliver other direct services to students and/or their parents; and
2. who work under the supervision of teachers or other professional staff who have the ultimate responsibility of the design, implementation, and evaluation of instructional programs and students' progress.³

Using this definition, paraprofessionals generally provide assistance to individual students and small or large groups of students under the supervision of a classroom teacher who has designed the instructional tools and strategies.


Ask your team if this is the definition they use for

the paraprofessional who works in the classroom where your child is a member. If the response is "yes," examine the definition more carefully by breaking it apart and discussing each section as it specifically relates to your child. For example, if your team agrees that the paraprofessional is a school employee "whose position is either instructive in nature or who delivers other direct services to students or their parents," then what are those specific instructional responsibilities? What are the other direct services, if any? As a team, generate a descriptive list and write the responses on chart paper so everyone can follow the discussion easily.

Next, discuss the second portion of the definition: "paraprofessionals work under the supervision of teachers or other professional staff who have the ultimate responsibility of the design, implementation, and evaluation of instructional programs and students' progress." As the parent-member of the team, ask the group, "Who is responsible to supervise the paraprofessional?" Followed by, "How often does this occur?" Additionally, ask the team to clarify which certified team member is ultimately responsible for the design, implementation, and evaluation of your child's instructional program.

In the next phase, the team clarifies the responsibilities of the paraprofessional more specifically. As a group, decide how you will deal with the following questions:

1. Who manages daily preparation and feedback tasks for the paraprofessional?
2. Who plans the weekly instruction for children without disabilities? Who plans the weekly instruction for children with disabilities?
3. Who creates the necessary adaptations for children without disabilities? Who creates the necessary adaptations for children with disabilities?
4. Who ensures instructional integrity and how is that

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monitored for children without disabilities? Who ensures instructional integrity and how is that monitored for children with disabilities?

5. Who is responsible to provide ongoing training and feedback to the paraprofessional?

It is important to be aware that in most cases, the paraprofessional should not have the primary responsibility for *any* of the above areas. As a rule of thumb, the paraprofessional should function as an “extra pair of hands” to assist in the classroom. Generally, these hands are not trained in curriculum and instruction and should not be given the primary responsibility for the development of your child’s educational program.

As a parent, if your team is relying on the paraprofessional to take the lead in these areas of curriculum and instruction, you need to communicate your concern by raising the issue in a very direct manner. Pose the question: “Why is it that a certified person, the general education teacher, is planning, implementing, and evaluating the curriculum for children without disabilities, while a noncertified person, the paraprofessional, is doing that work for my child who has a disability?” Your goal in asking this question is to help your team problem-solve other ways to meet the instructional needs of your child. The paraprofessional can assist with the implementation of instruction developed by the teacher, but he should not design the instruction. For example, the classroom teacher designs a lesson for a small reading group where your child is a member. On certain days of the week, the paraprofessional may implement the instruction the teacher developed, while on other days of the week, the classroom teacher will implement the instruction. This approach ensures that the original instruction is developed by a certified teacher who understands the scope and sequence of instruction. It also ensures the certified teacher is taking responsibility for working

directly with your child in the context of a reading group. This is critical because it ensures that the classroom teacher or special educator maintains the responsibility for your child, as well as for the direction of the paraprofessional’s work.

Communication

Establish and maintain direct communication with the classroom teacher. Avoid sole communication with the paraprofessional or the special education teacher. While they may augment the communication, it is important for you, as the parent, to communicate directly with the classroom teacher. After all, if your child is in an inclusive classroom, he spends more time with the classroom teacher than any other team member. If the paraprofessional is the primary person to maintain communication with parents, misunderstandings about who is really the teacher can arise. While the special educator might maintain primary communication with parents, she can only offer a part-time perspective as she probably does not spend the entire day in the general education classroom. If your child divides his day between a regular education and special education classroom or resource center, it is still important to maintain a direct line of communication with the regular classroom teacher.

The specific communication system may be written or verbal and the frequency may vary. Develop a reasonable system with the classroom teacher. For example, it is unrealistic to expect the classroom teacher to maintain daily narrative communication as she has approximately 25 or more students in the classroom. Daily written communication with all 25 families is a challenge to say the least! Work directly with the teacher to decide the type of communication and frequency that would work the best in your own situation.

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My Child Has a New Shadow...

Conclusion

As increasing numbers of paraprofessionals are working in public schools to support the inclusion of students with disabilities, parents need to provide support and direction in defining the variety of ways in which paraprofessionals can be helpful. In doing so, it is important to remember paraprofessionals are not substitutes for certified personnel. Rather, paraprofessionals provide an extra pair of hands in classrooms where the combination of needs necessitates two adults to coordinate and meet the needs of all the children in the classroom.

So, on the next sunny afternoon, take a moment to walk outside with your child and look closely at his shadow.



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1. Doyle, M.B. *A Qualitative Inquiry Into the Roles and Responsibilities of Paraeducators Who Support Students with Severe Disabilities in Inclusive Classrooms*. Unpublished dissertation, 1995. University of Minnesota.
2. Doyle, M.B. *The Paraprofessional's Guide to the Inclusive Classroom: Working as a Team*, Brookes Publishing Co., 1997.
3. Giangreco, M., Edelman, S.W., Luiselli, T.E., and Macfarland, S.Z. "Helping or Hovering? Effects of Instructional Assistant Proximity on Students with Severe Disabilities." *Exceptional Children* Vol. 63:1, 1997, p. 7-18.



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Resources

The Paraprofessional's Guide to the Inclusive Classroom: Working as a Team. Mary Beth Doyle. Published by Paul H. Brookes Publishing Co., 1997. ISBN: 1-55766-312-2. 800/815-9417.

A nicely organized book that is actually a workbook for special education teams. Dr. Doyle has done a superb job of breaking down the plethora of concerns paraprofessionals face as they attempt to be the "extra set of hands" for each member of the multidisciplinary team. The author outlines activities that help each team member express their ideas, visions, and thoughts about the mechanics of working together and the role of the paraprofessional. Additionally, Dr. Doyle suggests that the entire workbook will take approximately 5 hours to complete. Those five, well-spent hours could save triple the time needed to "fix" the problems that can result from unclear expectations.



The Inclusion Notebook: Problem Solving in the Classroom and Community. Kathleen Whitbread, Editor. Published quarterly by Pennycorner Press. PO Box 8L, Gilman, CT 06336. 860/873-1311. E-mail: tin@pennycorner.com. ISSN: 1089-4691. \$14.95.

The Inclusion Notebook is published four times during the school year. Each edition has ten pages of brief articles, book reviews, conference reports, checklists, lesson plans, resource guides, and management tips that are easy-to-read and useful for teachers and support staff. Each issue contains the "TIN Pull-out Page" containing ready-to-use tips or suggestions for the classroom.



Inclusion: An Essential Guide for the Paraprofessional. Peggy A. Hammeken. Published by Peytral Publications, 1996. ISBN: 0-9644271-6-8. \$19.95. Peytral Publications, P.O. Box 1162, Minnetonka, MN 55345. 612/949-8707.

Inclusion: An Essential Guide for the Paraprofessional provides tangible suggestions and tricks-of-the-trade that are helpful to the paraprofessional and the certified teacher.





Create-A-Team!

Advocating for your child with Down syndrome or related disability is often complicated. Emotions, politics, past experiences, and dreams all begin to collide as you sit at the table with the multidisciplinary team to discuss the student, your son or daughter. It is easy to forget that each person on the team has a unique set of responsibilities to your child and the team. It may be helpful to define what qualities you value and see as essential to work successfully with your child. It is helpful to include your child with a disability in the following activities.

The following activities are adapted with permission from The Paraprofessional's Guide to the Inclusive Classroom by Mary Beth Doyle. Published by Brookes Publishing, 1997.



Activity One: Create-Your-Paraprofessional

As a family, list the qualities each of you associates with an "ideal" paraprofessional. Be sure to include training, personality, talents, skills, and other abilities that would be helpful for the paraprofessional to have.



Discussion:

What do you do or what can you do as a family to support the paraprofessional in moving toward becoming the "ideal" paraprofessional for your child? How will you share information and provide feedback?

Activity Two: Create-Your-General Education Teacher

As a family, list the qualities that each of you associates with an "ideal" general educator. Be sure to include training, personality, talents, skills, and other abilities that would be helpful for the general educator to have.



Discussion:

What do you do or what can you do as a family to support the general educator in moving toward becoming the "ideal" general educator for your child? How will you share information and provide feedback?

Activity Three: Create-Your-Special Education Teacher

As a family, list the qualities that each of you associates with an "ideal" special educator. Be sure to include training, personality, talents, skills, and other abilities that would be helpful for the special educator to have.



Discussion:

What do you do or what can you do as a family to support the special educator in moving toward becoming the "ideal" special educator for your child? How will you share information and provide feedback?

Activity Four: Create-Your-Principal/Supervisor

As a family, list the qualities that each of you associate with an "ideal" principal or supervisor to the Multidisciplinary Team. Be sure to include training, personality, talents, skills, and other abilities that would be helpful for the principal or supervisor to have.



Discussion:

What do you do or what can you do as a family to support the principal or supervisor in moving toward becoming the "ideal" principal or supervisor for your child's team? How will you share information and provide feedback?

Activity Five: Create-Your-Specialists

As a family, list the qualities that each of you associate with the various support services your child needs (speech therapist, occupational therapist, physical therapist, adapted PE teacher, and so on). Be sure to include training, personality, talents, skills, and other abilities that would be helpful for these specialists to have.



Discussion:

What do you do or what can you do as a family to support the support specialists in moving toward becoming the "ideal" support specialist for your child? How will you share information and provide feedback?



Create-A-Team, continued

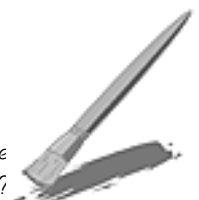
Activity Six: Create Yourself!

As a family, list the qualities that each of you associate with your own role as parents, the student, or the sibling involved in this process. Be sure to include training, personality, talents, skills, and other abilities that would be helpful for family members to have.



Discussion:

What do you do or what can you do as a family to support each other in moving toward becoming the "ideal" advocate for your child? How will you share information and provide feedback with each other?





Activity Seven: What Do They Have in Common?

Look at the lists for each member of the team and ask:

- ♦ What are the similarities and differences among the creations? Highlight comments that are included in every list.
- ♦ What do you understand more as a result of creating these lists?
- ♦ What kind of training, support, and qualities are essential for all members to have?



Design Your Team Meeting

by Mary Beth Doyle

As a parent, your days are filled with things to do: carpooling kids with neighborhood families, playing with the kids, helping with homework, doing laundry, and so on. As a parent of a child with a disability, you also juggle an unusual number of meetings related to your child in order to ensure she receives an appropriate education. It is important that these meetings are friendly, efficient, and productive. Take a moment to daydream: What would the ideal team meeting look like? Who would be there? What would they bring to the meeting? Where is the meeting held? Are there refreshments available? How would everyone work together? How would each person feel before, during, and after the meeting? List some of those thoughts here.



Discussion:

Answer the question: "What would it take to help bring this dream to reality in my situation?" Consider sharing your thoughts with one other person on your team, such as the general education teacher, and ask if they will join you in making it a reality.

Research Opportunity

Healthy Lifestyles in Down Syndrome: What Do We Know?

by Mia Peterson

Everyone wants to be healthy. It's not fun to be sick. We can make choices that help our bodies be as healthy as possible. Adults with Down syndrome want to be healthy too. I am working on a research project to gather information about what adults (ages 16 & up) with Down syndrome know about being healthy. Knowing this will help parents and professionals support and encourage adults with Down syndrome to be as healthy as they can be.

Let me tell you more about this project. My name is Mia Peterson. I work at Capabilities Unlimited, Inc. in Cincinnati, Ohio as a self-advocate intern, co-editor of *The Community Advocacy Press*, and am a co-researcher on the project, *Healthy Lifestyles for Adults with Down Syndrome: What Do We Know?* I am working with Joan Medlen, a registered dietitian, to research and investigate eating and exercise habits of self-advocates using a survey. Do self-advocates know how to be healthy? If they do, are they doing it? What makes it easy or hard to do? We are asking only adults with Down syndrome to do this survey because the extra chromosome we have makes our bodies work differently. We will also ask parents of teenagers and adults with Down syndrome what they think is important about eating and exercise for their children.

Why is this project important to me? This is important to me because I believe in exercising regularly and eating right so I can be healthy. There are many things we can do to be healthy. I am learning how to have a healthy lifestyle while living on my own too. A lot of people have health problems that can affect them and make them sick. Some of these health problems can be avoided by making good choices like getting plenty of rest, drinking lots of water every day, making good choices about what we eat, and exercising often. One of the things I have learned by doing this project is that people with Down syndrome burn calories slower than a person who does not have Down syndrome. If I have a

cookie and Joan has a cookie, my body will burn the calories from the cookie slower than Joan's body.

This project has just been funded. We have written a survey with questions about how we all can eat right and be healthy at the same time. If you are interested in helping us out by filling out a survey, supporting someone who wants to fill out a survey, or want more information about this project, please write, call, fax, or e-mail us. We will be happy to answer your questions. Thank you for your help.

**Want to Help?
Here's How!**

Write!

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Healthy Lifestyles Project
9220 SW Barbur Blvd #119-179
Portland, OR 97219

Fax!

503-246-3869 or 513-871-5893

E-mail!

Joan: jmedlen@teleport.com
Mia: miawrites2@aol.com

Please be sure to tell us which survey you are interested in completing: self-advocate or parent.

Note: All information is confidential. The results from data collected in this research survey will be presented through articles and presentations. Most importantly, it will be used to help determine the direction of future nutrition & lifestyle education projects for people with Down syndrome to promote healthy, self-determined lifestyles - J. Medlen

 Review

Medical & Surgical Care for Children with Down Syndrome: A Guide for Parents



Reviewed by Mary Wilt, R.N.

Medical and Surgical Care for Children with Down Syndrome edited by D.C. Van Dyke, M.D., Philip Mattheis, M.D., Susan Schoon Eberly, M.A., and Janet Williams, R.N., Ph.D. Published by Woodbine House, Inc., 1995. ISBN: 0-933149-54-9. (800)843-7323. \$14.95.

If you have a child with Down syndrome, I have three words of advice: buy this book! You won't be disappointed.

Of course, children with Down syndrome are first of all children. They have the same needs for quality health care as any other child. However, some medical conditions occur more frequently in Down syndrome, and require special treatment. Those unique concerns along with preventative health care are covered in detail in this comprehensive yet very readable book.

In the first chapters, the authors provide a good overview of how far we have come in the medical treatment of children with Down syndrome. Not too long ago, our children were not routinely given quality preventative medical care. They were assumed to be sickly, and often institutionalized without adequate medical treatment. Parents raising their children at home had a difficult time finding decent medical care from a knowledgeable doctor in their community. While there is still a need to improve medical treatment for children with disabilities, parents today have better options. Pediatricians and family practice physicians have more resources to turn to when questions arise and many communities have access to specialists in the field of developmental disabilities.

Many of those specialists who also have an interest in Down syndrome have contributed to this book. The depth and breadth of the knowledge represented is impressive.

The editors of *Medical and Surgical Care* include all of the specific medical concerns related to Down syndrome. Comprehensive anatomical descriptions are written clearly and in parent-friendly language accompanied by easily understood diagrams, graphs, and tables.

Each chapter is written by a specialist and devoted to a separate part of the body, such as the heart, the eye, and the ear. The authors carefully explain the importance of a body part and how it operates, before discussing any of the

potential problems or differences related to Down syndrome. Each author discusses the medical and surgical treatments, if any, indicated for the associated problems of that system. For example, in a separate chapter on surgery and anesthesia, the author describes special concerns of anesthesia for children with Down syndrome, describes common anesthetics, post operative pain relief, and precautions related to atlanto-axial instability. This chapter contains invaluable advice and should be required reading for parents.

In addition to describing major medical and surgical concerns, there is good advice about parenting a child with a disability. The authors of this section discuss decision making, parent-to-parent support, advocacy, and finding a balance between acceptance and therapeutic interventions. They also offer good advice on how to find a medical ally: a "reliable alliance" parents will need for support and guidance.

Although alternative health treatments are covered briefly, parents looking for in-depth information about alternative treatments will not find it here. Additionally, because this book is designed to address the health concerns of children, there is little information regarding adult problems beyond a chapter devoted to planning for health care in adulthood.

In short, this book belongs on your bookshelf. No matter the age of your child, or how much you have learned while parenting him, you will still find yourself looking here for information. *Medical and Surgical Care for Children with Down Syndrome* is an excellent book for parent groups to keep in their libraries. While much of this information is available elsewhere, I know of no other book that collects information as thoroughly about basic health care needs for children with Down syndrome and presents it in one, easy-to-understand book. Last, even though it is called "A Guide for Parents", I know several doctors and medical professionals who could benefit from having this book in their office as well. If you don't buy it for yourself, buy it for them!



Mary Wilt is the mother of three girls, one of whom has Down syndrome. She is an early intervention services specialist, registered nurse, and freelance writer. She and her family reside in Virginia Beach, VA.

