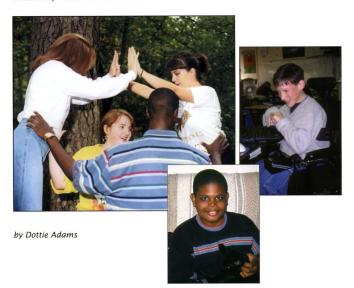
Inclusive Youth Development

A Guide for Promoting Positive Growth Through Inclusion of Youth With Disabilities



Institute on Human Development and Disability

Center for Excellence in Developmental Disabilities Education, Research, and Service A Unit of the College of Family and Consumer Sciences, University of Georgia

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Contents

Inclusion	3
Purpose	
Finding Value	
Viewpoints on Inclusion	
Individuals	
Parent	
Service Provider	
Community Members	
Youth Development	9
Support	
Empowerment	
Boundaries and Expectations	
Constructive Use of Time	
The Arts	
Sports	
Clubs	
Religious Activities	18
Commitment to Learning	
Positive Values	
Social Competencies	
Planning and Decision Making	20
Friendships	21
Respecting Diversity	
Resistance Skills	23
Conflict Resolution	23
Positive Identity	
Summary	
Appendix A - Disability Information	27
Appendix B - Supplemental Resource Materials	30



Inclusion

Excerpts from the Athens Banner Herald/Athens Daily News Article by Kevin Conner titled "INSPIRATION." Published with permission.

Though afraid to stick his toes in the water only three years ago, Trey Akridge conquered his fear in front of hundreds of spectators. He swam an exhibition lap during the Oconee County High School swim competition last fall at the University of Georgia's Ramsey Student Center.

While such a feat by one of his team mates would barely make a ripple, for the 18-year-old Oconee High special education student, his lap that day shines as bright as anything the swim team accomplished during its season.

Though born with the mental condition known as Down Syndrome, Trey was able to relish in the comradery, friendships and glory of competing alongside a team united with a common goal. Making the most of his chance to participate with the swim team, Trey made the quantum leap from a lifelong fear of the water to diving into the very thing he feared most, inspiring his team mates and opponents alike.

When he paused halfway through his lap at the Ramsey Center and grabbed onto the side of the pool for support, the room shook with chants of "Go Trey!" For everyone to recognize him in this attempt to be like

everybody else was just an awesome, awesome sight. He came out with his arms raised and said, "I did it." Did he beat the other kids? Certainly not. But who cares? He was in there trying for his school.

In all, Trey swam in four meets last season. While his laps were unofficial, he swam alongside the other competitors.

Trey's introduction to the swim team started with a routine trip to his speech pathologist – who, ironically, was swim team coach Marian Jones. Jones thought Trey could benefit from a team environment and asked Trey what sports he liked.

Trey told her he liked to swim. Jones allowed Trey to participate and said his involvement united the team and gave members a sense of responsibility. They really took responsibility for him, seeing that he was OK in the locker room and things like that. He gave them a better understanding of someone with special needs. They like to have fun; they like to be teenagers just like everybody else.

Trey helped the team understand what it means to do their best. As a whole, he helped the team know they could do better. Some people have to work harder than others.

Boys swim team captain, Craig Page, called Trey an inspiration. "It's wonderful having him on the team," Page said, "He's always energetic and the team backs him up 100 percent. Everybody gets on their feet and claps for him. Even the other team."

Trey helped them understand what it means to do their best. As a whole, he helped the team know they could do better. Some people have to work harder than others.

People couldn't believe it when they heard Trey had been accepted for the swim team. To be asked to be on the swim team is inclusion. That's really what it's all about. Kids like Trey should be allowed on the swim team, the baseball team, and other teams. They're not always invited to do so. He was invited to do so, and that's a wonderful tribute to the swim coach.

Teammates recognized his enthusiasm and uncanny ability to lighten up a group with his sense of humor. He's very outgoing, very excited about learning, excited about being on the swim team, very enthusiastic, eager to please, very popular at the school and has a great sense of humor. He likes to joke around and make people laugh. That ability to joke around is one of Trey's most notable qualities. He laughs with his team mates and gives them high-fives. He helps lead his team mates in a cheer before the swim meets. For Oconee County High School swim team, Trey Akridge's courage proved to be an inspiration.

Purpose

The efforts for promoting youth development closely parallel the efforts toward supporting people with disabilities to have positive futures in their communities. The similarities include focusing on capacity rather than deficits, tailoring supports to meet individual needs, promoting informed choice and self determination, and developing positive social roles for people in their communities.

This booklet is a guide to provide information, examples, and strategies to encourage the inclusion of all adolescents in youth development efforts. It is designed to share values, perspectives, and outcomes possible when adolescents with disabilities are given opportunities to grow and contribute. It also focuses on myths, fears, and barriers that need to be overcome.

Finding Value

Historically, people with disabilities have been viewed in negative ways by society. Some of these negative stereotypes can still be realities for people when there is a lack of understanding or experience. Some of the ways people are portrayed are as follows:

Eternal Children Dangerous Sick

Punishment from God Menaces to Society Objects of Ridicule Special Angels of God Subhuman Objects of Pity

Society responded to these views by isolating people with disabilities and congregating them together. People were not seen as individuals, and their

disability became life-defining as to where they lived, with whom they lived, and how they spent their time.

Over the past 25 years, efforts have been made to change the image of people with disabilities and to help them become active, contributing members of their communities. Children with disabilities are given an opportunity to be educated in public schools. Employers are encouraged to accommodate people's disability-related needs so that they can be employed. Community services have expanded in an effort to support individuals with disabilities and their families. There are wonderful examples of the positive contributions of people with disabilities when given the opportunity to share their gifts and talents. There are also painful examples for people with disabilities where they remain isolated and lonely due to exclusion. Our work is not done.

Values that help shape the design of positive supports for people with disabilities include the following principles:

- People with disabilities need to be present and participating members of their community.
- · People need to have choices and control in their life.
- · People need to be seen as more than their disability.
- People need to have their gifts and talents recognized.
- · People need families for a sense of belonging.
- · People need to grow and learn throughout their lifetime.
- · People need relationships.
- People need supports that allow them to participate now.

Viewpoints of Inclusion

Let's examine the perspective of various stakeholders in an effort to better understand the importance of inclusion for youth with disabilities.

Individual's Perspective

Polaris Walls is a 15-year-old young man who has experienced exclusion in his life. He shares these thoughts about the future:

"I have experience with not being wanted around in the past. I had a bad temper and I would go on a rampage. I

Polaris Walls

needed some space so I could work through it. People need to be very patient with teenagers.

"I think you should include everybody. It feels good when you are included. You know you are known. It is hard to put in words. It just feels good.

"Being a good friend is what I like about myself. Some people are shallow. You know who your friends are when they are there for you. That's the most important thing to me. I can still learn a lot. I learn from my family, from school, from my church youth group, and from experience. My family is awesome and

cool. I live with my mom and my grandma. They always support me and give me lots of advice. They look out for me. They supply me with all I need and want. I don't think a kid could ask for a better family. They don't spoil me. Mom is a hard worker. She is a nurse and works 12 hours at night.

"I go to my church youth group called Lighthouse. We talk about issues important to teenagers. We talk about what to do in different situations. We listen to music and go on trips sometimes.

"I spend half my time at the Psycho-ed Program and half my time at the high school. I'm taking World History and Pre-Algebra. I have great teachers, and I have made a lot of friends. I want to be the best scientist in the world. I love robotics and genetics. I like chemistry but it is difficult and

math makes me squeamish. I might like to work for NASA. I have ideas in my head that might be possible in the future.

"God has played a big role in my life. If he or she hadn't been there for me, I wouldn't be where I am today."

Mary Jean Bradley is a woman who was excluded as a child and who has learned the value of inclusion as she has found her place in the community.

"I went to live at Gracewood State School and Hospital when I was about eleven. My family could not provide the care I needed. My father always told me that I couldn't do anything because I was disabled. I missed out on a lot of things because I wasn't in my community. It wasn't until I got out of Gracewood 20 years later that I began to make choices about my own life. It was hard to learn to believe in myself because my father's

words kept ringing in my ears.

"I'm proud of myself now. I live in my own apartment. I have some assistance to do my shopping and manage my money. I volunteer at the library every week helping with the talking books. I am active in People First, a self advocacy organization that helps people with disabilities learn to speak out for themselves. I serve on several boards in my community. I help teach about the importance of including people with disabilities. I didn't have a life until I moved out of the institution. I want to make sure that other people have the opportunity to 'come back home' so they can live the life they choose."



Mary Jean Bradley at her

anartment.

Carol Dearing is the mother of Courtin Dearing. Courtin has always been included because of her mother's diligent efforts to make sure her daughter wasn't excluded. According to Carol, here's why inclusion is so important:

"My dream for my daughter is that she will have a home of her own and a job



Carol Dearing and daughter Courtni

that she loves. I know that for these things to happen that she needs to be a part of her community. I have always pushed to make sure that she had opportunities to be included. I know that I will not always be around to look out for her. The people her age are the ones that will be around when I am gone. I want them to know Courtni.

"They will be the bank loan manager who can help her buy a house or the employer who can hire her for a job. Since I have insisted that she not be excluded, these students are familiar with her. They aren't afraid and they see her potential. They, too, may be parents of a child with a disability in the future and may handle it better because of knowing Courtni.

"I get angry when people say, 'Oh, you just want her to be social.' No, that is not it at all. I want her to be challenged. I have expectations for her to do as much as she can for herself. I want her to contribute to her community. She is a caring person. I want people to really know the person that she is and see beyond her disability. I don't want them to cut her any slack if she is doing things that she shouldn't do. I don't want her time wasted on busy work. She needs to be learning things that are meaningful and will help her become more productive."

Service Provider's Perspective

Philip Jay, president of the Center Director's Association of Georgia, has incisive comments about the power of inclusion:

"Inclusion represents the lifeblood of personal growth. Through Godgiven exchanges of personal experience: by the touches, by the sights, and by the sounds of little people playing with one another, young children begin to learn who they are as common souls as opposed to separate beings. How they learn who they are depends on others whom they may see as somehow

different. Patience becomes a possibility; the truth becomes shared understanding; consideration becomes a way of life; and love becomes a consequence of knowing one is not alone; all gifts from one little person to another...and to us.

"It is said with each birth civilization begins anew. Nowhere is this more evident than when we create situations where children are supported in learning together regardless of their Inclusion represents the lifeblood of personal growth. Young children begin to learn who they are as common souls as opposed to being separate beings.

personal circumstances. Kids with privileged backgrounds can be relieved of notions that they are somehow qualitatively different. Blessings they took for granted can be exchanged for appreciation and responsibility. They can enter adolescence unafraid of people of whom they would otherwise have feelings of anxiety not delight and anticipation. Here, in an inclusive environment, they can begin to understand the richness of hearing, feeling, and seeing other children of different backgrounds...of having their own lives expand.

"Playmates that continue to struggle with their own perceptions of separateness and independence often bore children who have grown by virtue of inclusiveness. They miss the exciting processes of discovery and learning anew. The sameness of clothes, language, and skin from which children initially find comfort and security wears thin. These children now understand the world is more complicated than their own families and neighborhoods. And they want to know more.

"In this contrast as cynical adults, we can literally experience the future as working out to everyone's benefit; escape our pessimism and foreboding visions. For here our own biases and prejudices can yield to the hearts and minds of little children. It becomes clear that it is no accident that the great religions of the world advise us 'to become as little children to experience the kingdom of God."

"Dreaming? Wishful thinking? Neither. Spend a few hours in a truly inclusive classroom. Give kids a chance to teach you something. It will not only make your day; it may just change your world."

Community Member's Perspective

Reverend Terre Balof, minister of the Unitarian Church, enjoys having Ruthanne Hartel, a young girl with a disability, as part of their congregation:

"It is good to have Ruthanne as part of our church. We need her. She can teach our congregation a lot. She helps remind us of why we are here and about the value of all human life.

"We need to try to find roles for her to play here at church. Maybe she could help hand out the church bulletins and help collect attendance. She has such a wonderful smile she would make a good greeter.

Jason Brown, manager at Advanced Auto Parts, supervises Ross Kirkby, a high school senior who has been doing job training at his store:

"I have had both good and bad experiences with inclusion. The key to it working well is for people to have the support that they need. Ross is doing a great job at Advanced Auto Parts. Our shelves have never looked better. It has been a win-win situation. Ross works three days a week fronting the shelves, sweeping and buffing the floor, and straightening the break room. I can tell he likes it here."



Ruthanne Hartel and Reverend Terre Balof





Youth Development

The Search Institute has identified building blocks that promote the development of youth into healthy, caring and responsible people. The categories provide a framework for learning and evaluating efforts toward youth development in families and communities.

External Assets

Support

Empowerment

Boundaries and Expectations

Constructive Use of Time

Internal Assets

Commitment to Learning

Positive Values

Social Competencies

Positive Identity

Support

Families who have a child with a disability frequently find themselves in a position of having to fight for everything their child needs. They not only have the responsibility of their child's care, but they are often faced with the frustration and pain when they experience their child being rejected. Families sometimes become isolated and withdrawn themselves as a survival mode. It is difficult for parents to be the ones to have to ask for support because they see themselves as inadequate in meeting their child's needs, and their child is their heart so rejection becomes very personal and painful. An underlying fear of all parents is: What will happen to my family member with a disability when I am no longer around.

The concept of Circles of Support has been a positive way to pull together a group of people who are willing to listen to the dreams and fears of a person and help them move toward a positive future. There are various roles that people in the Circle of Support play that are important. These roles are described below:

Keeping the Home Fires Burning – Families are the key people to make sure that the person has a safe, comfortable, home where they feel secure and loved.

Teachers – It is important to have people within the Circle of Sup-

port who can help teach new skills. The skills taught should be relevant in that person's life and the teaching techniques should take into account the individual's preferred learning style. This may include academics but might also be leisure skills or life skills.

Cheerleaders – It is vital to have people in your life who cheer you on to do your best. They believe in you and help you believe in yourself. They challenge you to try difficult things and give you confidence. They support you in your successes and in your failures. Grandparents often are wonderful cheerleaders.

Warriors – It is necessary to have people in the Circle of Support who are willing to go to battle on your behalf, if necessary. They will fight for your rights and push for the things that are important.

Administrative Allies – It is helpful to have people in the Circle of Support who understand how systems work and can help get through the red tape that slows down progress.

Bridge Builders – It is valuable to have some people in the Circle of Support who are well connected in the community. They are the ones who can help open doors and find opportunities. They use their connections and knowledge of the community to link the individual and expand the social network.

Circles of Support need to have all these roles represented. It is difficult, if not impossible, for families to play all of these roles. That load is the reality for many families who lack a support network. The Circle of Support gives strength and validates the dreams of the individual. It gives them a louder voice and more control in determining their future. It is important for Circle members to be good listeners.

Jonathan's Circle of Support

Jonathan Hughes developed a strong Circle of Support when he was in middle school. His circle included his mother, an attorney with the Georgia Advocacy Office, regular education and special education teachers, and classmates. Jonathan's mother was a single parent who worked full time and she also provided all of Jonathan's care. Jonathan has cerebral palsy and uses a wheelchair. He talks, but is difficult to understand. He has a communication system that has a voice to make it easier to understand him. Jonathan's mother was concerned that he did not have any friends. She was the only person in his life who was available to meet his physical, emotional, and social needs. She realized that she could not do it all and reached out for help.

During Jonathan's initial circle meeting, some of his needs and dreams were discussed. Jonathan needed help to do homework and his mother was exhausted after work. It took them several hours to get his work done at the end of the day. Jonathan did not have anybody his age to do things with. He was lonely and bored. The adolescents at Jonathan's Circle Meeting understood the importance of having friends. They had not known that Jonathan was lonely and bored. One girl said that she didn't have anything to do after

school and offered to come over every afternoon to do homework with Jonathan. Another girl offered to put together a social calendar with activities going on at school and in the community. Jonathan's mother offered to drive the kids to any activities in the evenings or on weekends in her lift van. Two teens offered to go shopping with Jonathan and his mother to buy him "cooler" clothes. He wore black shoes and all the kids wore white ones. He wore elastic waist pants and needed more stylish clothes.

Jonathan had a dream to go to Germany to visit a neighbor who had moved away. One kid was willing to help him learn some German so he would

be better prepared for a visit. Jonathan's mother was overwhelmed at the response of the kids. The kids recognized that they shared many common interests with Jonathan. They all loved video games, pizza, movies, music, and bowling. They all liked to talk on the phone and loved computers. They all were insecure about boy/girl relationships. They all liked to be on the go and didn't want to always be with their parents. They all had a sense of what was cool and what it meant to be accepted. They were willing to challenge Jonathan on issues that were problematic for him. They were more effective in addressing those issues than adults had been. The adults in Jonathan's Circle just needed to be available for guidance or support. The kids were the ones to design and carry out the activities.



Jonathan Hughes swims with one of his Circle of Friends at Panama City, Florida.

Empowerment

It is often the role of the person with a disability to be the one who receives support. It is uncomfortable to always be on the receiving end and makes one feel obligated to others. There are many ways that an adolescent or young adult with a disability can contribute if their talents are recognized and valued. There may be leadership qualities that can be developed.

Tommy McGahee is the president of the Student Council at Malcom Bridge Middle School. At age 13, he has already discovered some of his talents and leadership skills. Tommy meets with the school advisors to set the

Tommy and Ms. Bowie, an advisor, discuss meeting plans.

agenda for the Student Council meetings. He solicits suggestions from other students and assigns roles during projects so that the group will stay on task and accomplish their goals. Tommy has a real eye for the Big Picture and sees his role as helping everyone fit in so they can contribute. He is proud of their fund raising achievements. Their efforts have raised money to buy playground equipment, copy machines, and microwaves for the cafeteria.

They had a can-a-thon and raised money for homeless people. Their newest project is based on a "Survivor" theme where they are going to raise money to fight cancer. Ms. Bowie, Student Council. Advisor, says, "Tommy has been a great president for the Student Council." Tommy has developed organizational skills, public speaking skills, delegation skills, and financial responsibility skills. Quite an impressive list of qualities for a 13-year-old. Imagine what kind of business and community leader he will be in the future!

The need for service to others should also be explored. It gives a more rounded view of the world and helps people put their disability into perspective. It helps everyone recognize that anyone can benefit from support at one time or another.





Larkin Sasseville never forgets a birthday, and also sends thoughtful notes to let people know she is thinking about them when they have a difficult time in their life.

Patrick Burgess, 14, has shared his musical talents with residents of the Ouiet Oaks Health Care Center.

Boundaries and Expectations

This category deals with rules and consequences in the family, school, and neighborhood as well as expectations and peer influence.

Expectations can be a double edged sword for people with disabilities. Too often people's expectations for a person with disabilities are too low. They hold the old stereotype of people with disabilities being always "child like" so they do not expect much from them. It is best to consider people's chronological age and treat them accordingly. If a person is treated like a child, they will respond in a child-like manner. If you want them to learn a skill, think of an age-appropriate activity that can be used to teach that skill.

On the other hand, people may have expectations that are too high, which can set the person up for failure. It is important to have reasonable expectations so that the person can experience success. They may need some accommodations or support so that they can participate. It might be best to look at how the person can partially participate in a setting if they cannot do the complete activity.

In some settings, people with disabilities are expected to be "perfect" before they are allowed to be included with others. One young lady was not allowed to eat lunch with typical students because she had called one of them an inappropriate name. If every student were held to that standard, the cafeteria would be empty. It would have been better for the girl to let her peers tell her that they did not like being called a name. That peer influence would have a greater impact on her than having adults impose a consequence for a behavior that is very typical of teenagers.

It is always helpful to have rules clearly defined and consequences consistently delivered. Consequences can be either positive or negative.

Inclusion is a Mind Set

Seeing is believing....or I'll believe it when I see it. If you believe that inclusion is the right thing to do, then your awareness of opportunities will be heightened. It will be hard to look at a situation without thinking about ways to involve people with

disabilities in the activity.
There become very different expectations for what is possible.

Loganville High School is a setting where opportunities abound. The traditional approach is to channel students with special needs into special education classes where all their needs are addressed. If the goal is to figure out how to make a student with special needs an integral part of the school

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Courtni Dearing in the Cosmetology Lab at Loganville High School.

life, then the entire school campus and variety of academic and extracurricular activities become the stage.

Courtni Dearing is a freshman in high school. She started high school primarily in special education classes. Her mother wanted her opportunities expanded so Mrs. Dearing offered to observe in some classes to see if Courtni's individual education plan could be addressed in an array of settings. Courtni has dreamed of working in child care, a beauty shop, or a hospital. With this in mind, here are the opportunities that her mother found:

Consumer Science and Education class (formerly Home Ec) was a place where Courtni could learn kitchen safety, following recipes, measuring ingredients, learn facts about nutrition, and baking and packaging cookies that are sold in the cafeteria at break time. The teacher also is sponsor for the Future Homemakers of America. She knows Courtni because her son played on Courtni's brother's ball team.

The Health Occupations class was a place for Courtni to learn about hand washing at the standard for health care professionals, making hospital beds, and developing first aid skills. In addition, her mother wants to explore the possibility of Courtni being a candy striper at the local hospital.

The Early Childhood Education class, which is an actual preschool program for 4-year-olds, could be a Mecca for Courtni. The classroom aide

had been a camp counselor and Bible School teacher for Courtni and felt that she would readily fit in. The opportunities included work on the computer to get ideas for games and art projects, fixing snacks for the kids, making art materials and bulletin boards, and playing with kids in the various centers.

If you believe inclusion is the right thing to do, your awareness of opportunities will be heightened. It will be hard to look at a situation without thinking about ways to involve people with disabilities in the activity. The aide even welcomed Courtni to go along with her to the grocery store on Mondays to purchase the ingredients for the children's snacks.

The Cosmetology class had a dispensary for beauty supply products that needed to be organized and managed. There were chances to launder and fold towels, sweep up cut hair, sterilize implements, sort rollers, and learn to wash someone else's hair. The teacher had experience with inclusion and felt that Courtni's objectives could be worked on during any period of the day.

The number of places available for Courtni to learn skills that would promote her vocational marketability and

her independent living was incredible. The hard part is to help others see the relevance of thinking outside the "special" boxes. Creativity becomes contagious once people feel they have the permission to look for options. Take the challenge and expand your Mind Set.

Constructive Use of Time

There are numerous activities that young people can become involved in to use their time constructively. Examples of ways that youth with disabilities have been included in meaningful activities are spotlighted below:

The Arts

Music – Patrick Burgess is a musician. He was sick a lot due to his disabilities when he was younger. While other kids were outside playing sports, he was inside playing a little toy piano. His mother, Merian Burgess, said that he could "make it talk." It wasn't long before he moved up to a full size set of keys and made them talk, too.

When a person has a talent, it is important that it be used and shared with others. Patrick, at the young age of 14, has freely shared his musical gift for years. He and his family have found opportunities for others to enjoy his musical talents. As others have heard him perform, his invitations to participate in different events have multiplied.

Patrick is a spiritual person who uses his God-given musical abilities as an expression of his faith. He sings in his church choir, and he is a frequent performer at benefit gospel sings. He reaches out to others with his music. He played piano for elderly residents at Quiet Oaks Health Care and for participants at the Senior Citizens Center. He has found ways to use his music in multicultural and human rights events. He played piano and sang at the Martin Luther King, Jr. Celebration and the Martin Luther King, Jr. Youth Pow-Wow, as well as at the Multicultural Emancipation Celebration. He is a regular performer at the annual Human Rights Festival. He helped others expand their thinking about possibilities for people with disabilities as

he played at the Dreams Can Come True Scholarship Dinner sponsored by the Edwards-Miller Foundation for Physical Disabilities.

He wowed audiences at school performances as he has participated in the Middle School production of Guys & Dolls, Jr., and the Adventures of Lewis and Clark. His principal wrote his parents a note that said, "Patrick's performance in the Lewis and Clark production was outstanding. He brought a lot of talent to his role. He's a wonderful contribution to the outstanding school we have."

Music is Patrick's way to express his love and joy. It has helped shape the person whom he has become. It has been a vehicle for him to meet people that he might not have met in his life. His family surprised him for his 14th birthday by arranging for a private meeting for Patrick with Bishop T.D. Jakes, a well known international spiritual leader. Patrick played the piano for Bishop Jakes at the Woodruff Arts Center in Atlanta.

Patrick is from a very small rural community where some people might think that opportunities are limited. Patrick has used his musical talents in his local community, and by sharing his gift opportunities have arisen in very prestigious places. Patrick says he doesn't know if music is his calling, but he adds, "The future will tell."

Theater – Tommy McGahee has found that he has a talent for drama. He has been involved in plays sponsored through the Oconee Youth Playhouse. He says that theater has helped him overcome shyness and learn to speak louder. He has gained confidence in himself and he feels comfortable speaking to large audiences. Tommy said the best part about theater is seeing it all come together after all the hours of preparation. It feels really great to have a good final product. Drama helps bond people together in friendship. It allows you to speak freely. It gives you a safe environment to try something new without feeling embarrassed. Tommy says that he focuses more on the acting roles and leaves the dancing roles in the musicals to others.



Tommy McGahee (far left) participates in acting with the Oconee Youth Playhouse. (photo by Wingate Downs)







Kyle Redd

Sports

Soccer - Hillary Petter was born early, weighing only 1 lb. 15 oz. Her mom, Jean, commented about how far Hillary has come since then. Hillary started playing soccer about six years ago. She plays at the YWCO. Hillary can play offense or defense. She finds being part of a team is much fun. She practices twice a week after school and has a game on the weekend. When asked what she likes about soccer, Hillary said enthusiastically, "It's fun!"

Baseball - Kyle Redd is an athlete and loves to play baseball. He has a hearing impairment, but is able to participate with others in the Jefferson Recreation Department Program. Kyle's mom says that she likes to talk to the kids before he joins the team to help them know how to interact with Kyle. He remembers players better by the number on their jersey rather than by their name. It is nothing personal, just how he seems to relate. He might say, "#29 is really fast." The coach was a little concerned at first, but has learned to look at Kyle when he gives instructions and to use hand gestures as all good baseball coaches do to signal their players. If Kyle doesn't understand an instruction, he will give a puzzled look, see what others are doing, or turn to his family to help interpret if necessary. His mother, Mitzi, said, "I think it is just as important for the other kids as it is for Kyle. It helps them learn to appreciate differences in people.

Clubs

4-H - "This is Daisy," David Froetschel said as he introduced his black & white calf. He was neatly dressed in white jeans and a white shirt as were the other 4-Hers. David led Daisy into the ring and concentrated on keeping her moving steadily.

Just a week ago was David's first attempt to show his calf as a 4-H Project. His calf was a bit of a handful for him and he showed his frustration by talking loudly during the event. After the first show, his parents questioned whether they had made the right decision in letting him take on this 4-H Project. He struggled and didn't seem to be enjoying himself. They coached him and helped him understand what was expected. They let him know that he wouldn't have to take on this project another year if he didn't like it. David rallied. He let them know that he wanted to participate this year and in the future. Maybe it just took one show to prove to himself that he could do it. Maybe it was the loving support that he received from his entire family that made the difference.

David had watched his older sister, Erin, show calves for the past two years. For David the best part of showing his calf is that he gets to be in

cluded in the same activity with his sister. 4-H is a family affair. His parents proudly gave encouragement as their son and daughter entered the arena. David's dad slipped him a piece of butterscotch candy, a clever way to help him remember not to talk during the event.

David and Erin entered two classes. One that judged their showmanship and one that evaluated the calves. Erin won the Junior Showmanship Championship. David went over and gave her a congratulations hug. In the second class, David's calf, Daisy won 2nd place and Erin's calf, Rose, won 3rd place.

The judge gave encouraging feedback to each contestant, letting them know their strength and areas to improve. It was a good way to educate them on what they needed to do to progress in their project. Each 4-Her was handed an envelope with prize money as they left the ring. David opened his envelope and closely examined his \$50 bill and reported that Grant's picture was on it. He said, "You can buy a lot of toys with \$50." But he added an afterthought, saying to his dad, "I'm going to get something for you." His mother chimed in, "And he will. He is such a generous person."

For David, a pre-teen who experiences autism, participating in 4-H means much more than just winning. He is gaining poise and confidence. He is proud to be in 4-H and feels like a winner just being a regular 4-Her.



David Froetschel with his prizewinning calf,

Scouting — David Froetschel has also found enjoyment being a boy scout. His troop is a small group of boys, some of whom have been in his class at school. He goes to the regular meetings and has participated in scout fund raising activities such as selling popcorn. Their troop is currently planning a campout. His mother, Dana, says, "I really don't know what it is that he likes about it, but he always wants to go. He knows the boys and has fun with the activities." Troop leaders may need some education about working with kids with disabilities. They have to be willing to accept the information. Parents are great resources to help figure out what might work. For David, it helps to have structured activities with clear directions.

Religious Activities

Joey Romano attends temple and joins in the religious rituals of his faith. It gives him a foundation for his beliefs and values. He has learned the

traditions of Hanukkah and Passover in his religious education.

Larkin Sasseville had been a part of her church youth group for several years, but it wasn't until she went to church camp with the youth group that they really learned to appreciate who Larkin is and see the talents she possesses. Larkin has a lovely voice and touched everyone's heart when she got up in front of the crowd and sang a solo. Her voice rang out with such purity and joy. She also participated in the team building program on a ropes course. In addition, she serves as the official photographer at church, taking photos of new members and at programs and special events.

Ruthanne Hartel has joined a Sunday school class for teens. She had previously been in a class that her mother taught, but Ruthanne had gotten older and needed to be in another class. After a meeting with the church personnel and with the Sunday school class, Ruthanne joined in. The kids in the class came up with the idea of making a card for Ruthanne when she joined their Sunday school class as a way to welcome her.

Kyle Redd has a sign language interpreter who assists him in his Sunday school class at Saint Joseph's Catholic Church. She helps him follow along with the lesson and explains concepts to him. At times, rather than attending mass, Kyle goes to the church nursery and helps out with the younger children. It is a way he can contribute to his church family.





Ruthanne Hartel (right in group photo) shares activities with other teens in her Sunday school class.

Joey Romano's participation in temple activities gives him a foundation for his beliefs and values.

Commitment to Learning

School should be a positive experience for all students. For lifetime learning it is important for youth to love to learn. They should find internal motivation to try to do their best and achieve all that they can.

There are ways that the school environment should be structured to insure that students with disabilities achieve success. It is important to assess their current level of performance. Learning tasks should be designed to challenge the student, but should not be too difficult for the child to grasp.

Teachers need to be aware of students' individual learning styles and developmental levels so that appropriate educational materials and teaching techniques can be used to promote the child's cognitive development. Task analysis, which is the breaking down of a task into its components, is a good teaching tool. Backward or forward chaining is a teaching technique that allows the child to learn one step of the task at a time.

Hands on experiential learning is very valuable for all students, but especially for students with special needs. Presenting the information using auditory, visual, and tactile means give students a chance to learn using different sensory input. Group projects are a way for children to learn together and allows students with different talents to share their expertise. The availability of technol-

availability of technology is a real plus in schools today. Teachers should be striving to motivate students through the latest technology in an effort to prepare them for their futures.

Scott Davis is a 14year-old eighth grader who uses a lap top computer at school in his classes. He participates in regular educa-



Scott Davis in Language Arts Class

tion classes with his favorites being social studies and language arts. Having technology available to him at school helps him participate more independently. He drives a power wheelchair and has independent mobility around the school. Scott says, "I have used computers for about six years. I really like the laptop because it is so portable. I use it for everything from taking tests to doing daily worksheets in class. It lets me be independent in my school work."

Positive Values

Helping youth develop positive values that will influence and guide their actions is a critical piece of the puzzle. The desirable traits should include caring, integrity, honesty, self restraint, equality, and responsibility. Students

should have a sensitivity toward others and believe in and stand up for social justice.

Some schools become involved in community activities that help the students learn to contribute to others. Kids gather canned goods for the Food Bank or might participate in the Relay for Life, a fund raiser to fight cancer. These type of activities help kids see needs that go beyond their own. It teaches them responsibility and social concern. All kids can get involved at some level and learn valuable lessons that will help them be better citizens.

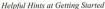
Social Competencies

The development of social competencies will probably be one of the most important areas for people with disabilities. These social skills cannot be left to chance and need to be taught to youth with disabilities.

Planning and Decision Making

Many young people with disabilities have not had the opportunity to make their own decisions. Other people act on their behalf to decide what is best. It is critical that from an early age youth begin to be given choices and be given chances to make their own decisions.

Laurie Beth Ash is a 15-year-old who uses a communication system to express herself. Her speech therapist at school has programmed the Dynavox Communicator with phrases so that Laurie Beth can give her response. She uses it out in the community when her class goes out to eat. Laurie Beth can order a chicken taco salad and large Dr. Pepper all by herself. The cashiers seem impressed with her communication device. Her mother is pleased because it allows Laurie Beth to have more control of her environment.



To be able to learn to make a decision, people need to be informed about their choices. Some young people with disabilities may have

had limited life experiences so that they do not really understand their options. For example, if you ask a girl if she wants to be a Girl Scout, but she has no idea about what Girl Scouts do, she may not be able to make an informed choice. It would be better to let the girl go to several scout meetings or on a camping trip with the troop so she has real life experiences that she can use in making a choice about whether she enjoys that activity or not.

For youth who have intellectual disabilities, it might be helpful to give them selected choices rather than leave the whole spectrum of possibilities open. For example, rather than asking what do you want to do for fun, it might be better to ask would you like to go swimming or go horseback riding. Using a picture or a symbol to represent the activity might also be a good strategy to use. That way it is clearer to them about what their choices are. It is important to honor the decisions that youth do make, even if it is not the choice you might have made. Don't offer a choice if it is not an option that you are willing to follow through with.

As with all adolescents, providing choice is a great way to avoid power



Laurie Beth ordering lunch at Taco Bell.

struggles. It gives them opportunity to have some control and decision making. It can help diffuse anger and at the same time teach life skills that can build character and competencies.

Friendships

Adolescents with disabilities need to gain an understanding of the reciprocal nature of friendships. Learning what it means to have a friend and to be a friend are important lessons.

Alana Davenport and her group of friends meet every day at 12:40 to eat lunch together. Lunchtime is an important social event of every school day. They enjoy sharing their time together and talk about everything including school, boys, family, activities, music, and friends. Alana's mother characterizes this group of girls as kind young people who don't look at the differences in people but appreciate each other. It is a boost to one's self esteem to have other people want to spend time with you. Alana gives as much to this circle of friends as she receives, but it also helps to feel like you belong. Jennifer Boswell, one friend, said that she met Alana in kindergarten. Regina Taylor, another friend, said she got to know Alana in Girl Scouts. It pays to have kids included in activities from

an early age!

In a note written to Alana's mother, her friend Jennifer pointed out qualities about Alana that she appreciates and admires. Jennifer said, "Alana is truly an amazing girl and deserves the best of everything. She is so sweet and loving, and she is also such a strong person. I admire her for her courage and strength she carries with her every day at school. She shows forth an awesome attitude



Alana (center) and friends value their time together.

and she never lets anyone or anything get her down."

Friendship is when people accept you for who you are and help bring out the best in you. And can you imagine the pride in a mother's heart when she received the letter where someone else readily acknowledged her daughter's qualities and attributes.

Jennifer works at Food Lion and Regina works at Winn Dixie. They are always glad to see Alana and her mom come into the store to do grocery shopping. They make sure they take time out to greet them.

In talking about what lunchtime was like, Alana said, "We are kind of wacky at lunch." Jennifer chimed in, "We like to sing at lunch, don't we. What is your favorite song, Alana?" Alana grinned and started a chorus of "Who Let The Dogs Out?"

Helpful Hints for Getting Started

The key to helping people become friends is to make sure they recognize the things that they have in common. Many times typical kids may view a youth with disabilities as being completely different than they are. It has been helpful at times to meet with the typical kids prior to the youth with disabilities joining their group. It gives them a chance to ask questions and sets the stage for building friendships.

Putting up some chart paper and writing down the kids' responses is a good way to get them talking. They like to see their ideas written down. A good question to start off the discussion is asking them to tell you things that they like to do with their friends. Kids know the importance of friendships. They just need some help seeing that life can be lonely for a person with disabilities if they are excluded. Ask them if they can imagine what it would feel like in the following situations:

- Never being invited to a birthday party.
- Never having anyone call on the phone.
- Never going to spend the night with a friend.
- Not having anyone to sit with at lunchtime.
- Always spending time with your parents.

These situations are more often than not the reality for kids with disabilities. When the other kids understand, they are often the ones who find solu-

tions to making sure the child is included. It might also be important for the kids to be given a chance to recognize traits about the person that they really appreciate. It may take them a longer time to get the know the person with a disability, but they will find characteristics that are endearing when they are able to look beyond the disability itself.

Help kids with disabilities learn other people's names and make sure they call people by their name. Encourage them to smile or wave to others. Some kids with disabilities want to hug people whom they may not even know. This is usually acceptable and cute when people are younger, but it can become scary for a stranger if a

larger teen approaches them wanting to hug. Take a cue from other teens about what is an acceptable way of greeting people. A "high 5" may be more appropriate greeting to teach.

Respecting Diversity

Students need to learn to appreciate differences in people and acknowledge the similarities in people's humanity.

Helpful Hints for Getting Started

It is a positive environment when youth can be themselves, showing both their strengths and their weaknesses without feeling put down. It is good when youth can learn to recognize and appreciate their gifts and talents and laugh at their own shortcomings. When such a safe setting is established, youth feel free to express themselves.

Teasing is a big part of the teen culture. Kids give each other a hard time. It needs to be kept in check so it doesn't become cruel and degrading. Adolescents need to develop a little bit of "tough skin" to take some kidding. They will be less taunted if they learn to laugh at their own faults.

It should be unacceptable to make fun of people because of their disability. Disability is as random as people being born with certain colors of eyes.

It may take longer to get to know a person with a disability, but one will find characteristics that are endearing when looking beyond the disability itself. An appreciation should come when people learn how strong the youth with disabilities is in learning to function in a world that isn't very accommodating.

A good way to let others experience what it is like to have a disability is to have an awareness day. Having typical kids try to maneuver in a wheel-chair or get around with a blindfold or ear plugs might heighten their sensitivity to the day-to-day challenges that are present for kids with physical disabilities or sensory impairments. "Walking a mile" in someone else's shoes can be a real eye opener.

Resistance Skills

Teens with disabilities need to decrease their vulnerability by learning to resist negative influences. This social skill area is a major concern for many parents who worry about their family member's well being.

Helpful Hints for Getting Started

Role playing is a great way to allow people to practice how they would respond to different social situations. It is important to teach both what to say and what not to say in various situations. Youth with disabilities may not generalize from one situation to another so you might want to have several different situations that they can practice role playing.

The more youth with disabilities "belong" to their community, the safer they become. There are more people who know them and who look out for them. When they are "regulars" in a number of community settings, people in those places will question if they have not been in for a while or will report if they are being mistreated in any way.

Conflict Resolution

A valuable skill to develop is to learn to handle problem situations and resolve the issue in a peaceful manner.

Helpful Hints for Getting Started

The best way to teach conflict resolution is to model a calm response in problem situations. It is important that the different points of view are heard and respected. You want to make sure that there is compromise. It might take a mediator to help the teens learn to "give and take" as they work through to resolution.

Too often, people give into the demands of youth with disabilities to avoid conflicts. This can create tyrants and set people up to have problems in the future. It is not good for anyone to *always* get their way. That will not happen in real life. It is better to learn that sometimes you get what you want and other times you have to give in to another person's wishes.

Positive Identity

Youth who have a sense of self are a step ahead. Being able to take one's own personal power and act on it toward a purpose gives direction and a

Person centered planning takes a close look at people's interests and passions; it builds on capacities and supports deficit areas.

sense of achievement. People with disabilities have strong spirits but often need support to soar to the heights of success. As adolescents they are a "work in progress" and their sense of self comes from their life experiences.

Person centered planning or personal futures planning is a tool that is used in the disability arena. The process takes a close look at people's interests and passions. It builds on capacities and supports deficit areas. It identifies valued social roles for people to play within their community. It helps tailor the supports that people need in order to live a life that has a desirable future. It looks to the community for opportunities.

Janeanne Napoli is a 19-year-old who has just begun thinking about her future. She invited family and friends to come to a futures plan where they brainstormed ideas about a possible future. Janeanne needs to separate from her dependency on her parents, but it is scary to become an adult. She needs to develop her work skills and find a job that matches her interests. She needs social activities with other young people where she can have fun. She loves to be a sports spectator and needs to find others who share her passion for baseball and gymnastics. She needs to find a compatible roommate with whom she can share her first apartment. She needs to learn skills in getting around the community on her own and in managing her money with some help. She needs to find valued roles in the community where she can contribute her gifts and talents. She needs to

learn to interact as an adult and show respect to others. She needs to build her confidence in her own abilities.

Janeanne's church was the gathering place for her futures plan. People who knew and cared about Janeanne filled the Sunday School room and shared their ideas and perspectives. A dozen or more ideas about possible jobs were generated including working at the student center, retail jobs, science related lab jobs, animal care jobs, etc.

Janeanne's future is just beginning. People volunteered to make contacts in an effort to find Janeanne a job. Service providers discussed funding options and support needs and how they might be addressed. Family members felt the warmth and support of the people who attended and were glad to have a "road map" of where to begin to help Janeanne toward a future where she can be happy and productive.



Person-centered planning by family and friends is helping Janeanne to find her role within community life.

Gail Bottoms is a woman from

Griffin who has served as a pioneer in self advocacy in Georgia. She speaks from her heart and writes touching poetry that helps everyone understand the importance of valuing all human life. Her understanding of positive identity is expressed in the following poem which she wrote entitled, "Listen."

Listen
I'm a human being too!
I have feelings just like you!
I have needs and hopes and dreams!
Though not as high as yours it seems!
But no less important to me you see!
So to you I make my plea.
Don't skip my dreams, listen to me.
I have talents that are God-given!
To be able to use them to me is livin',
Give me a chance, see what I can do!
I am full of dreams just like you.



Gail Bottoms is a pioneer in self-advocacy.

Summary

The Youth Development Movement should have a positive impact on the future of our children and our communities. The concern is that the Youth Development Movement needs to be all inclusive and work to support all adolescents in their growth. Sometimes our lack of knowledge of how to support youth with disabilities has led to their being excluded.

The role of adults in the home, school, or community should be about helping prepare youth for positive futures. This will require diligence, patience, and persistence. There are tremendous negative forces that our youth must combat. They need the skills and the tools to help them develop a social consciousness and sense of self that will allow them the strength to make good choices.

School needs to be about more than just learning the academics. Character development should be a major focus. There should be value in acknowledging and welcoming diversity in our schools and our communities. This diversity must include a sensitivity to disability as well as cultural and ethnic awareness.

People with disabilities have a large role to play in the teaching and learning about youth development. Their courage and perseverance through challenging life circumstances make them excellent teachers and role models. They need the support just as other youth do to become adults who are healthy, caring, and responsible.

Our communities will be better places to live when the citizens learn to respect and affirm each other as we live, work, and play together. There needs to be an appreciation and acceptance of the gifts that each person contributes. This may require that we learn new skills in communicating, observing, and relating, but the rewards will be monumental for the future of our youth.

Appendix

Disability Information

This appendix was designed to provide a brief explanation about disabilities that were represented by the young people in this booklet. It is helpful to have a basic knowledge about disabilities so that you can understand yourself and be able to answer questions that might arise. Parents can be excellent resources if you need additional information.

Attention Deficit Disorder with Hyperactivity (ADHD)

People who experience Attention Deficit Disorder with Hyperactivity find it hard to focus and concentrate. It is difficult for them to sit still and they can be very distracted. It is helpful to provide some structure to activities and give them chances to move around if the activity lasts an extended period of time. They will need some encouragement to stay on task and to complete the activity.

Autism

People who have autism may be sensitive to loud noises and to touch. They usually have difficulty when there is a change in their routine. They usually have excellent memories although communication may be problematic. They might have trouble expressing their emotions. They also can become fixated on a particular object or can get stuck on an idea and repeat it over and over. It is important to be aware of the environment. If a person with autism is becoming upset, it might be because there is too much stimulation going on. They might need a chance to be in a quieter place to relax. Some people have "comfort" objects that they like to keep with them that help them feel secure. It is important to prepare the person ahead of time so that they know what the rules are and what is expected. It might be better to give them verbal instructions and demonstrate what is to be done rather than to try to physically assist them since they might be sensitive to touch.

Cerebral Palsy

Cerebral palsy is caused when the part of the brain that controls movement is damaged. This can happen at birth or may be caused from an injury. Depending upon the severity of the brain damage, cerebral palsy might effect one side of the body or all four extremities. For some people with cerebral palsy, they may have low muscle tone and be kind of floppy. Other people with cerebral palsy may be very stiff and rigid. Some people with cerebral palsy can walk, but others may be dependent upon a wheelchair to get around. It is important that a person who uses a wheelchair not sit in it too long without having a chance to get out and stretch. It is important to know how to help the person get in or out of their wheelchair and to know what kind of support they need. Some people with cerebral palsy are able to talk and other people may have difficulty talking. Some people might need total assistance to help them with eating, drinking, going to the bathroom, or propelling their wheelchair. A person with cerebral palsy can have normal intelligence or may have some learning problems.

Conduct Disorder

Young people who have a conduct disorder are resistant to authority and following rules. They are seen as rebellious. They can find themselves with legal problems if they break the law. It is helpful to be consistent with the rules and consequences when working with the individual. They should be encouraged to be involved in the activities and to stay within the boundaries and limits that have been set. They may use their "attitude" to avoid participating in activities that they may not feel like they can do well.

Depression

Depression is a mental illness that can be caused by a chemical imbalance in the brain. It is often characterized by sadness, decreased interests and activities, decreased energy, sleeping a lot, and loss of appetite. In extremes, depression can lead to thoughts and attempts at suicide. It is important to listen to a young person who is feeling depressed. Help link them with professional counseling if they continue to express these feelings.

Down Syndrome

Down Syndrome is caused from a chromosome abnormality. People with Down Syndrome usually experience mental retardation. They have some physical characteristics such as slanted almond shaped eyes that make them distinctive in appearance. People who have Down Syndrome sometimes have heart problems and can have thyroid problems. Some people with Down Syndrome have a weakness in their neck so it is important that they be evaluated by a physician prior to participating in very physical activities. People with Down Syndrome may have problems with speech, but you can become more in tuned to their speech pattern if you are around them and listen closely.

Golden Har Syndrome

A person who has Golden Har Syndrome is born without an ear. They can also have facial distortion and experience health issues with kidney problems and a curvature of the spine. Plastic surgery is often used to create an outside ear structure. The person might also need reconstructive surgery to restructure the jaw or other facial features that can be involved. It is important that adults working with a child with Golden Har Syndrome make sure that other children are not cruel and make fun of them. It is important to build the child's self esteem and help them find ways to express their gifts and talents.

Hearing Impairment

Hearing impairments can impact one or both ears. Some people have difficulty hearing certain sounds and other people might be totally deaf. There are hearing aids that can be worn that amplify the sound and make it louder so the person can hear. Some people with hearing impairments learn to read lips, but it is important for the person speaking to look directly at them so they can see the lip movement closely. Sign language may be another way for a person with hearing impairments to communicate. People who are going to be around a person who is deaf who signs also need to learn sign language so they can understand and respond.

Heart Defects

There are a variety of heart problems that can impact a person's life. A heart murmur may exist and may not limit the person's activities at all. There are some valve problems or structural problems that can only be corrected with open heart surgery. If a person has had heart surgery, it is important to know that they need to have an antibiotic before they have any intrusive medical treatment like dental work or surgery. It would also be safer to have antibiotic treatment before they get their ears pierced. The physician will make the parent aware of any physical restrictions that may be imposed. It is good for circulation and strengthening the heart muscle to have some exercise, but this should be okayed by the physician first.

Hydrocephaly

This is a health problem where there is fluid build up around the brain. It usually requires the person to have a shunt inserted to drain off the fluid so it does not cause damage to the skull and brain. If a child has a shunt, it is important for people to know warning signs if the shunt is malfunctioning. Headaches and vomiting are warning signals to be aware of. The shunt will usually have to be replaced as the child grows. A physician will monitor the shunt and do periodic tests to let them know when a new shunt needs to be inserted.

Impulse Control Disorder

Young people who have an impulse control disorder will react quickly without thinking about the consequences. They may lack the self control needed to think through a situation and decide what is the best way to respond. A person supporting a youngster who has impulse control disorder may need to be more aware of dangers because they may need to alert the child if they are putting themselves in harm's way.

Mental Retardation

People who have mental retardation learn slower. There are different levels of mental retardation (mild, moderate, severe, and profound). People with mental retardation can learn, but may need different ways to understand material. They may have problems understanding concepts that are very abstract. Having a picture or a visual example might help them understand. Showing them how to do an activity might be a good way for them to learn. They might need more practice and more repetitions to master the skill. They might have trouble generalizing the skill from one setting to another. For example, if they learned how to use a microwave

oven at school, they might not be able to use the microwave at home if the buttons or controls were different.

Seizure Disorder

Seizures are caused by electrical impulses in the brain. There are different kinds of seizures. Some seizures result in the person falling down and going through jerking type motions for a short time. The person might need to rest after a seizure and they may have a toileting accident during the seizure and need to change clothes afterwards. Other seizures may just involve an arm stiffening up or might just cause the person to stare into space for a few seconds. The best way to respond during a seizure is by moving any furniture or objects out of their way to make sure the person does not injure themselves. Do not try to put anything in the person's mouth during a seizure. You just need to wait it out. If the person continues to have more than one seizure after another, they need medical attention. Note how long the seizure lasts and how the person responded following the seizure. This will be good information for the family or for the doctor.

Speech Impairment

Speech problems can range from having trouble pronouncing some sounds to stuttering to having no verbal abilities. Speech is characterized in two ways. Receptive speech is what the person understands that is spoken to them. Expressive speech is what the person can say or how they get their message across to others. Everybody communicates in some way. Non-verbal communication can be facial expressions, gestures, pointing, or sign language. People can become very frustrated if they cannot make others understand what they want and need. There are communication systems that have voices that some people use when they cannot talk themselves. They can push a button and make the machine speak. The important thing is to listen and be attentive. Some people are very comfortable repeating themselves if you don't understand what they say the first time. Sometimes you can ask them questions that require a yes/no response that makes it easier for them to answer.

Spine Problems

There are several ways that the spine can be involved. Some people have an 'S' type curve in their spine called scoliosis. Other people might be curved forward at the spine with a problem called kyphosis. There are some problems that can be caused from benign tumors located on the spine. Spina bifida is a disorder where there is an opening

at the spine at birth. Spinal cord injuries that result in the spinal cord being severed result in paralysis. Surgery is performed in some instances. Some people have a metal rod inserted that helps straighten their spine. Some people wear trunk braces to help support their spine in alignment. If a person has a spinal problem, it will impact their positioning and their movement. Ask the family to let you know if there are any ways that you need to assist the person so that they are more comfortable. Ask about any activities that the person should not participate in due to spinal problems.

Urinary Problems

Some people do not have control over their bladder and may need to wear disposable briefs. Some people can let you know if they need to go to the bathroom, but might need physical assistance to get on the toilet. Other people might need to be catheterized. There are some young people who are able to learn to catheterize themselves. They will need space and privacy to take care of this procedure. It is important to handle these situations in a respectful and private manner. It should not be a big deal to assist someone to go to the bathroom or to change their disposable brief. It is good to wear latex gloves when handling any body fluids, so be prepared if this is going to need to be done.

Vision Problems

Vision problems can include a variety of impairments. Some people need corrective lens to help them see at a distance or to help them see close up. Some people have a limited range of vision and may see best out to the side. A person who has droopy eye lids may be a result of Horner Syndrome. At extremes, a person can be totally blind and need assistance for their care and mobility. If you are working with a child with a vision impairment, be aware what type. You might need to make sure that materials are in larger print so they can be easily read. You might need to seat the person at the front of the group so they can see better. You might need to remind the child to put on their glasses if they need them for reading. Some people may need materials presented on tape if they are unable to see them sufficiently.

Supplemental Resource Materials

Circles of Support

<u>Laying Community Foundations For Your Child</u> with a Disability by Linda J. Stengle

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