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## ABSTRACT

This anthology was written by a group of Kansas educators and others with knowledge about the special needs of children with severe disabilities and deaf/blindness. The book was created to describe effective educational practices for these students identified by research and to serve as a resource for teachers and parents. The anthology is divided into eight topical sections, each of which includes a personal story or vignette and a summary of best practices related to the topic. The eight sections address the following best practice areas: (1) belonging; (2) self-determined lives: values, planning, and transition; (3) collaborative teaming and systems change, working together for change; (4) teaching and learning; (5) life activities, adaptations, and supports; (6) communication; (7) positive behavioral supports; and (8) sensory experience. (Contains approximately 100 references.) (DB)

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# Collective Wisdom

An anthology  
of stories  
and best practices  
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and deaf-blindness

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# Collective Wisdom

An anthology of **stories**  
and best practices  
for educating **students** with  
**severe disabilities**  
and **deaf-blindness**

Published by the Kansas State Department of Education, 2001

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Stories are **medicine...**

They do not require  
that we do,  
be, act **anything—**  
**only** that we listen...

Stories are embedded  
with **instructions** which **guide us**  
about the complexities of **life.**

Clarissa Pinkola Estes

WOMEN WHO RUN WITH THE WOLVES

---

In the beginning...

## “We Stood Back”

Dave was an 8-year old boy with autism who had been fully included in my regular 3rd-grade classroom. His classmates had accepted him as a member of our community, he felt accepted, and I had developed a real rapport with him. As I moved around the classroom, Dave always followed me with his eyes; he knew where I was at all times.

One particular day, the students were working with their small chalkboards; Dave was working with his cooperative group on his IEP objectives. All of a sudden, Dave picked up his chalk and started “drawing.” Instead of intervening right away to keep him on task, the para stood back. She realized that he was writing something. He was writing “Mrs. Tillberg.” He spelled it phonetically, but he used correct punctuation and capitalization. The para and I were so excited! We wanted to save his work for his parents and

handing over their chalkboards. The para and I just stood back in amazement as the children at Dave’s table took over. The group huddled together in the middle of the table like football players. There was a buzz of excitement. Their energy filled the room. By the end of the math period, Dave had written my name on all of their chalkboards!

When the special education teacher came in at the end of the day, several of Dave’s cooperative group members remained after school with him to share his success. He beamed with excitement. The amazing part about this whole day was that nobody had ever taught Dave to write my name. Dave could write his own name, and he did so independently when he was asked.

his other teachers to see, but Dave wanted to erase and continue writing. By this time, his classmates were

But he had never used or written any other letters. How did he know how to put the sounds together to write my name? Where did he learn how to use a period after Mrs.? How did he even know to capitalize Mrs.? We

You can never  
be **SURE** what  
children are  
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classroom  
Who are **WE**  
to deny them  
the  
opportunity?

didn’t know, but the evidence was clear that he picked up this information. You can never be sure what children are picking up in a regular classroom. Who are we to deny them the opportunity?

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## Foreword

# Collective Wisdom

People seem to have an almost natural desire to tell and respond to stories. As Levi Strauss commented in 1966, "Everyone every where enjoys stories... they reflect a basic and powerful form in which we can make sense of the world and experience... some people claim that the story form reflects a fundamental structure of our minds."

Stories serve numerous functions: they enable us shape or structure the general chaos of personal experience; they convey truths too simple or too complex to be stated in other ways; they help us make sense of memories and experiences; they prompt us to wrestle with problems and create our own meanings, and they connect us with larger ideas and, most importantly, to each other. As W. R. S. Ralston has stated, "one touch of storytelling may, in some instances, make the whole world kin."

In July, 1998, a group of Kansans came together in Lawrence, Kansas, to spend four

days talking about issues, reading literature, and telling stories about educating children with severe disabilities and deaf-blindness. Many of the participants were teachers who had served as field-based consultants in the area of severe disabilities and deaf-blindness. A parent, a principal, an audiologist, a speech-language therapist, a physical therapist, an assistive technology specialist, and a special education director joined them. Together, participants were guided by two goals: to learn from each other, and to write an anthology that would help other teaching teams in Kansas learn from their experiences. With the publication of this book, the goals have been met.

This book was created to serve several purposes. First, it describes some educational practices identified by research that teachers, parents, and other educators might use to enable students with severe disabilities and deaf-blindness to have richer, more meaningful, and empowered lives. Additionally, the book is

intended to be a resource book to which people can turn for assistance. The numerous stories told by teachers and educators, which are the heart of this book, provide a human face for the research and best practices documented here.

As you read this book, we urge you to read it with an open and critical mind. These stories reflect human experiences and, as such, they document personal triumphs and mistakes; they are taken from real lives of students, parents, and educators. The stories are not fictionalized in order to minimize the tensions and the incongruities of authentic experiences of teaching and learning, though they have been edited for length. As you read, you may have questions: questions regarding the teaching practices employed by the storyteller, questions about their own interpretations of the story's meaning, questions about the philosophical presuppositions of the authors. We encourage you to bring your experiences to

your reading as you consider the perspectives of the authors. Reading these stories can be seen as engaging in a respectful, collegial conversation with the authors who, like you, are concerned with educating students with severe

disabilities and deaf-blindness in Kansas.

This anthology is divided into eight sections. Each topical section has two parts: a story and a brief summary of best practices related to that topic. Participants in the Summer Institute wrote the first drafts of the stories and the best practice summaries.

The facilitation team deserves special

thanks for their work and contributions to this product. They are: Susan Bashinski, Gwen Beegle, Margy Hornback, Joan Houghton, Jim Knight, Lynette Lacy, and Jaime Sweeney. In addition, Donna Wickham, Pam Shanks, and Ellen Vogts served as editors. Gwen Beegle and Jim Knight designed the writing workshop process by infusing the principles of Partnership Learning designed at the Center for Research on Learning at the University of Kansas. Finally, the contributions of the following individuals were instrumental to the completion of this project: Emily O'Shaughnessy, Nena Murphy-Herd, Deb Matthews, Cynthia Thomas, Vera Williams, Randa Vollert-

sen, Rebecca Obold-Geary, Andrea Zody, Sue Meisel, Tara Bachmann, Amy Killinger, Shirely Wilson, Megan Cote, Sara Skopec, Jennifer Tillberg, Dawn Haynes, and Angie Reeder. ☺

Everyone  
every where  
enjoys stories...  
they reflect a basic  
and powerful form  
in which  
we can make  
sense of the world  
and experience...  
some people claim  
that the story form  
reflects a fundamental  
structure  
of our minds.

# Collective Wisdom:

An anthology of stories  
and best practices for educating  
students with severe disabilities  
and deaf-blindness

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# Belonging

The other kindergarten kids must have thought,  
“Oh well, she is touching him; she’s talking to him... she’s laughing with him; that must be okay.”  
That taught me a lot about children’s perceptions.  
I wish those perceptions were more contagious for adults.  
I know it is never that simple, but it would be nice to see it that simply... to see people first and disability second.

Every child needs a strong sense of belonging within social groups in order to develop wholly. Many schools seem to underestimate the importance of social development to the ultimate academic and career achievements of students with disabilities. Years of isolation and artificial environments have constrained their learning experiences and social relationships. Recently, schools that neglected to nurture proper social environments for their students have suffered tragic results. Fortunately, attitudes are changing. Educators now know that effective academic education includes proper attention to children’s and adolescents’ needs to belong inside a network of social relationships. Honoring existing relationships and promoting new ones helps every child learn and grow.

Families are the first social group to which children belong and families can have an immense effect on their children’s education. Family involvement has long been wide-

ly considered to be very important to children's educational achievement. This involvement takes on particular relevance in the lives of children with severe disabilities, including those with deaf-blindness, whose families often provide lifelong support for them, in addition to fulfilling the typical role of family. For these and other reasons, families of children with disabilities have a legitimized role in setting the priorities of their children's individualized education program.

Families are the driving forces behind children's individualized educational programs. Families and the professionals who work with their children must work to achieve an equitable partnership to be effective members of collaborative teams developing education and support plans. The burden of building effective team relationships should not be borne alone by families, however. Professionals should consider the establishment of a good working relationship with families to be one of their most important responsibilities.

Social networks in schools support the social, personal, and academic development of every child. Wise educators know that acceptance and belonging are important elements in children's self-esteem. Educators set the occasion for appropriate social growth through their personal examples and through the skills they use to support the social development of their students. Prejudice, judgment, fear, or simply a lack of knowledge can inhibit meaningful relationships from occurring naturally among children who have different cultural identities or learning characteristics. When students with severe disabilities or deaf-blindness are educated in schools or classrooms with typically developing children, respect for others and the value of diversity should be embedded in curriculum in structured ways.

When educators reinforce and model these attitudes, social networks are created naturally between people gravitating toward others who can help meet their relationship needs. Educators can also develop social supports for children who appear to be left out of the social milieu of the classroom as a caring, supportive community, benefiting all students.

### **Families are central figures in their children's lives**

Family-centered service delivery "recognizes the centrality of families in the lives of individuals. It is guided by fully informed choices made by the family and focuses upon the strengths and capabilities of those families." (Allen & Petr, 1996, p. 68) In order for families to act as empowered members of a team, they must be fully informed of their choices. The strengths, values, and resources of families, rather than weaknesses and deficits, form the foundation for the goals and interventions designed for their children's educational program. Decisions are made by the family, in concert with the professionals who assist them in enacting their vision for their children.

### **Families are self-defined**

Persons who matter most to the individual can be a part of that person's family, if they so desire, regardless of traditional conceptualizations of "family." Families may have single parents or two parents; they can be adoptive, foster, blended, or multigenerational. They can involve any relationship that matters to the individual. For many persons with severe disabilities and deaf-blindness, sibling relationships are extremely important. Brothers and sisters frequently have the longest adult relationship with the individual (other than their parents), and

many times take on increasing responsibility for their sibling as their parents' age.

### **Families are invested in seeing their children learn**

Families want their children to learn, to grow, to be safe, and to have friends. Parents and other family members are connected with their children over the long haul, acquiring historical knowledge of their children that professionals seldom share. Because of their unique perspective, families have a great deal of knowledge to offer in partnership with professionals. Families have much at stake in the educational decisions made on behalf of their child, given that their child will live with the results of those decisions for a lifetime.

### **Families can provide leadership within collaborative teams**

Families need to be encouraged to maintain or to take on a leadership role in their child's education. Professionals need to examine their practices to determine if they support, or undermine, family involvement. At times, families need to be encouraged to have a larger vision for their child. More often, families need professionals to act as their agents to bring to life their hopes and dreams for their child.

### **Families can help professionals understand their perspectives by sharing their hopes & dreams**

Professionals can use assessment methods that honor family perspectives and values, like COACH (Giangreco, Dennis, Cloninger, Edleman, & Schattman, 1998), to create educational programs that lead to preferred outcomes for the individual. An open line of communication between families and educators

encourages consistency and enhances program quality across time and settings.

### **A sense of belonging is fostered when children are sensitive to and value of diversity**

According to Maslow's hierarchy of needs, "belonging" is a basic need preceded only by physiological and safety concerns. Children do not have to earn the right to belong based on their ability to meet a certain academic, social, or physical standard. It is the teacher's responsibility to set the standard that "belonging" is based on appreciating and embracing our differences, as well as celebrating our similarities. By reinforcing positive interactions, modeling and teaching social skills, teachers can facilitate friendships and personal growth.

### **Teachers should use a variety of formal and informal groupings**

Cooperative grouping, peer tutoring, "Circle of Friends," and peer buddies are techniques that help the student become a contributing member of the classroom community and foster the development of friendships. Students are given the opportunity to practice friendship skills as they participate in structured and unstructured groupings in a holistic and integrated environment. Each naturally occurring social experience gives children a foundation for success in the future. When groupings occur, students with disabilities need to have opportunities to be in a variety of reciprocal roles (reporter, leader, timekeeper, etc.) and to participate in meaningful ways in order to gain respect from peers. As students with disabilities have many opportunities to participate in these groupings, other children will begin to see beyond the disability of the child.

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### **Opportunities for friendships develop when students with disabilities are with "typical" peers**

Structured programs such as "Circle of Friends" can help facilitate familiarity and the beginning of friendships between students. As relationships grow, peers begin to gain knowledge and understanding of each other outside structured social interactions. When friendships grow through shared interests and common experiences, these relationships are more likely to be maintained outside the school setting. Friendships among children often develop while giving and receiving support.

### **Children's natural curiosity about each other typically draws them toward their peers**

Differences in appearance, behavior, and equipment, however, can be intimidating for children. Thus, staff should prepare typically developing peers for the inclusion of a child with severe disabilities. This preparation may include a question and answer period, embedding ability awareness in the curriculum, and the emphasis of similarities versus differences. Students will need to know basic information about the child with severe disabilities and deaf-blindness, so they can work together as a team.

### **Summary**

Schools can be places where people who care can act to make children with learning and cultural differences feel a sense of belonging and respect. When teachers set the stage for positive attitudes and friendships to develop, children and youth will act in caring and responsible ways toward each other. Social networks provide students a structure to develop relationships with people who are different

from themselves. A classroom community includes and meets the belonging needs of all children and youth who participate and reaches out to the families of those children. Good relationships between family members and educators encourage team development and support educational progress across the years. Even the most committed families need to be invited to continue to participate in their child's education and the life of the school. Educators can help families by sharing information, communicating progress and concerns, and building on family strengths and values. Families need professionals to bring them the current, technical information they need to promote their child's education. ☺

# *They were singing*

*A teacher's story...*

☺ A few years ago, when I was an inclusion facilitator with a large caseload, one of my elementary students, David, was admitted to the hospital because his appendix ruptured. He was able to have visitors, so I went to see him after work, just to kind of say that I had been there; maybe see his mother. I picked up some books and some things I thought he would like. As I went in the hospital doors, I expected to find him alone in his room all day and night, with nothing to do. I thought we could play a little while before I went home for the day.

When I got to his room, there were a half-dozen people already there. His former foster parents, and their pastor, and the pastor's teenage children were standing around his bed. He had tubes, he was hooked up

to almost everything. He was in very bad shape and was really struggling. But the most amazing thing was, they were singing to David. They were singing hymns like "Jesus Loves Me" and "Amazing Grace" right there in the hospital. It was one of the most gorgeous things I had ever seen people do. The pastor was praying for him, and it wasn't a quiet prayer! They would reach out and touch him now and then. They stood around David in this cold, sterile little hospital room, and they made it a warm and caring place.

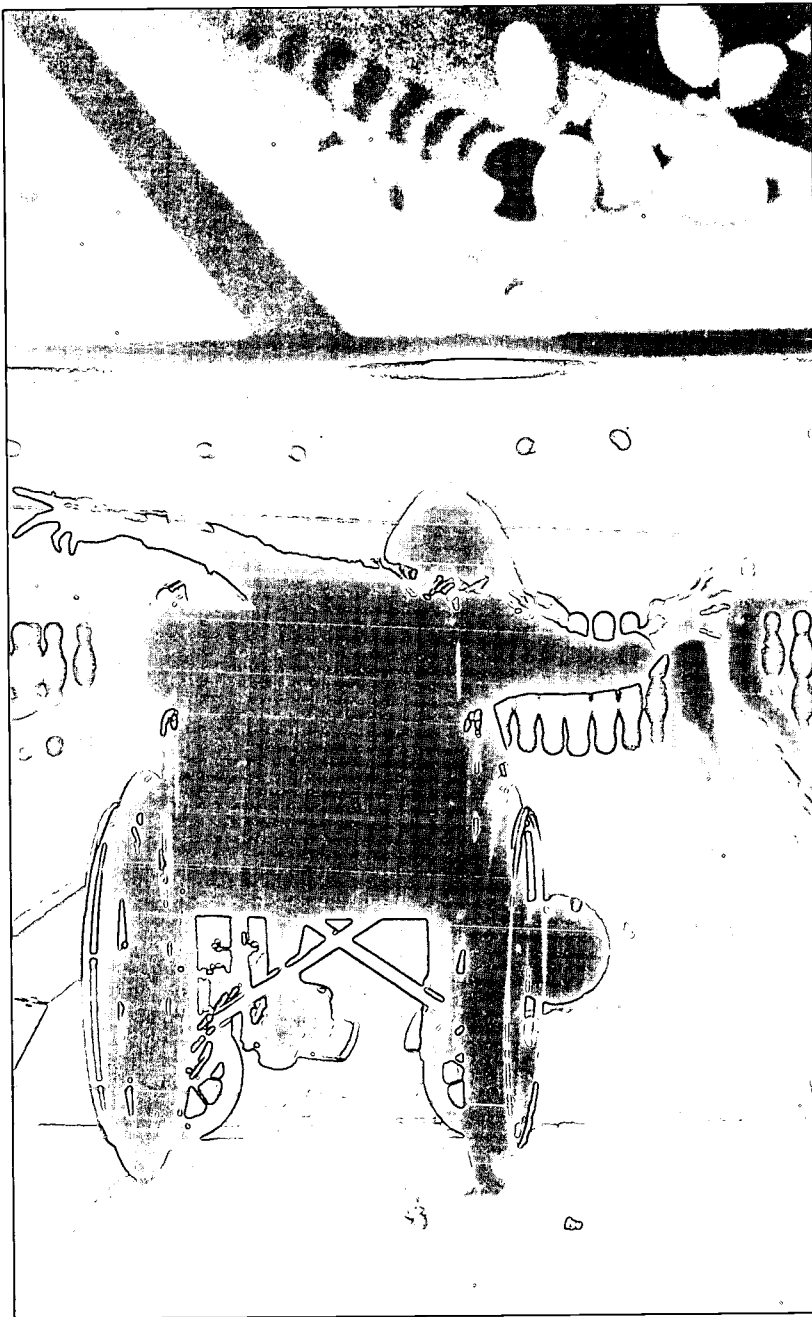
You know, David wasn't alert, and he didn't have his hearing aids or glasses. I'm not sure how much he could hear or see, but that didn't matter. What mattered was that they were there. FAMILY mattered... the people he was closest to... his church.

So I just stayed and sang with them! It was a neat networking thing for me to find out that this child had a support system that I didn't know existed and that I hadn't tapped into. I hadn't asked enough questions, or looked through all the papers to find out this family and this church had been so supportive of this child. So I stood there and I sang and I cried.

I went to help David, and instead I learned about belonging and what it meant. I learned about what mattered. Sometimes, kids teach us so much more than we teach them. ☺

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## The skills that support self-determination



must be valued, promoted, taught and practiced in responsive, person-centered environments from the time a child enters school until she leaves as a young adult.

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Self-determined lives:

# Values, planning, and transition

As educators, we need to realize that to reach a goal is an on-going task.

We don't just finish something and then we are done—there is more.

We have to respect the fact that our students face adversity forever.

Students who have severe disabilities, or who are deaf-blind, are entitled to a rich quality of life that involves experiencing the sorrows, joys, failures, and successes resulting from meaningful personal choices that shape personal destiny. The skills that support self-determination must be valued, promoted, taught and practiced in responsive, person-centered environments from the time a child enters school until she leaves as a young adult. Teachers who teach students with severe disabilities and deaf-blindness need to project their respect of each child's dignity to other children and adults. Teachers also need to protect children's basic humanity through informed, supportive practices relating to issues such as privacy and social validation with the expectation that other community members will learn that a disability does not define a person.

Person-centered planning is a critical tool that teams use to incorporate personal prefer-

ences, valued life outcomes, and contributions of people who care to the educational plan for an individual with deaf-blindness or a severe disability. Person-centered planning is a way to capture a person's hopes, dreams, choices, and preferences for work, home, and play. When planning is person-centered and ability-oriented, persons with disabilities are able to acquire dreams once thought impossible. Person-centered planning is particularly important during that period of time known by educators as transition, when specific supports and interventions help a young person in school succeed as a young adult in their community.

The purpose of education is to eventually prepare students to enter adult life. Until recent years, transition to adulthood for many students with disabilities was met with despair, uncertainty, and confusion. Many families saw their children leaving school without a job, a place to live, or services to support them. As awareness of these post-school realities grew, transition initiatives were developed to implement services, develop linkages between school and adult services, and institute policies to ensure student-centered programs with the necessary supports are in place. Successful education results in students who are successful in the lives they choose, living where they want to live, and working where they want to work. As teams consider how best to plan and provide appropriate, integrated educational services for children and youth with disabilities, several points are important to remember.

### **Children are unique and their disabilities do not define them**

Quality learning opportunities occur in heterogeneous environments, where children

can be known as more than their disability label: by their diligence when working on a task, by their ability to be a friend, by their sense of humor, or by the content of their character. Each child brings a gift to each classroom, and it is the teacher's responsibility to find that gift.

### **Children have the right to participate and to make choices within the natural settings of their lives**

The right to community participation should not be earned. From an early age, students have the right to make meaningful choices and participate in typical school, extracurricular, and community settings at their own level of ability while being challenged to improve their skills and increase their participation. A student's participation, regardless of its simplicity, lends him or her competency in the eyes of their peers, families, and communities. Altering the understanding of competency from complete mastery to development of their highest potential allows students to become valued, reciprocal members of their homes, schools, and communities.

### **Children have the guarantee to privacy; the right to discretion should not be earned**

Children and youth with severe disabilities and deaf-blindness often have self-care needs that require both assistance and privacy. For example, going to the bathroom requires that the doors are shut and that only those persons needed to help are present. Many times, students who do not talk cannot assert their need for privacy in the same way as other children. Therefore, adults who assist them must model these practices and advocate for the basic need for privacy of each child.



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**Children need responsive partners to communicate choices and exert control over their experiences**

Everyone can and does communicate. Individuals with severe disabilities and students who are deaf-blind often have to depend on people within their environment to recognize and interpret their behavior as communicative. Responsive partners must acknowledge subtle cues and build on the current abilities of the individual. Quality inclusive environments provide opportunities for individuals to practice choice and decision-making skills through multi-modal communication systems. This decreases the need for individuals to control their environment with challenging behaviors or respond to an overly controlling environment that leads to learned helplessness.

**All person-centered planning should promote quality of life, personal choice, and self-determination**

Person-centered planning is an action-oriented model in which core team members (including family, friends, and the persons themselves) take responsibility to make opportunities happen by capitalizing on each member's connections, gifts, and talents to improve an individual's quality of life. As needs are identified or new connections are made, different members may be invited to join the core team. There are many different person-centered planning processes, directed toward different situations and age groups. However, each style of person-centered planning has commonalities. Each has the ultimate goal of ensuring a quality of life through the collaborative efforts, and each contains a process to envision the future based on the individual's preferences, choices, communication styles, friendships, and life contexts. Person-centered

planning assumes that "nothing is impossible," because team members are committed to ensuring that each barrier is overcome and every available resource is used.

**Skills that support self-determination and achievement of a preferred lifestyle must be emphasized**

Opportunities to promote self-determination must be recognized and encouraged in the home, neighborhood, school, and community. Making choices, solving problems, and setting goals are skills that should be taught using systematic instructional strategies. The learning environment must provide the individual with the freedom and safety to make meaningful choices and experience the consequences of those choices, even when the consequences are not positive or desired. The safety and well being of the individual must be responsibly and carefully balanced with the individual's right to make choices. Students should, within reason, experience risk as they make decisions and experiment with their environments. These experiences parallel those of their same-age peers and promote truly self-determined behavior.

**Transition planning to adult life begins at age 14 with more extensive planning occurring at age 16**

When a student is 14-years old (or younger if the IEP team wishes), future services including instruction, related services (such as vision rehabilitation or orientation and mobility services), community experiences, employment, post-school adult living objectives, daily living skills, and functional vocational evaluations need to be considered. Team members may address graduation requirements or alternate graduation require-

ments, self-advocacy training, and guardianship or conservatorship (once the student turns 18). Again, these transition services must be linked to annual measurable goals and objectives or benchmarks in the student's IEP.

### **Person-centered planning transforms choices and preferences into situations and opportunities**

Self-determination and choice-making skills taught earlier now allow students to have more control over activities in their lives and interactions with others. Choices and preferences are an integral part of planning future activities in person-centered and transition planning process. Team members evaluate activities and environments to identify those situations in which the individual is allowed to make frequent and varied choices in life. For example, one person may prefer working in small groups, in quiet environments, and taking many small breaks, rather than receiving many directions, working with little variety, and touching soft textures. If the team were considering a job based on individual preferences for this person, the team may consider a library setting in which the person worked with one or two other people stamping books or taking inventory by scanning books with a bar code wand.

### **Transition is action oriented**

Transition planning works most effectively when every team member shares responsibility toward the implementation of established goals. Tasks and activities can include finding the location of the next meeting, contacting a business owner as a potential job contact, or obtaining home community-based waiver services. Progress toward the imple-

mentation of activities listed on the action plan need to be reviewed, revised, or terminated as transition progresses.

### **Summary**

In summary, families, students, and educators have long realized the importance of incorporating student choice and acknowledging student preferences within their educational programs. This is especially true for students with deaf-blindness or severe disabilities who have often had their choices and expressions of preferences unrecognized. Too often, students communicated their frustrations by acting out or shutting down.

Tools now exist to lay the groundwork for students to become increasingly self-determined. Teachers can create environments that are responsive to students with severe disabilities and deaf-blindness. When people respond to students' efforts to communicate, they help students learn to communicate more. When teachers encourage students to make even the simplest choices, they facilitate their students' learning. Students who are encouraged to make small choices are better prepared to take on the more important decisions that follow later in life. The dignity and respect of a self-determined life is a valuable goal for everyone. ☺

# Think big and work hard

*A mother's story...*

☺ I think I've always sort of done person-centered planning for my daughter, though I didn't know it was called "person-centered planning." I think all families and professionals should consider the child first. That is really the only way to make a plan that works for everybody—for schools, families, communities—to sit down and think what that child is doing today, tomorrow, and what their choices, desires, and goals are.

But the first time I did any formal plan of this sort was with the school psychologist when my daughter entered a regular elementary school. The school psychologist was a wonderful person and did her job quite well. She listened to parents, and she tried to find tools to help parents. One of the tools she used with me was the COACH system. I had never seen it before. We

sat down and talked about the assessment, and it really helped me to put a lot of things into perspective.

One mother told me that she shocked the physical therapist at school because she wanted to work on flexibility and tone in her daughter's legs to make sure that they were doing everything to ensure that if her daughter got married someday, she would be able to have sex with her husband. That sounded very shocking, and the therapist thought that was very weird. But parents think along in those terms because they don't want to give up on anything too soon. They don't want to limit their view of what their child might be able to do, whether that's living in an apartment alone or having sex with a spouse. Those are still valid things to think about.

Then there was the father who played tennis, and his vision was that maybe someday his daughter would be able to play tennis with him. We must not take that dream away. We must build on it. It may seem unrealistic when the child is 6-months old, but when she is 14-years old and in her wheelchair, with her own customized racket, and she is playing tennis with her dad, it's not Wimbledon but it's a beautiful thing to see.

Sometimes you have to think big and work hard to make those dreams a reality. You should never limit what you expect for a child. ☺

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Effective **team collaboration** is teaching and  
**learning** skills so that I can do  
what you do, and **you can do** what I do  
to establish a **comprehensive**  
individualized education program for the **student**.



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Collaborative teaming and systems change:

# Working together for change

You have to let your child  
have the present  
as well as the future.  
Their life is now;  
it doesn't start  
at some magic moment  
when they turn 21.

Many school districts have begun systemic change toward inclusive educational practices through developing collaborative teams to support and educate students with severe disabilities or with deaf-blindness within natural environments. These collaborative teams typically include general educators, special educators, related service providers, parents, and the students themselves (especially older students). At times, other persons who know and care about the student can be a part of the team, including friends, extended family, or community service providers. Inclusion through inter-professional collaboration is based on the beliefs that (a) each professional brings unique knowledge and skills to the team, (b) the ownership and responsibility for implementation belongs to all persons on the team, and (c) family members are equal members of the team. A model collaborative process includes persons meeting as a team on a regular basis to

(a) evaluate students together, (b) develop common goals and objectives, (c) plan activities by looking at individual student strengths and needs, (d) create learning opportunities within daily routines and natural environments, and (e) monitor student progress. As team members share knowledge and grow together, the team process enables them to respond to a student's changing needs. Effective team collaboration is teaching and learning skills "so that I can do what you do, and you can do what I do" to establish a comprehensive individualized education program for the student.

Collaborative teams reconfigure educational programs and redesign educational environments to create reform for the student and at the school level. As educators and families begin to collaborate, a myriad of changes for school organizations, school districts, and professional development providers become evident. Often, supported experiences in collaboration are needed to ensure that people who work in teams are using effective interpersonal skills and that the team process results in effective inclusive education. This is only one of many changes often needed to support quality educational programs, however.

Reform that is systemic in nature seeks to change schools, districts, state departments of education, and universities in coherent and fundamental ways. Teachers must provide access to general education curriculum and effective instruction, holding students to high standards of achievement without ignoring their disabilities. Related service providers must redesign their services to effectively integrate them into a total educational approach. Administrators must organize schools to marshal and coordinate resources that will improve teaching and learning for every student who lives in his or her school communi-

ty. Community members, including parents and families, must know more about the problems facing young people so entire communities can work together to improve the well being of children and youth. State department of education personnel must remove policy barriers to inclusive education and promote appropriately educating students with disabilities in inclusive, least-restrictive environments. University professors need to prepare novice teachers to use their technical knowledge in inclusive educational environments, while lending a hand to schools undergoing reform. As each of the interrelated parts of the educational system changes to improve its practice, its counterparts are affected and signaled to improve as well.

#### **Collaborative teams work toward the common goals of effective teaching and learning**

A collaborative team is comprised of individuals with varied expertise and perspectives, who share the planning, instructional, and evaluation responsibilities for the same student. Creating meaningful educational experiences for the student takes precedence over discipline-centered objectives. Members of a team benefit through the positive interdependence of working together toward a common goal. By working together, teams (a) make better use of resources, (b) are more creative and efficient when solving problems, (c) make higher quality decisions, (d) provide better services, and (e) support each other through difficult times or change.

#### **Collaborative teams share information and skills to create meaningful learning experiences**

Children experience interrelated, multiple learning needs that cross school, community,

and family settings. No single individual has expertise in all the areas that affect the student's education. Educational teams, which should always include family members, must join together to assume ownership and share expertise and responsibility for student learning. Collaboration depends upon each team member becoming skilled in taking two roles: that of a "teacher" who shares knowledge and skills, and that of a "learner" who uses the skills and knowledge of other team members. Each team member learns to listen, contribute ideas, support other members, value expertise, and solve problems creatively within a supportive group. By applying these skills, team members effectively work together to benefit the learner in a comprehensive rather than segmented fashion. Students benefit from an educational program based on the diverse perspectives, skills, and knowledge of collaborative teams.

#### **Systems change involves thinking about problems in an interrelated way and on a system-wide scale**

Many educators have been involved in creating an inclusive educational program for one student, or in one classroom. At times, positive change stops at this point, when one program, one classroom, or one school becomes more inclusive. Systems change occurs when a whole school, district, or state facilitates effective, supported, inclusive education to the extent that individualization of instruction within typical environments is a typical expectation for any student. Systems reform can't wait for all parts of the system to be "ready" before beginning. Anticipate that one change will ripple through the system, creating opportunities for more change. Skills learned through participating on collaborative teams help prepare us all to work together toward changing a system.

#### **An individual or a team can stimulate change, but convincing others creates momentum for change**

Michael Fullan, a famous educational researcher, claims change is too important to be left to others. People must become an agent for change in their school or district by promoting excellent, inclusive schooling in daily practice. Individuals who model new practices at the same time promote new ideas and ways of thinking that facilitate change on a larger scale. For reform to occur, more individuals must affect change or be affected by change. Connecting special education reform with school improvement has been a successful strategy for schools in Kansas.

#### **Interprofessional teacher preparation and on-going inservice opportunities are essential for change**

Interprofessional preparation encourages teachers from the beginning to interact with other service providers while learning common skills. When teacher preparation programs promote collaboration and other practices that support inclusive schooling, teacher candidates are more prepared to work in inclusive schools. However, veteran professionals also struggle to involve students meaningfully in classrooms geared toward academic disciplines. Therefore, ongoing professional development and technical assistance is crucial for teams to learn best practice techniques, like collaboration, so they can effectively educate students with significant disabilities.

#### **Top down, bottom up, outside in, and inside out strategies are all important for systems change**

Administrative leadership is widely recognized in the literature as essential to school

change, and educators in Kansas agree that state and local leadership is important. Schools can educate communities about the contributions of students with severe disabilities and deaf-blindness and the issues related to their education. Informed community members are more likely to become involved in the development and implementation of a shared vision that requires a commitment to change.

While local motives, skills, and commitment are individual in nature, positive attitudes and open minds are always critical for schools to sustain change. It is important to remember our children learn these positive attitudes. Schools should communicate respect, high expectations, and educational responsibility for all children in their community.

## Summary

Through collaborative teaming, students, families, teachers, and other support providers can effectively meet the complex needs of students. Students are best provided services when teams address their education in a holistic manner, drawing on various disciplines and experiences to create the best education possible. Teams share responsibilities and support each other to plan, implement, and monitor educational programs. Though many adults are not experienced in working effectively in teams, collaborative teaming is key to student success. Implementing collaborative teaming in a school or district is an example of a systemic change. The nature of collaborative teaming can provide a stimulus for further systemic changes that benefit each child. 🌟



# *We weren't ready, but we started anyway*

## *An administrator's story...*

☛ Over the last 10 years, it has become a challenge for administrators to live our philosophy. In the early 80's, we essentially predestined the way kids in special education were going to leave school. If a child with severe disabilities was bused from one community to another to be in a clustered program, we could pretty much guarantee that this situation would occur for the rest of that student's life. Then, it struck me what we had been asking parents to do. Would I, as a parent, be willing to have my child with or without a disability placed on a bus, driven past the school in the neighborhood where our family chose to live, to go somewhere else? But how do you go about changing the way we had done things in special education, even if for a short period of only 20 years? Well, in our case, we began with Lance.

In the spring, Lance's foster parents requested that Lance, who had severe disabilities, attend his home school in the fall. At the time, Lance was enrolled in a self-contained classroom in a clustered program in a community 30 miles away. Because we had been preparing for such requests philosophically, we really could not say "no" to his parents. It would be interesting, though, because this boy would go to school where only students with mild disabilities had attended. How could we make this change?

First, we knew we would need a good idea of the IEP that we would implement in the fall. We needed to write down all the key activities that would take place. For example, someone would need to go into the school, explain to the staff what would be expected of them, and introduce them to Lance. Then, when

fall came, we met once a month with Lance's parents and service providers for 35-40 minutes to solve problems on the playground, in the hallway, or with a teacher who was frustrated in some way.

We were really lucky to have a great paraprofessional, good support from the principal, and constant support from Lance's parents. But the key person was Lance's teacher. She said, "Did I have enough training and enough information when I started? The answer was no. Would I ever have had enough information and training to start? The answer was no again." As an administrator, this says an awful lot to me. It says, "Is there ever a right time to start, or more importantly... can our students afford to wait for us to be ready?" ☛

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...it is important  
for the student to **participate**  
in **all** aspects of the activity  
in order to make sense  
of the **learning** opportunity.



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# Teaching and learning

Students aren't going  
to learn everything they need  
to know within the four walls  
of the classroom.

You can't talk about going  
to the grocery store and making  
change unless you go  
to the grocery store and  
make CHANGE.

Education is often synonymous with curriculum and instruction. Exemplary education includes a curriculum that prepares a student for his or her future, adapting and augmenting traditional academic content to ensure personal relevance and functionality. Systematic instruction, including monitoring progress and evaluating teaching effectiveness, is essential to ensuring that the student learns the essential skills identified in his or her individualized education plan (IEP). Appropriate instruction, adaptations and well-chosen curricular goals enable students to actively participate in their learning community.

Curriculum describes the goals and content of education. Students with severe disabilities and deaf-blindness have seldom followed the same curriculum as general education students. Prior to the 1970s, curriculum typically followed a developmental skill sequence. With the publication of several landmark articles in the late 1970s, the field of severe disabilities

and deaf-blindness began to embrace a more functional curriculum based upon the demands of adult life. As research demonstrated the value of inclusion and the power of peer influence on student learning, many educators and advocates learned how to support students with severe disabilities in general education settings. The 1997 reauthorization of IDEA explicitly states that IEP objectives for students with disabilities must be linked to the general education curriculum, thus challenging educators to blend individually tailored goals with general curriculum standards. Making curriculum meaningful for students with severe disabilities and deaf-blindness while maintaining access to the richness of general education curriculum and settings will continue to be a challenge for educational teams in Kansas, and in the nation.

For students with severe disabilities or with deaf-blindness, instruction has mainly focused on the functional application of skills across age-appropriate environments, using systematic, data-based techniques to support learning with special attention given to generalization. Further, since skills are often broken down and taught in smaller parts, it is important for the student to participate (at least partially) in all aspects of the activity in order to make sense of the learning opportunity. This necessitates creating and using adaptations to compensate for the discrepancy between the student's current ability and the activity's demands. Educators use interdisciplinary practices to bring general and special education resources together with related services to promote individually designed learning programs. Teachers are challenged to be creative, innovative, and responsible for the results of their efforts in terms of student learning. Reflective practice empowers teachers to make informed

decisions about teaching based on a conscious awareness and careful evaluation of the ethical consequences and underlying assumptions of those decisions. Reflective teaching allows teachers to act before, during, and after to improve their instructional skills.

### **Students with severe disabilities can meaningfully participate in general curriculum by embedding differentiated objectives in activities**

Because the student's IEP objectives help to define the student's curriculum, educators and related service providers must work together to determine whether the student will use a multilevel or overlapping curricular approach. For a student who has different learning outcomes, a multi-level curriculum allows the student to work within the same curricular area with a different learning expectation. For example, the student with a disability may be learning basic knowledge or comprehension, while other students may be working to synthesize the information.

Curriculum overlapping allows a student to work within the same curriculum area or different curriculum areas. For example, a student may be working on comprehension and communication within a science activity, while his or her peers are learning a specific science objective like using scientific scales to determine mass. A useful tool in planning to infuse objectives into the day is a matrix. This visual tool shows the daily schedule and where the IEP objectives can be embedded in a variety of settings or activities. The skills addressed in the matrix will help define the student's participation within the diversity of the regular education classroom.

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### **Environments can be structured to provide opportunities for making choices**

When a classroom is aesthetically pleasing and planned from a learner's perspective, the environment invites spontaneous exploration and making choices. Placement of materials in an accessible, consistent place allows children to choose materials with increasing independence. Simple things like pulling baskets or trays of materials to the fronts of shelves can make them easier for students to see and use. Teachers can enhance the environment by adding tactile cues, visual schedules, or calendars to meet the specific needs of each student. Teachers can also increase the students' opportunities for making choices. Models of choice diversity allow a team to increase or provide a more diverse range of choices simply and without new equipment or materials. When teachers provide frequent and meaningful opportunities for choice, students grow in their ability to make decisions and direct their own learning and growth.

### **Each student's educational program builds toward the goal of interdependence & independence**

Beginning transition planning at age 14 is too late for students with severe disabilities and deaf-blindness to prepare for adult life. All IEP objectives need to contribute to a student's participation in real-life activities, including interacting with his or her same age peers, to the greatest extent possible. In many cases, this requires blending general education standards, functional applications, and family activities.

### **Partial participation means actively engaging in activities throughout the day**

By using partial participation, students actively learn within the context of natural

environments. Partial participation assumes that students have the right to participate in activities to the fullest extent possible, and that some participation is preferable to being denied access to natural environments and the activities that occur within them. It is not mere presence, a different activity in the same setting, or just passing out papers to other students. Rather, students can hand out the materials to their cooperative learning group, then join the activity to do a unique task critical to their group's success. Students who participate are seen as competent and contributing members of classrooms. Partial participation allows students to participate while practicing individualized student objectives meaningfully.

### **Task analyses and prompts are effective means to teach skills to students with severe disabilities**

Task analyses break skills into the sequential steps needed to complete a task successfully. These steps take place within naturally occurring activities. For instance, the lunchroom routine (e.g., getting one's tray, silverware, napkin, choice of food) is divided into sequential, manageable steps so the student can be systematically taught small increments of the lunchroom routine with the goal of becoming independent throughout the whole routine. Prompts are different ways to help a student progress to the next step with as only as much cuing as needed to be successful. There are many types of prompting and ways in which those prompts are implemented. Once a student can progress with one prompt, it is faded out. Prompts also cue a student to expect the next step in a routine or schedule. Examples of this include a teacher gently touching a student on the front of her shoulder twice to let her know that her chair will be moving forward or manipulating a student's hand under the

teacher's hand to make the "stand" sign before assisting her to stand after lunch.

### **Teaching and learning adaptations must support the student**

Student considerations need to be addressed when selecting adaptations. Possible adaptations may include learning style, sensory input, setting, and difficulty of task. Once these considerations have been made, adaptations can be chosen from a variety of options including environmental (e.g., seating and proximity in classroom), materials (e.g., enlarged print), instructional (e.g., oral or written presentation of content), rules (e.g., tangible reinforcement versus verbal praise), expectations (e.g., a five-word spelling test versus the traditional 20-word list), personal assistance (e.g., peer tutor in lieu of full-time adult intervention), and technology (e.g., talking calculator). There are many adaptation options to embed skills in ways that allow students to meaningfully participate with their classmates. (For more about adaptations, see the Life Activities section, pp. 25-29.)

### **Comprehensive planned data collection is required to make sound instructional decisions**

Data are the crux of developing appropriate educational programs for students with severe disabilities and deaf-blindness. Periodic and continuous objective data collection can help support or refute teacher intuitions as to whether instruction is effective. Without reliable information, a student's instruction may move too quickly or slowly. Data can be qualitative or quantitative in nature depending up on the student's annual measurable goals.

### **Reflective practice can help teachers make immediate decisions to improve teaching practice**

Reflection-in-action is a sequence of "moments." The teacher reflects in the midst of action, without interrupting it, while still making a difference to the situation. The teacher is able to reshape what he is doing while he is doing it. Because it enables immediate action, reflection-in-action is different from other kinds of reflection. There is no single model for inquiry that works for every situation. Some ways are more or less formal and rigorous, and can involve a wide range of different techniques and methods. Examples include teaming, awareness plans, cooperative learning, and developmental discipline.

### **Educational leaders can support others to engage in reflective practice**

Administrative support for teachers to "look back" or to reflect on what they learned and at the process they experienced is vital for encouraging the development of reflective practitioners in a school. The same factors that enable students to grow and develop also enable teachers to grow and develop. Principals can use transformational leadership to elevate teachers and themselves to higher levels of morality and motivation. The reflective practitioner must take on the role of educational leader as well as follower.

### **Schools and their communities can be united through engaging in reflective practice**

For meaningful change to occur, schools must work together with a variety of other social institutions to achieve goals. While educators have accepted responsibility for problems originating in the larger society, even

though they may not have solutions, these problems affect many other organizations, too. Educators need to use a systems approach and share decision making with other organizations. Reflective thinking enables parents, teachers, and administrators to problem solve and make decisions that effect change.

### **Educators can act on their ethical principles through reflection**

Reflective practitioners are concerned and involved with issues of social justice and ethics in education. Ethical decisions and judgments involve dilemmas in which one is presented with two or more undesirable options from which a choice must be made. Personal preferences and valued judgments are logically and practically distinct. Only value judgments should be taken into account when deciding public matters and disputes. Good ethical decisions and judgments are the result of reflective interaction involving others, especially those not directly involved in the ethical dilemma.

### **Summary**

Once students with severe disabilities and deaf-blindness are included in natural environments in the community and general education classrooms, teachers often realize that these environments offer a wealth of possible curriculum options. It is now a common occurrence for students to have IEP objectives or benchmarks that necessitate instruction in general education classrooms and community settings. In some cases, the outcomes for these students are the same as those for their classmates; in other cases, the outcomes are different. The challenge for teachers of these stu-

dents is to deliver the curriculum in relevant settings while keeping in mind the need for systematic instruction and routine evaluation. Although reflective practice has its roots in general education teaching, this tradition parallels and expands the special education tradition of data-based instruction. When teachers thoughtfully reflect upon the contexts, assumptions, and results of the programs provided for students with severe disabilities and deaf-blindness, they can improve their teaching skills and the outcomes for their students. 🌱

# Baby Steps

*A teacher's story...*

Ichmad, who had deaf-blindness and very low muscle tone, came to my preschool classroom in the early 1980s. His mother was becoming a strong advocate for him, and it soon became clear that she wanted Ichmad to walk, despite the fact that he wasn't doing anything except scooting or rolling a little bit. The physical therapist felt that developmentally, Ichmad wasn't ready to walk. But he was very long and lanky and adding weight. His mom couldn't carry him anymore. Also, she was firm that she did not want a wheelchair in her life at this point. She wanted him to walk.

The PT wasn't real thrilled about the idea. She told me that she thought this was a not productive path for Ichmad to be taking at this point. Being a young teacher, I was ready to look at the PT and say, whatever you say is right. But I had to balance this parent in my ear saying, "I don't care about developmental stages; I need my child

to walk." I could empathize. So I asked what we could do to make it a productive path. The PT felt working on leg strength had to be first. So, we worked on leg strength in the classroom, while the PT continued her therapy.

Initially, when Ichmad stood, his legs would collapse. He had no ability to lock his knees. However, we (the para, the PT, and I) tried to think of times when he could practice bearing weight. We decided he would have to stand at a shelf and hold himself up—first with help, then independently, whenever he chose an activity. After choosing his materials, we would take him to a table and again we would make him stand and support himself. He also practiced this skill when he was finished by putting things away. So, we practiced leg strength, by embedding it throughout the day.

And lo and behold, Ichmad started locking his legs. Then he could stand for greater lengths of time, holding himself. As he

began to do that, the balance was important—getting to hold himself upright without falling. Then we tried to get him to begin taking baby steps by bumping his foot forward. Then, when he could actually cruise the furniture, we began to have him walk around the classroom, using our bodies for support. Within a year, he was using a walker and moving around the classroom.

In retrospect, the things we all did were baby steps that led to this wonderful transformation. I think Ichmad's classmates were very important to his success. Preschoolers are very warm and accepting. To them, Ichmad was a child first. They naturally celebrated his small steps, and that motivated him. It was one of those times when "never say never" hit me in the face. It's okay to teach skills out of sequence sometimes. If the child shows progress, follow his lead. The obvious path might not always be the most productive one. ☺



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# Life activities, adaptations, & supports

Take it one step at a time.  
You want to have your goals,  
and you want to work  
for your goals,  
but break them down.  
Work through them.  
Make adjustments as needed.  
Don't get in  
too big of a hurry.

Learners with severe disabilities and deaf-blindness often need additional supports, tools, and adaptations to accomplish the same or parallel activities as their peers. Because of the nature of some disabilities, intervention is often needed to improve the learner's health or decrease the process of physical degeneration. Specialized procedures and equipment formerly viewed as only medical treatments are now intricately included in students' education in order to increase their quality of life, increase their dignity in interactions with care providers, and prolong life in the best possible way. Improving a learner's quality of life by any adaptation or support that increases independence and dignity contributes to her educational program.

**Assistive technology makes things possible for  
many learners with a disability**

The acquisition of skills to utilize adaptive devices and specialized equipment increases a

learner's independence and enhances self-concept. She may not be able to complete all of an activity, but each accommodation potentially allows her to partially participate, with at least some degree of independence. Many activities of daily living are made available to learners with severe multiple disabilities and deaf-blindness through technology-based applications and therapeutic accommodations. A lever door handle certainly makes it easier for most persons to open that door when their hands are full. For a learner with physical disabilities, who has limited wrist rotation and grip strength, a modified "door knob" makes opening the door independently a realistic possibility.

#### **Written plans must be incorporated in the IEPs of learners who require assistive technology**

Federal legislation that provides funding for special education programs has recently recognized that a significant number of learners with disabilities require some type(s) of assistive technology in order to benefit from special education services. In an effort to increase program accountability to individual learners, the 1997 reauthorization of the Individuals with Disabilities Education Act requires that learners' needs for specialized equipment for health-related procedures, adaptive devices, augmentative communication tools, and assistive technology applications be written into the learners' IEPs. Assistive technology has been formally recognized as an element of a free appropriate public education.

#### **How assistive technology, adaptations, and supports maximize seven life skill areas**

**In education:** Computer access allows a learner to participate in parallel activities. For example, while classmates are reading a book,

a learner with a visual loss is listening to the same text via headphones and a talking word processor. In order to compose sentences about a story, a learner may use an alternate keyboard with an overlay that offers sentence combinations.

**In therapy and habilitation:** Seating and positioning affect comfort level, attention span, range of motion, hearing, and vision. A learner's functionality and participation can sometimes be significantly improved through proper positioning alone. While health-related procedures such as gastro-tube feedings, clean intermittent catheterization, suctioning, and tracheotomy care are not typically addressed in the education preservice curriculum, many of these procedures are required by some learners who have severe multiple disabilities and deaf-blindness. These procedures can be handled at school by school personnel under the nurse's discretion. With school nurse supervision and other supports (e.g., proper training, training updates, and reliability checks), health-related procedures can become routine for school personnel. Access to such required procedures now available in the school environment facilitates a learner's inclusion in the general education classroom and leads to greater participation with peers who do not have disabilities.

**In self-help:** Adaptive equipment makes providing routine care for a learner who has severe multiple disabilities and deaf-blindness easier. Advancements in the field of assistive technology have provided more families with the realistic option of supporting the member of their family who is in need of care in their home environment. Equally important is the fact that adaptive devices afford learners the

opportunity to gain additional functional independence. For example, velcro makes it easier to strap on shoes. A special plate with a guard or lip or a built-up swivel spoon facilitates the development of self-feeding skills. Hand-in-hand with increased independence comes enhanced dignity and self-concept.

**For mobility:** Mobility is an issue for learners with vision losses, deaf-blindness, and physical disabilities that limit independent ambulation. A learner's perception of the world changes dramatically when she becomes able to move through the world in an upright position. Access to independent mobility affects organization of and orientation to the environment, as well as daily living skills. Clearly, a driver learns more about the route to a particular location than does a typical passenger. A learner's independent mobility may be enhanced with the use of a walker, tricycle, scooter board, rigid cane, or power chair, thus enabling more independent movement between locations.

**In recreation:** Adaptive devices and specialized equipment allow learners with severe disabilities and deaf-blindness to participate in community-based recreation and leisure activities with nondisabled peers and neighbors. Peer relationships and leisure skill acquisition are enhanced with low-tech, single-switch activation of a battery-operated toy, adapted handles on racquets, golf clubs, sewing devices, lifts, floatation devices for the pool, bowling ramps, beeper balls, and a variety of other devices.

**In vocational education:** Assistive technologies facilitate a learner's active participation at vocational sites within the commu-

nity. The functional independence afforded a learner through adaptations and accommodations includes enhanced vocational opportunities. A learner's vocational program may utilize a tape recorder for listening to a pre-recorded sequence of instructions, learning the layout of a work environment through tactile maps, or managing her own work station through environmental controls she has mastered.

### **The characteristics of assistive technology devices should match the learner's needs**

Due to the myriad of adaptations and assistive technology devices available, assessment of assistive technology is critical to student success. Assistive technology assessment includes analyzing a learner's individual needs, the task(s) that need to be accomplished, and all environments in which the learner is likely to participate—both current and future. Using this information, a good match of tools, devices, and adaptations can be accomplished. No single adaptation or assistive device answers each learner's individual need. The feedback, support, and reinforcement afforded a learner within each situation must be considered to maximize his or her potential.

### **Individuals of all ages can benefit from access to assistive technology in daily environments**

Neither very young children and their families nor older adults should be denied access to assistive technology and adaptive devices. Research indicates that children as young as one and one-half years can benefit from access to power mobility. Young children with visual losses or deaf-blindness must learn how to move safely about their environment.

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This helps them learn about the relationship of their bodies to objects in specific environments. Care providers for individuals of all ages who have severe multiple disabilities and deaf-blindness can benefit from assistive technology, adaptations, and supports. These applications help to maximize learners' functional independence and participation in multiple life skill areas, from early education through adulthood.

### Summary

A learner's individual assistive technology devices and adaptations need to be available in all of her environments in order to allow her access to a free and appropriate public education. For example, because communication takes place in all environments, it is quite likely an augmentative communication device would not only be used in school and community environments, but also in the home. Or if a computer or computer adaptations are used at school, it may be necessary to use the same at home in order to allow the learner to complete assignments. ●

# *Learning to fly*

*A physical therapist's story...*

☛ Jamie was an 18-year-old girl who experienced cerebral palsy. She was able to walk about 10-15 feet with assistance and the use of a walker. She had athetoid spasticity, and the increased muscle tone made it very difficult for her to do any activity with speed or accuracy.

In her first 18 years, Jamie had never experienced independent mobility. At no point had she ever been able to walk by herself. She had a manual wheelchair, but because of her muscle tone, she was unable to propel it by herself.

Eventually, Jamie's team was able to purchase, with family support and resources, a power wheelchair for her to use. Through a lot of work with different types of switches and joysticks, we prepared Jamie to use the wheelchair. When it arrived at the school, we went to the high school lobby where

there was a lot of space. We put Jamie in the middle of the lobby and turned on the power.

The first time she used the joystick to make the wheelchair move, Jamie just laughed and laughed! It was almost as if she had learned to fly. She had wings! She had been in a cage all of her life with a manual wheelchair she couldn't use, and all of the sudden someone opened the door. Later, she learned to manipulate the chair throughout the school and became an office aide, delivering mail from one building to another.

Since the only way Jamie's parents could transport the chair was in the back of her father's pickup, the wheelchair rarely went home—unless her parents were taking her shopping. A month or two after receiving the chair, Jamie went with her parents to Wal-Mart.

While they were in the store with Jamie next to them, Jamie's parents turned their backs on her. When they turned around again, however, Jamie was gone! She was nowhere to be seen. For the first time in her life—in 18 years—Jamie had some control over where to go. I can't remember where they found her; maybe by the music. Her parents were very happy about Jamie spreading her wings on her own. And so was I. I felt like we really had climbed a mountain and reached one of those major goals. Jamie's independent mobility opened a whole realm of possibilities and opportunities for her. ☛



The development of **communication** skills  
is grounded in an  
**individual's interacting**  
with the world in an organized way,  
and establishing a **trusting** relationship  
with the **people** in that world.

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# Communication

If you can let them know  
they have the right  
to make choices  
and they have the right  
to have some control  
over what happens to them—  
and to initiate  
and not just be responders—  
they'll never forget  
that someone once gave them  
that right.

Communication is the essence of human behavior and should be the cornerstone of any educational program for learners who have severe disabilities and deaf-blindness. Though communication serves a variety of purposes, it is primarily a social process. All communication consists of an exchange of information between two or more human beings. The development of communication skills is grounded in an individual's interacting with the world in an organized way, and establishing a trusting relationship with the people in that world. Though the sequence through which communication and language typically unfold can be generally described, communication development is highly individual, especially early communication development.

**Communication is a basic human right  
and all learners communicate**

Even without formal language, all human beings communicate. Communication begins

moments after birth and is nurtured through attentive caregiving experiences. There are no prerequisites to communication. Each learner brings a unique set of strengths and limitations to the communication process. Just because a learner cannot "speak" in a traditional sense does not mean she has nothing to "say." Some learners' communication behaviors are so subtle that they are not recognized as communicative. Some potentially communicative signals are idiosyncratic to such a degree they are difficult for others to interpret or understand. Nonetheless, these behaviors must be given communicative status. All learners should be expected to communicate in some way(s).

#### **All communication programs should be multimodal**

"Multimodal" refers to the multiple forms through which meaning can be conveyed. The three primary modes of human communication are vocal, aided, and unaided. Vocal communication includes not only verbal speech or a voice-output augmentative communication device, but also crying, moaning, laughing—any production of sound. Aided communication involves the use of things external to a communicator's body: objects, photographs, abstract icons, written or brailled characters, an augmentative device, or a computer. Unaided communication, sometimes called gestural communication, consists of movements, gestures, or signs produced with only a communicator's body: orientation, pointing, nodding, cued speech, palm signing, or Signed English. People without disabilities use multimodal communication (e.g., "She can't talk without using her hands.") in everyday interactions. Augmentative communication programs, therefore, should incorporate multimodal elements for learners who communicate

at both the nonsymbolic and symbolic levels.

#### **Communication includes both receptive and expressive skills**

Receptive skills consist of those that enable a human being's comprehension or understanding of a message that has been communicated to her. Expressive communication skills are those that enable an individual to send or encode a message. True communication occurs only within the context of a meaningful interaction. Merely helping a learner master the repetition of some expression does not, alone, constitute communication. For communication to take place, participants in the interaction must alternate the roles of "speaker" and "listener"—even if not deliberately. By sharing a common focus, the learner and her partner are able to share information about that person, place, or thing. Therefore, communication programs for symbolic and nonsymbolic learners should address both receptive and expressive skills.

#### **Communication consists of content, form, and function**

Content refers to the meaning conveyed through a communicative effort; it is the "what" of communication. Communicative signals and symbols to express needs and wants, develop social closeness, and exchange information should be considered for inclusion in a learner's lexicon or vocabulary. Specific content should derive from a learner's own experiences and preferences, as well as those of her family and employer. When teaching symbolic language content, teachers need to facilitate a learner's development of an internal understanding of a concept before attaching a



language label (e.g., symbol—picture, sign, word) to that concept, if at all possible. Otherwise, one will be attempting to teach two things at the same time.

Form involves the way(s), or mode(s), through which meaning is conveyed; form refers to the "how" of communication. Communicative forms may be nonsymbolic observable behaviors (e.g., levels of alertness, facial expression, muscle tone, stereotype, or aggression) or symbolic (e.g., pictures, braille, words, or ASL). At both the nonsymbolic and symbolic levels, multiple modes of communication should be encouraged.

Function is the purpose for, or use of communication; it is the "why" behind communication. Both nonsymbolic and symbolic communication serve multiple, equally-valuable functions, including to request someone or something, regulate the behavior of others, comment on something, deliver a social greeting, or inquire regarding something observed. At the nonsymbolic level of communication, a learner's communication partner must infer function.

### **Context influences communication in a number of ways**

Contextually rich environments best facilitate communication skill development. At the nonsymbolic level, in particular, communicative context is a critical component of learner-partner interactions. Even at the symbolic level, contextual cues should be identified for a learner and utilized in communication programs in order to optimize learning. For many learners who have severe multiple disabilities and deaf-blindness, features of the social and physical environment (e.g., numbers of peers and/or adults present, noise levels, lighting characteristics) facilitate or inhibit commu-

nicative attempts and effectiveness. Because a learner's communication skills will be enhanced through identifying and capitalizing on naturally occurring opportunities, elements of a learner's communication system should be derived from and designed for current and future environments—home, school, vocational, and community. Communication instruction, at both the nonsymbolic and symbolic levels, should be embedded within the context of other instructional programs and natural routines within natural environments.

### **Nonsymbolic communication is a legitimate system of communication**

Nonsymbolic communication consists of the elements of content, form, and function. While much of the content of communication at this level is derived from the communicative context, nonsymbolic communication takes many forms, including levels of alertness and responsiveness, emotional responses, vocalizations, changes in muscle tone and/or respiration, facial expressions, gestures, body movements and/or orientation, manipulations, aggressions, and stereotype or self-injurious behavior. All of a learner's observable behaviors, including unique, difficult-to-interpret behaviors do mean something. Even the most challenging, acting-out behaviors are important forms of communication. When interacting with a learner who is a nonsymbolic communicator, one must "listen with one's eyes." Teachers, family members, and employers can problem solve and help learners develop more formalized communication skills by carefully observing and analyzing behaviors in terms of the function(s) they might be serving for the learner. At the nonsymbolic communication level, it is up to a learner's partner(s) to interpret the function of her behavior, because at

this level, communication is nonintentional. As a learner's nonsymbolic communicative behavior is shaped to become more conventional, through repeated associations and practice, the more effective it becomes. It is not unusual to see a simultaneous decrease in a learner's acting-out behaviors as her communicative competence increases.

### **Partners are primarily responsible for a learner's nonsymbolic communication interaction**

Partners include parents, siblings, grandparents, peers, teachers, paraprofessionals, related service providers, bus drivers, job coaches, co-workers, and community workers—anyone with whom the learner interacts. Communication interactions are built upon a foundation of trust. The levels of trust in a learner's relationships with her frequent communication partners undeniably influence her further development of communicative skills. For a learner who communicates nonsymbolically, development of more conventional, symbolic communication skills is related to the directed, systematic efforts and responsiveness of her communication partners. A learner's intent and meaning must be consistently inferred, and contingently assigned, on the basis of sensitive observation of her behavior and responses to naturally occurring events. Therefore, partners must be sensitive and responsive to nonsymbolic communication by recognizing the communication, acknowledging the learner's likely meaning and purpose, and responding in a consistent manner. It is critical that communication partners respond to a learner's initiations—particularly regarding preferences and choices.

### **Facilitating nonsymbolic communication development**

Programs to increase a learner's nonsymbolic communication skills should be multi-modal—both in terms of input provided for the learner to facilitate development of receptive skills, and in terms of expressive skills targeted for the learner to utilize in communicating messages to partners. Four guidelines are provided for enhancing nonsymbolic communication instruction: enhance partners' sensitivity, augment input, utilize routines, and increase opportunities for communication.

One of the most critical implementation practices for facilitating communication development is focused on increasing partners' awareness of, and sensitivity to, a learner's nonsymbolic communicative signals—or potential signals (i.e., her observable behaviors). Communication partners' responsiveness is necessary, though not sufficient, for shaping a learner's skills into conventional and more symbolic communication forms. All partners must respond to a learner's communication signals consistently for progress to be achieved. A nonsymbolic communication signal dictionary can be developed for this purpose. A learner's signal dictionary should include for each of her nonsymbolic signals the meaning to be inferred for that behavior, what the communication partner will do when that signal is observed, and what the partner will say.

A learner needs to experience partners using the same modes of communication that she does. Input for all learners, not only those who experience deaf-blindness, should be augmented by their communication partners, through the incorporation of touch cues and object cues. Just as consistency in responding to a learner's expressive signals is critical to

her progress, partners' consistency in providing input to a learner is critical to her development of receptive communication skills. An augmented input dictionary can be developed for this purpose. The dictionary should include for each touch or object cue utilized by a learner's partners when the cue is to be given, specific details regarding what to do (e.g., touch the learner's right shoulder one time), learner behaviors to watch for, and a brief rationale.

Implementation of consistent routines with a learner, particularly within natural contexts, enhances communicative skill development. Both within- and between-activity sequences assist learners with building anticipation regarding "what happens next." Calendar boxes and anticipation shelves can be utilized with a learner to help establish predictability, as well as to provide a concrete object for a shared focus in communicative interactions.

A learner is most likely to make maximum progress in developing communication skills if she has frequent, repeated opportunities to use her current skills. Skillful environmental arrangements like locating materials within sight but out of reach, refraining from anticipating a learner's need or desire, introducing novelty, or providing only a portion of materials needed are examples of strategies easily implemented. Passive versus active choice, particularly in regard to personal preferences, is very appropriate for learners who communicate nonsymbolically.

### **Symbolic communication consists of all systems of agreed-upon representations**

Symbolic communication systems are effective because they are conventional. A learner's ability to communicate through the use of symbols is grounded in her representational thinking ability. Many times, when

attempts to augment a learner's communication at the symbolic level is unsuccessful, failure may be attributed to an inappropriate choice of device, or a lack of motivation or interest on the learner's or her family's part. In reality, symbolic augmentative systems often fail because the learner has not established a well-grounded foundation of nonsymbolic communicative skills.

Like nonsymbolic communication, symbolic communication consists of content, form, and function. Similarly, symbolic communication systems should also be multimodal, including vocal or verbal, aided, and unaided elements. Symbolic communication takes many forms, including aided components (e.g., pictures, photographs, graphics, language codes, braille, raised alphabet, spoken and written words, Minspeak, and tangible symbols) and unaided components (e.g., ASL, visual and tactile signs, cued speech, and palm writing). Augmentative communication systems empower learners by providing increased control over the environment. As evidenced from this listing, aided symbolic augmentative systems need not necessarily be expensive. A wide variety of low-tech applications (e.g., remnant books, minibboards, topic setters, or object boards) have been utilized very effectively with learners with severe multiple disabilities and deaf-blindness. High-tech applications range from simple, single-switch augmentative tools to multi-thousand dollar dedicated devices (e.g., Macaw, Vanguard, or Dynamite) and non-dedicated, computer-based augmentation systems (e.g., Speaking Dynamically). High-tech aided components of a learner's communication system must be kept in good working order at all times, and be available to her in all environments. For a learner to be successfully included in a com-

munity, the community will need to be provided exposure to, and experience with, the learner's augmentative communication system.

### **Facilitating symbolic communication development**

Programs to facilitate the development of symbolic communication skills should be multimodal for all learners, not only for those who are deaf-blind. Input for all learners should be augmented by their communication partners—peers, family, teachers and related service providers, job coaches, co-workers, and community members—so that she sees others using the same modes she does. When communicating with a learner who has sensory loss(es), stand in front of, rather than behind, her. Speak in a normal tone of voice; it isn't necessary to over-exaggerate in an attempt to compensate for a learner's hearing loss. If the student needs the support of an interpreter, the interpreter should never be the focus of a communicative interaction.

Aided augmentative communication systems require design and development of the following components: input mode (e.g., direct selection, scanning, or encoding), display mode (e.g., static or dynamic), layout organization (e.g., single overlay, multiple levels, or branch network), content (i.e. lexicon), and output mode (e.g., visual, auditory, tactile, or in combination). Unaided system elements should be considered and analyzed in terms of motor requirements for production (i.e., one or two-handed, hand shape, movement involved, symmetry of movement, and complexity of movement), iconicity (i.e., transparent, translucent, or opaque), and syntactical structure (i.e., correspondence to written or spoken English). Availability of a variety of skilled partners is also a primary consideration in the

selection of unaided elements for a learner's communication system. Development of the various components of a multimodal system of augmentation involves matching the features of a device or manual system to a learner's unique profile of skills.

Strategies for effectively implementing learners' symbolic communication programs include naturalistic time delay, scaffolding, mand-model instruction, and incidental teaching. Symbolic communication teaching should be continually embedded within the context of on-going academic, functional, vocational, and community-referenced instructional programs. ©

# Yes or no

## *A teacher's story...*

☞ Last year, I had a student named Joe who came from a district out-of-state where he had never been integrated in any general education classrooms, not for academics or even extra-curricular activities. He had spent 100% of his time in a self-contained class. I did not receive a lot of pertinent information about his functioning level, so I spent our first few days trying to determine his preferences, strengths, and needs—those types of things.

I began working with Joe to develop a communication system that was functional for him and more generally understood by different communication partners. Until Joe was 14, no one ever told his mother that if you talk to him, he could make choices—that he could tell you "yes" and "no" and that he could actually have preferences. So the

first thing we did was establish a yes/no response for this child. He did it in two ways. He would nod his head yes or no, or he would use yes/no cards to indicate preferences.

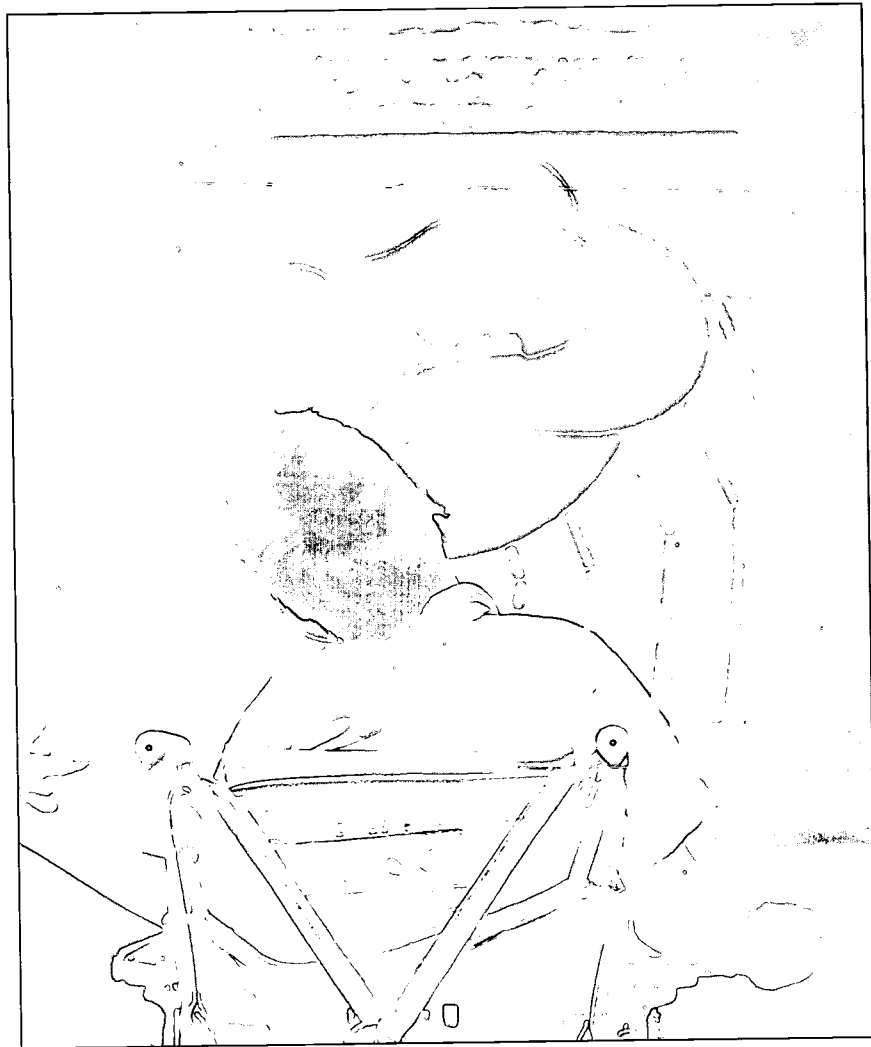
During the first week of school, I immediately started integrating him into general education classes. One of his favorite classes was art. All of the students in his art class immediately took hold of him and became his good buddies. Within that first week, I taught the students how to communicate with Joe so he could be more independent and start making some choices. One day, the students were making folders in which to keep their artwork. To do this, they cut out pictures about themselves and glued them to the folders. To find out about Joe, they began asking him questions. "Do you have a pet?" He shook his head

"yes." "Do you have a cat?" He shook his head "no." When they asked if he had a dog, and he shook his head "yes." He started hysterically laughing and clapping his hands. Later, when his mom came at the end of that art class, the kids immediately ran to her and told her how excited they were to find out that Joe had a dog.

So, keep trying. Take every waking opportunity that you have with children who have more complicated issues and maximize learning during those times. Just believe that if you keep trying, you will find something that will excite them, something they want to communicate, someone they want to communicate with, and a way to do it. ☞

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Making **positive** changes  
in a person's home, neighborhood, school, and other  
community settings requires a **long-term commitment**  
that integrates natural supports and  
**systematic** programming  
into a worthwhile and satisfying **lifestyle**.



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# Positive behavioral supports

You can't look  
at the disability and know  
how to deal with the child.  
You have to look at the child's  
personal likes and dislikes.  
It's like taking every  
kid in special education bowling:  
just because  
they have a disability  
doesn't mean they want to bowl.

Positive behavioral supports is a general term referring to a process of providing support for persons whose actions challenge systems. Making positive changes in a person's home, neighborhood, school, and other community settings requires a long-term commitment that integrates natural supports and systematic programming into a worthwhile and satisfying lifestyle. Functional assessments and the development of hypotheses are a part of the process of developing a support plan. Positive behavioral support plans are developed, implemented, and evaluated by the individual, family members, professionals, and other members of the individual's support network. They differ from traditional behavior management plans in that they emphasize respectful, enriching interventions that support positive self and social images of the person. In addition, the interventions take place within the framework of a personalized long-term vision for the individual. Often, positive behavioral

support plans are more artful in how they incorporate antecedent environmental changes rather than relying solely on reinforcement, punishment, and avoidance responding to change behavior.

**The purpose of the functional assessment is to determine the context and functions of the behaviors in question**

Functional assessment is a process of gathering information about environments and events that predict and maintain harmful actions. Information for a functional assessment is collected using a variety of methods and may include: (a) functional analysis of behavior, (b) review of student portfolios and cumulative records, (c) environmental assessments, (d) preference inventories, and (e) other formal and informal means of gathering information. The best functional assessments lead naturally to clues about how environments can be altered for two main purposes: to select meaningful activities and settings, and to help individuals learn more positive or more effective ways to express their communicative intentions and meet their personal needs.

**A variety of strategies are used together to create positive support**

From the functional assessment, hypotheses about the relationship between the context and the purposes of the individual's actions are developed. An example of a hypothesis statement might be, "Jody becomes frustrated with classroom work that is too difficult, and she screams to communicate that." Support plan strategies may be: (a) changing the individual's environments to provide him or her with a desired level of challenge and predictability, (b) teaching new skills that will

help the individual obtain what he or she needs in ways that are not harmful, (c) providing information in ways that are meaningful to the individual and considerate of how he or she processes information, (d) increasing the individual's access to inclusive environments, and (e) developing a crisis plan for emergencies. Positive strategies do not rely on removing choice, denying preferred activities, or denigrating individuals in the eyes of others or themselves.

**Ongoing assessment is critical to understanding the effects of positive support strategies**

Regular meetings with the individual family members, professionals, and other members of the individual's support network are important. Intervention strategies will need to be updated as the individual and the settings change, or as new needs for support arise. Sharing formal and informal assessment information guides the team in increasing the possibility of long-term changes for the individual and his or her quality of life. 🌟



# Trent gets a life

*A teacher's story...*

☛ When I re-entered teaching after five years, I had a student who I found to be really challenging. Trent would refuse to do the things that we thought he should do. He would run out of classrooms, throw things, swear loudly, and sometimes be aggressive. Ultimately, the director requested some consultation. This seemed like a good idea, because anything I tried did not help. I figured that when the consultants came, they'd see how crazy this kid made us. They'd shake their heads along with us and wonder what we were going to do with him.

I was shocked when the consultants told us that we, the staff, needed to change. They didn't even seem worried about what Trent was doing. This surprised me, but I guess I was desperate enough to listen. When they questioned some of the activities we were having him

do, and his lack of opportunities to make choices and to be with peers, I found that we really didn't have any good reasons for the decisions we had made about his life at school. So, we had to learn to really look at Trent; to listen to him and to his family. We began to understand his strengths and interests and to give him experiences based on those. He could work like crazy when it was something he really enjoyed and he felt good about! We began to see that he had a lot to give and share.

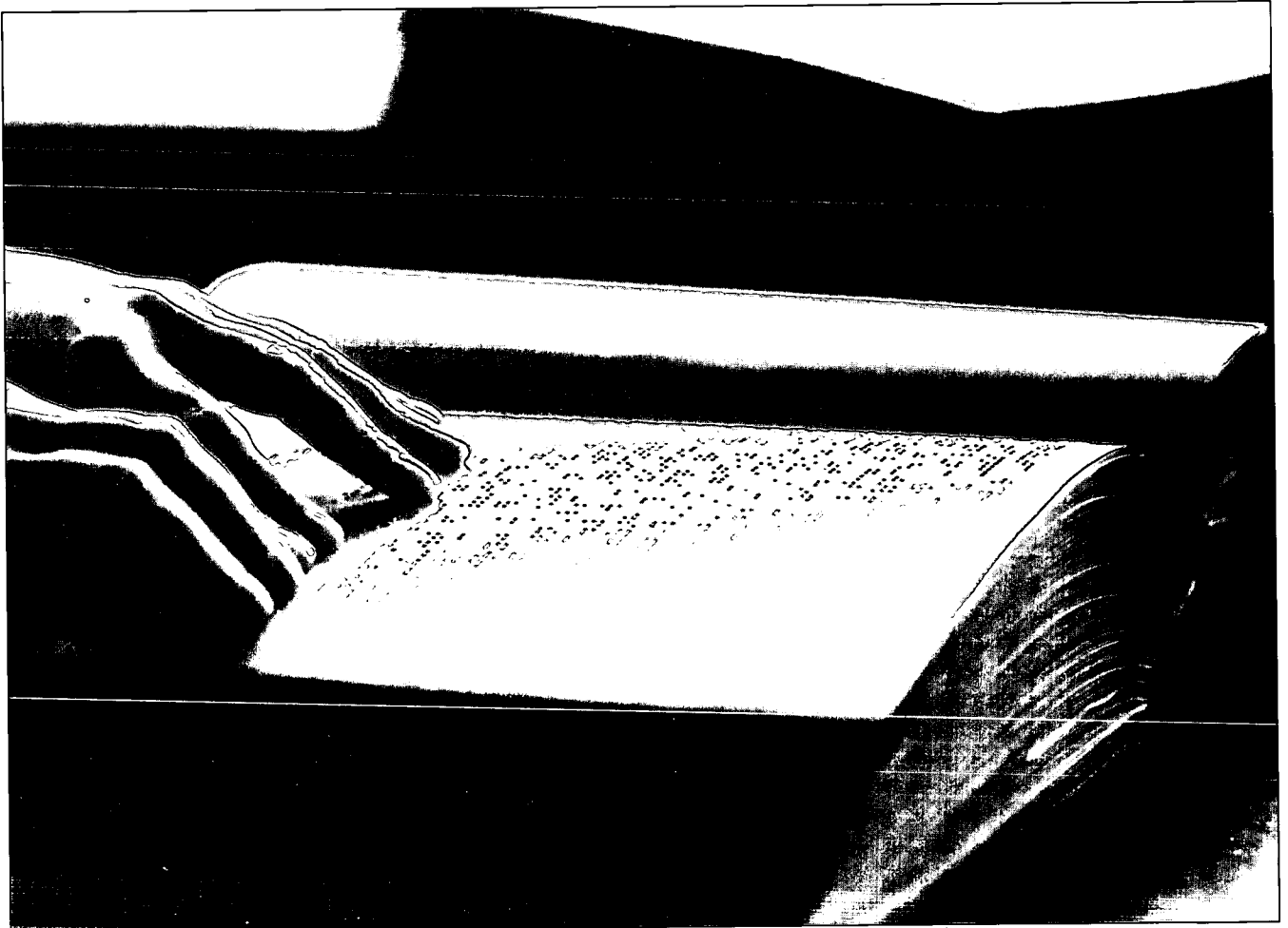
This was the tail end of the behavior mod era, so some reinforcements and contingencies were added to his program. But the longer we worked with Trent, the more I realized that those things did not make the difference. The difference came when he helped design his life. He stopped throwing things and running away. Those things still

occasionally happened, but because our perspectives had changed, those instances became opportunities for us to get together to see what was going on and learn what Trent was trying to tell us.

Since then, I have worked with many people who are concerned about kids who challenge our systems. Even with positive behavioral supports, the first thought tends to be that we should add contingencies and consequences to a life that none of us would want to have. We are still asking people with disabilities to lead lives that we would not want, and then wonder why they don't want them, either. I think positive behavioral supports really need to be about listening, supporting a vision, and helping children have the kind of life they'll want to experience every day. ☛

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In combination,  
**senses** facilitate **information**  
**gathering** about events  
happening in the immediate environment  
as well as **events** removed  
from the immediate **environment**.



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# Sensory

I remember seeing the girls' mother after we had the audiologist look at the girls and fit them with hearing aids.

I remember the look on her face, saying, "My kids are not retarded, they are not dirt, they are people."

Getting that affirmation helped her overcome her biggest obstacle: to feel good about her daughters.

Everyone has the right to experience life. These experiences are taken in through the senses of hearing, vision, touch, taste, and smell, as well as the process of moving through the environment and the awareness of where you are within the environment. In combination, these senses facilitate information gathering about events happening in the immediate environment as well as events removed from the immediate environment. This experience allows concept building, communication, and active participation which in turn enhances learning. It is the educator's job to maximize sensory input for all learners including those who may not receive clear information or may not receive information incidentally. This information may include cues from the environment, social communicative interactions, and instructional activities and routines that drive formal instructions and incidental learning.

Although each sense in isolation serves an

important function, the two primary avenues for gathering information are hearing and vision. For this reason, any partial or total loss in the ability to functionally use either of these senses alone or in some combination will dramatically hinder the learning process.

Considerations for instruction should include sensory issues, communication, individual differences, ongoing assessment and evaluation, environmental and contextual issues, activities and routines, and adaptations and modifications. Formal instructional strategies must be embedded into naturally occurring routines along with the above mentioned considerations.

### **Assessment and evaluation**

Both formal and informal assessments are utilized in determining educational programming for students who are deaf-blind. Formal assessments may include ophthalmological and audiological diagnostic evaluations providing baseline information regarding eye and ear functioning. In addition to the formal diagnostic components of such tests, professionals may benefit from reports gained from informal observations of student behaviors. Therefore, accompanying team members who are most familiar and communicate most effectively with the student can ensure that full information is gained during the evaluation process.

Informal site-specific, task specific, or person-centered assessments may include ecological inventories, environmental evaluations, learning style inventories, preference and choice surveys, and family interviews. Each of these provide direction for the individualization of educational programming and take into consideration sensory issues, communicative styles, adaptations and modifications, environ-

ments, and activities.

In combination, the results of these assessments yield vital information regarding the complex interaction among each of these areas. This serves as a starting point for the development of information-gathering opportunities.

### **Sensory issues**

Sensory issues include the relationship between the underlying senses and the ability to functionally use these senses when trying to gain meaningful knowledge about the world. Awareness of this relationship is vital when fluctuations in the underlying mechanisms confound the functional use of the sense on a day-to-day basis. The ability to monitor external influences, and effectively gather information, is directly impacted by the overall functioning of the sensory system. Any fluctuations in functioning will impact the ability to respond to cues in meaningful way.

Similarly, changes within the environment will impact information gathering. For students who experience fluctuations in their ability to functionally utilize their sensory systems, these changes within the environment facilitate the maximum use of their remaining senses. Since the use of senses is dependent upon the demands of the activity, the manipulation of environmental factors such as lighting, sound, and position within the setting should be the primary considerations when designing information-gathering opportunities.

### **Communication**

Communication is all encompassing, touching every aspect of the student's experiences. The opportunity to communicate with others, and control and act on the environment

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is critical to the information-gathering process. In fact, communication serves as the vehicle for information gathering about people and the environment.

For individuals who may not incidentally learn about the communicative process, communicative responsibility rests with the communication partner. The opportunity for a communicative interaction must be enhanced through the remaining senses, such as touch, movement, or the use of residual vision and hearing. In addition, the use of external and tangible objects within the environment and more formal communication devices may facilitate learning. In this way, isolation of the student from people, context, environment, and activities is eliminated, thus connecting that student to the meaningful life events occurring around him or her.

### **Adaptation and modifications**

The overriding goal of adaptations and modifications is to enhance existing opportunities for interaction with others and the environment, communication, and instructional activities. In this way, these accommodations promote active and meaningful student participation both within and outside the classroom. In order to achieve this goal, two primary considerations dictate their development. First, adaptations and modifications must capitalize on the residual use of hearing and vision. Further, the design of adaptations and modifications must support or supplement the ongoing development of information-gathering skills.

Adaptations and modifications are not necessarily complex phenomena that require extensive planning. Simple, yet effective examples include a modification in lighting to

enhance contrast for a student with cataracts, use of a magnifying glass to enlarge text for a student with myopia, preferential seating away from the air conditioning vent for a student with hearing impairment, complementing verbal directions with written reinforcement, or utilizing white print on a dark background for students who have retinitis pigmentosa.

In addition to visual and hearing adaptations and modifications, tactile adaptations support or supplement sensory input. Examples of such adaptations include the application of tactile markers or materials directly onto visual materials already being utilized, or the use of touch cues paired with verbal interaction to signal changes in activity, communicative partner, or environment.

### **Environmental & contextual issues**

A secondary result of tactile adaptations and modifications is improved orientation and mobility. Utilizing strategies or adaptations that enhance one's awareness of their surroundings provides students with information such as knowing when a person enters or exits the immediate environment or cues them as to where they are within the environment. In this way, students will learn where they are in space, the relationship of their bodies to objects within space, and their ability to travel within space.

### **Individual differences**

Each of the above examples may be used separately or together based upon the demands of the environment or activity and the individual sensory needs of the student. Demands of the environment or activity may include changes from one setting to another, such as

from school to the community or home, as well as within the same setting. For example, for a student with both vision and hearing losses, transitioning from the classroom to the playground may require a verbal communication to indicate a change in environment, a decrease in the volume setting of a hearing aid to adjust for increases in loudness associated with the outside environment, and a visor to reduce glare from the sun. Individual sensory needs of the student may include overall functioning of vision and hearing, as well as any fluctuations that may occur throughout the day or from one day to the next. The student described above may require touch cues in addition to verbal communication to indicate changes in environment, no change in the volume of a hearing aid, and a visor and sunglasses to increase environmental contrasts.

Recall that the overriding goal of adaptations and modifications is to enhance existing opportunities for interaction with others and the environment, communication, and instructional activities. Therefore, during the design process of adaptations and modifications, professionals need to be careful not to overwhelm the student with materials that are too burdensome, cumbersome, or several in number. If the adaptations and modifications overwhelm the student, they become ineffective, serving to further isolate the student from others.

### Activities & routines

To better facilitate learning, activities should be meaningful, revolve around functional context and real objects, and incorporate the use of more than one sensory modality for concept attainment. This means embedding goals and objectives into the existing curriculum, and providing the student with repeated

opportunities to gain experience with actual materials found in the environment. For example, the incorporation of real and tangible objects into the activity in place of pictures or artificial models of objects allows the student to utilize all existing senses to gather information about the object (e.g., texture, taste, smell, size, and shape characteristics). This in turn, provides students with more information with which to base their knowledge about the world and to discriminate between different objects.

Activities that are structured and routine provide additional cues for the student in regard to the anticipation, sequencing, and completion of the tasks. Ensuring that activities incorporate clearly conveyed learning sequences that have a beginning, middle, and end allow the student to understand the nature of the activity and how to conduct themselves throughout the activity. Additionally, this allows the student to concentrate on the material to be learned within the activity, rather than becoming overwhelmed by the process of learning. ☺

# *How does Chase talk to you?*

*An audiologist's story...*

☞ Chase was an 8-year-old elementary student who had cortical vision impairment. I met him while I was doing a project for my augmentative communication class that revolved around non-symbolic communication.

One of Chase's best friends was a student named Reggie. Reggie looked forward to taking Chase to the playground. One day, I went out to the playground with Chase and his para. The playground was complete chaos with kids running everywhere. Then I spotted this little haven, where Chase was sitting in his wheelchair. One by one the kids came over to Chase. I asked the para to step back so that I could watch how Reggie interacted with Chase. I was so involved in observing it seemed as if everything else just kind of went away. Everything was in "stop" and "go" in slow motion as I noticed what was happening.

Every time Reggie would come up to Chase, he would place his hand on his shoulder—without fail. I just looked at Reggie and thought, "WOW." I started talking to the para about it as we watched, and she said it was the most amazing and wonderful thing. "Reggie started this whole communication thing," she said enthusiastically. "He just decided that every time he said hello to Chase he was going to touch him on the shoulder." Without any intervention from the teachers or the para, the word got out that everybody had to have a special sign to say "hello" to Chase. Each student paired a touch cue with their greeting. Reggie touched Chase on the shoulder, somebody else patted his head, and then somebody else stroked his cheek. This was a wonderful thing unfolding.

I was amazed that the strategies I was learning in my classes right then, these kids were just doing naturally. These 8- and 9-year olds were using great instructional strategies. Curious, I asked Reggie, "How does Chase talk to you?" He responded, "Oh, well you know, when he gets mad, he cries and when he wants to play he laughs." No teacher sat down with these kids and said this is what we do with Chase. It just kind of worked out that way because they knew Chase. When the children touched Chase, he reacted. Reggie and his classmates taught me that sometimes teachers or adults need to back off. We need to know that sometimes things unfold naturally, without artificial instructional strategies even for kids with dual-sensory impairments and their friends. ☞

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And in the end...

## “Look, Mom! Kids!”

My daughter, Sarah, had been in a segregated setting. She was doing well, learning some skills, and life was pretty smooth. But parents can tell when their children aren't flourishing.

Because Sarah's an only child and loves to talk, I wanted her to be around other children. When you walk down the hall of a school where all the kids have disabilities, the hallways are always really quiet. They're not necessarily dark, but they give you the impression that they're dark. There's just not a lot of activity. On the other hand, when you go into a regular school, even if the kids are in the classroom, a certain amount of noise is generated out of the classroom so there's a sense of activity. I wanted Sarah to experience this energy—to just be a part of everyday life and have that same sort of energy. So, in second grade, we made the decision to put Sarah in a regular elementary school.

The first day I pulled into

the school's driveway, it looked like 100 kids were milling

around, waiting for the bell to ring. My daughter pulled herself up straight in her wheelchair, looked at them and said in a voice I'll never forget, “Look mom— kids!” Like she had never seen another kid before! That moment took away any doubts I had about changing schools.

There was a wonderful second grade teacher at the school. She had been a special education teacher and had some training on facilitating inclusion. I also think she had a lot of extra work preparing to support Sarah in her class. But, she did it, and she did it without complaint.

Sarah blossomed. It was like

pouring water on a flower that had withered. The friendships that were created in that class really lasted all through elementary school and into junior high. Sarah still has strong friendships with a couple of kids from that first year. It really, truly changed the course of her life.

I think our whole family would have missed out on so much if Sarah hadn't had the opportunity to be in that class and if the teacher hadn't known how to make it a positive experience and foster the friendships. I never really got a chance to tell Sarah's teacher how much I appreciated her effort in helping my daughter. I don't know if she would have even seen it as being so extraordinary. I think she just thought she was doing her job. I will always be grateful to her.

I never really got a **chance** to tell Sarah's teacher how much **I appreciated** her... I don't know if she would have even seen it as being so **extraordinary**. I think she just thought she was **doing her job**.

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