



## IN THIS ISSUE...

### Don't Be So Sure

In the press box of a New York ballpark long ago, a young sportswriter loudly, and with conviction, announced that the pitcher struggling that day had no chance of remaining in the major leagues. Just then a wizened, white haired writer tapped the young man on the shoulder and asked, "Wanna hear my only rule for succeeding as sportswriter covering a major league team?" The young sportswriter regarded the older writer quizzically. "Just one rule?" he asked. "One rule," the older sportswriter replied. "What's your one rule?" the younger writer asked. The older gentleman replied, "My one rule is: Don't be so [bleeping] sure."

Many children with multiple disabilities find themselves all but written off by well-meaning, cost-conscious school professionals who are sure that a child's limitations disqualify him or her from using the full range of assistive technology devices that might enrich the child's educational experience. What those professionals often forget is how they themselves learned to use a computer: by trial and error. Many children with multiple disabilities utilize the same method when learning to use computers and other AT equipment. The key is to give them the chance to try, to fail, to try again to learn and to succeed. This issue examines AT accessibility issues associated with children with multiple disabilities.

### June Downing, Ph.D. Speaks

In the 1960s, when she was a member of her high school swim team in Colorado, June Downing's coach asked if any swim team members would like to remain after practice to help support children from a nearby school for blind and deaf students, which had no pool. Dr. Downing immediately said she would stay to help. She remembers feeling trepidation when some blind children emerged from the locker room and began feeling their way toward the pool. Other children were deaf and they were signing back and forth in a highly animated fashion and they, too, made their way to the pool. Still others, she recalls, had multiple disabilities and she wondered how she would be able to communicate with any of them to convey her love of the water and her joy in swimming. However, after scant minutes together in the pool, Ms. Downing's trepidation was erased. Swim team athletes and kids with multiple disabilities were bonded by the need to improvise and by the epiphany of discovery.

A few years later, armed with a BA in sociology from the University of Colorado, she accepted an aide's position at her old high school to assist in the teaching of students who had multiple disabilities. Later she earned a Masters degree in special education from the University of Northern Colorado and a Ph.D. in special education from the University of Arizona with an emphasis on multiple disabilities, sensory impairments and severe mental retardation. The author of several books and many articles and presentations, Dr.

Downing is a professor at California State University, Northridge. She is a strong advocate for inclusion and for AT accessibility for children with multiple disabilities.

Supporting our interview with Dr. Downing are resources to assist in furthering AT accessibility for children with multiple disabilities. We also feature members of our **Knowledge Network**. The members spotlighted this month focus on children with multiple disabilities. We invite you to contact these members for further information.

Please share this newsletter with other organizations, families and professionals who may benefit from it. We invite you to contact us at <http://www.fctd.info>. We welcome feedback, new members and all who contribute to our growing knowledge base.



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## **Children with Multiple Disabilities: AT Accessibility is Key**

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### ***An Interview with Dr. June Downing, Teacher Preparation Expert***

Dr. June Downing envisions a day when inclusive classrooms are an accepted reality nationwide, a day when the full range of assistive technology devices and equipment is readily available to children with multiple disabilities. Until that day arrives, however, she improvises, advocates and teaches teachers.

"Kids with multiple disabilities could really benefit from the right kind of assistive technology if that AT was readily accessible and was designed specifically to meet their needs," Dr. Downing remarks. Unfortunately, she adds, "some professionals believe that certain disabilities get in the way of access." In some quarters, she comments, "the belief exists that if a child has severe multiple disabilities, s/he is not at a certain cognitive

level or if a child does not possess certain skills then that child is incapable of using AT."

When that attitude prevails, she said, children with multiple disabilities "never have the opportunity to explore and experiment with equipment." The result is a "catch-22 situation for the children because the only way any of us gain expertise at anything, whether or not we have disabilities, is by adopting a hands-on approach and by making mistakes and learning from those mistakes."

Using a computer as an example, Dr. Downing explains, "we know that a computer can probably do a whole lot more than what most of us use it for, but if we were provided access to that computer we would never acquire even the minimum skills necessary to use it." Children with multiple disabilities, she notes, are often confronted by that conundrum. "This is an obstacle that the field needs to get past," she declares.

Cost consciousness among professionals and school officials also comes into play, Dr. Downing states. "There's a money issue involved in the lack of AT accessibility for children with multiple disabilities because there's the sense that 'We don't want to spend a lot of money on a piece of technology for someone who may not be able to benefit from it.'"

The word "benefit," she says, needs to be more carefully examined because individuals can benefit from technology in a variety of ways." Children and professionals alike, she adds, "need to get over the fear of utilizing technology to the maximum extent possible."

As a professor at Cal State/ Northridge, she says she is "constantly amazed at what my students who are teaching in classrooms and who are teaching students with severe multiple disabilities don't know" about available AT. Teachers "may have one piece of software they're familiar with but they are not aware of the different augmentative communication devices or the various switches." Teachers may have a single switch "but if the child can't access

that one switch then the teacher feels that the child won't benefit from the technology."

What many teachers do not realize, she observes, "is that there are many, many ways to operate computers, environmental controls or an augmentative communication device. It's a matter of teachers not knowing what is available."

### **A State of Constant Upheaval**

Teaching the teachers, Dr. Downing explains, is all too often an uphill struggle, not because teachers are unteachable but because many leave the field prematurely. One of the significant factors inhibiting accessibility, she comments, is teacher retention. "The field," she notes, "is in constant upheaval. Retention is difficult, so we are perpetually in a state of training new people."

On the other hand, she emphasizes, "technology continues to advance and we are making incredible gains year after year in what we can do for children and adults who have the most significant kinds of disabilities." A critical gap exists, Dr. Downing insists, "between what we know, what we are able to do and what practitioners in the field are aware of." That gap, she declares, "keeps growing, I fear." The money issue, she stresses, underlines the knowledge gap, exacerbating its impact on the children who most need AT accessibility. Even though federal legislation requires school districts to provide AT to students who require it, school districts often, but not willfully, skirt the intent of the law.

School districts circumvent the law "because if members of the IEP team simply do not realize that a specific piece of AT is available than they are unable to discuss its possible use by the child."

In addition, she remarks, "If there's any kind of concern that the child won't be able to benefit from [the AT], for whatever reason, usually cognitive, then the school district won't want to put out the money" because the district is likely strapped for financial resources. This, she explains,

"puts a lot of pressure on family members to advocate for their child." Also, she continues, "Many families are not aware that there is AT that is available and, in general, what is possible for their child." AT centers, she states, "do a good job of lending out to families who need it, and we need more of that."

### **Doing What's Best for the Children**

However, she cautions, acting as an advocate minus any assistance is grueling, frustrating work, especially in underserved communities. "In Los Angeles, where I live and work, there are a tremendous number of minority families who are unaware of their rights, who may not be highly educated and who may not know what is available for their child or what can be done." Going up against an urban school system, she warns, "means doing battle with a big, complex bureaucracy and that is difficult under the best of circumstances." Dr. Downing also cautions that field professionals need to be "sensitive to cultural preferences that minority families have." For example, many minority families are unfamiliar with the technology associated with AT devices. Citing augmentative communication equipment, she points out that "family members may be concerned because they do not know how to program the equipment, fear that it will break down" or are uncomfortable with technology in general. More likely, she adds, "AT just doesn't fit into the way they operate as a family and they are not going to use it."

As a family wrestles with the decision to utilize AT, "the school will sometimes weigh in favor of using, which, once again exposes the gap between home and school" regarding AT use. Yet that gap, Dr. Downing notes, "exists for *all* families," regardless of income or social status. Children, she chortles knowingly, "behave one way at school and another way at home." Practitioners, she states, "have to respect what families want but, at the same time, there's a responsibility to do what's best for the children."

## **A Major Barrier to Overcome**

A major obstacle faced by practitioners who are responsible for educating children with multiple disabilities is the lack of a way to make available technology efficient and effective for children whose disabilities are the most significant and severe. Many of these children, she explains, may be blind and unable to access visual information. Others may have very limited movement of their bodies. "These kids may not yet have experienced the sensation of understanding the concept "that if they do something, something else happens in return."

She cites the example of a boy who attends an inclusive middle school in her area. The child, a sixth grader, possesses limited physical capabilities. "It's not that there aren't things we can help him with," Dr. Downing comments. "He can't see and because he can't move his body well it is difficult for him." His practitioners, she notes, "are trying different things so he can somehow make a connection to the AT." Progress, in this case, she insists, is slow, in part due to methods that were used before Dr. Downing's team took on the challenge of helping him. "Before us," she recalls, "people kept grabbing his hands, which he uses as his eyes, to force him to touch, feel and hold things." The child, she remembers, "got into the habit of clenching his fists tightly, which is very bad if you're severely disabled to begin with, can't move well and suffer from numerous seizures." On the positive side, she notes, "He's in a wonderful environment, he's popular, kids are totally interacting with him." His peers, she says, "lead cheers for him, do rap songs and read poetry, all of which he's interested in, especially rap, and have put it all on a DVD for him." The boy activates the DVD with a switch. "The DVD plays for a time and then he has to hit the switch again to continue listening." His classmates, says Dr. Downing, "are excited about doing this for him, and it gives him a way to learn that he's got some control over things in his life."

## **Totally Inclusive**

Dr. Downing's sixth grader is in an inclusive school environment. "There's no pullout to a specialized environment." According to Dr. Downing, "He's a perfect example of why inclusion is so important because, if he were in a special ed environment with kids with disabilities similar to his, he'd have no one to interact with." The young man, "is not able to initiate and others would not have been able to help him." In his current situation, however, "he's probably one of the most popular kids in the school." His classmates, she adds, "are always helping out, encouraging him, talking to him, engaging him, which makes a world of difference for the young man."

Yet Dr. Downing is reluctant to have the boy's story end there. "There are many things I want to do with him and I am trying to figure out how to do them." Ordinarily, she explains, "if a child is blind I'm going to want him using his feet or her hands quite a bit." Unfortunately, she adds, "that is not an option for him because he doesn't have sensitivity in his limbs nor the ability to move his hands and arms."

She declares: "I'd like the boy to learn about auditory scanning and he's doing some of that now. He does hear." The trick, she says, "is figuring out exactly what he understands." She longs for options that would enable him to auditorially scan, listen to a message then use a switch and repeat that message "so he can then tell us exactly what he wants or needs – that's one thing we really need to start working on," she asserts.

## **Time to Try**

One of the keys to effective utilization of AT by children with multiple disabilities is teaching children how to use the equipment. "It's not just a matter of giving children something – a device, a switch, an augmentative communication device. What counts most is empowering them to use it themselves."

In our society, she remarks, "we're a little hasty. We want an immediate response. We

might teach for a little while and if the child doesn't quite get it, we say 'Well, that doesn't work,' and we change course." Such course changes, she notes, are discouraging and disorienting for children and, ultimately, can doom both teacher and child to failure.

Again, Dr. Downing cites computer usage to make her point about inadvertent denial of accessibility. "Most people don't use a computer to its full capability," she reiterates, "and the computer often gives them a hard time, depending on what software they're using. They don't understand what they did or why they can't do what they want to do." However, "nobody takes their computer away from them, saying 'You don't have a total understanding of how this equipment works and what it's capable of doing – so we're not going to let you access your equipment!'"

Adopting a perspective that encourages a trial and error approach should help practitioners to be more patient when they teach AT use. "It should remind professionals," Dr. Downing advises, "that this is a learning experience and that children – and adults – not only need access to various kinds of equipment and devices and anything else that falls under the banner of AT, they also need time to be taught."

In fact, she comments, "they need a lot of time to try things over and over and over again until they feel fairly comfortable with the equipment." While time passes and teaching continues, she says, practitioners "should not despair while a child is learning, failing, learning, trying again and, eventually, succeeding."

### **Access: Looking Beyond a Single Piece of Equipment**

Dr. Downing says she often sees children equipped with but a single piece of assistive technology, usually a relatively simple device that only enables a child to indicate whether he or she wants a glass of water or needs to go to the bathroom. She says that school officials see the child operate that equipment and then announce, "Yup, we've

got him hooked up with some AT. End of story." The trouble is, she asserts, "Too many professionals are afraid to look further than that single piece of equipment because they're not exactly sure how to teach the child."

Looking beyond that lone piece of equipment, she insists, requires information sharing, training and teaching. "I do a lot of in-service training," Dr. Downing says. "Professionals in the field whom I regard as more expert than me do a lot of training." Many, she says, attend conferences specifically devoted to technology issues. "Attendees come away from these conferences with the sense that, wow!, there are real possibilities out there." Unfortunately, the low retention rate among those who teach children with multiple disabilities constantly reflects the loss to the field of professionals whose training and growing experience ought to have been peaking. "Our burnout rate is high," she notes. To lower it, she asserts, practitioners need to be more supportive of the professionals who enter the field. "As much as we need them, we need to caution those who want to enter this field," Dr. Downing advises. In her program at Cal State/Northridge, "we try to warn people about what the work really involves, because we find that individuals who are kind of floundering in life know they can get a job teaching fairly easily so they do it." Teachers "who take our profession seriously and know its highs and lows for having experienced them" ask pointed questions of prospective newcomers to it, she says. "We know that it is a highly emotional job and we know that it takes a fair amount of perseverance to hang in there and not get discouraged." Teachers who stay, she says, "must have a passion so they can advocate for children." Coming to the profession with that passion is mandatory, she states, "because commitment to the field and to the kids is a bedrock requirement. And I want to make sure that the people who enter this profession do it for the right reasons with the right attitude and with reasonable expectations for what they can

accomplish and for what will be required of them.”

### **Penetrating Questions**

When screening prospective teachers of children with multiple disabilities, Dr. Downing reveals that she asks “penetrating questions about candidates love to do.” She says, “I tend to scare them a little bit by telling them what a typical working day might look like and how many hours there are.”

She also reveals to them other truths that may not be self-evident. “I tell them that we do not get summers off, and that we don’t get home by 2:30 PM.” She also tells them, she says, “that most teachers of kids with multiple disabilities spend long evenings working and then work all weekend as well.”

Some candidates, she notes, “become shy when I inform them of the physical needs that some children have and what is going to be expected of them as teachers” in addition to the actual teaching. “I tell them that there are physical needs that the kids have that need to be addressed.”

Some candidates, she reveals “decide pretty soon that this is not the field for them, which is fine.” Unfortunately, she adds, women tend to try to enter the profession in far larger numbers than men. “I say that’s unfortunate because we then have role models that are primarily female.” A lot of boys and young men that could benefit from having male role models do not have the opportunity, she points out. “As kids get older and the boys need help going to the bathroom it’s obviously preferable to have men providing the help.” Her own teaching programs, she remembers, “were very heavy on female instructors.”

She is mystified at the failure of the profession to attract more men. “I haven’t figured that one out,” she commented. “The few men who have remained in the field are very, very good.” Most entered it because “they have a family member who has a disability, for example, or maybe they’re accustomed to performing some of

these physical chores at home for their own kids and are not shy about it.”

She also presents teaching candidates with hypothetical situations and then gleans their response. She declares, “I love it when they look me in the eye and say, ‘been there, done that, not a problem.’”

This is a profession, she claims, that consists, literally, of much heavy lifting, both physical and emotional. “It is a mistake to lure people into the field when you can clearly sense that their hearts are not in it.” Those who stay the course, she declares, “must bring passion with them and then be able to sustain it for years without a break.” That, she says with great conviction, “is a lot to ask from anyone but it’s what’s necessary if we and the kids are to keep pushing ahead, breaking new ground and making meaningful progress.”

### **Showing Them the Door**

To Dr. Downing, passion equals commitment. “When a candidate tells me why she wants to get into the field, why she wants to earn a degree, why she wants to obtain a teaching credential and then informs me how many careers they’ve tried and failed at but believe, now, finally, that they can get a job as a teacher, I show her the door.”

In the past, she observes, teaching was regarded as a solid career that was well respected and that paid its professionals adequately. All that has changed, she says. “Now the business world, combined with the explosion of technology, has hired potential teachers away to careers “where the money is quick and the emotional commitment is not the same.” Business careers, she remarks, “are more black and white as far as what is possible and what needs to be done.”

However, she admits, “there are, fortunately, very committed individuals in this field who are doing incredible things for kids with multiple disabilities – and these accomplishments must not be overlooked.”

## **Inclusion Has Changed Teachers' Lives**

Just a few years ago, Dr. Downing comments, inclusion was a concept, not a daily reality in teachers' professional lives. That equation is changing. Inclusion, for many teachers in many school districts nationwide, is a concept that has been translated into reality, especially she explains, for special educators. Special education teachers, she recalls, "were once sealed off with their students from the school at large, but no longer."

Those closed environments, she says, are fading out in many school districts across the nation and in charter schools. At charter schools in California, she notes, "we don't even have special ed classrooms; it's a shared teaching environment." In inclusionary schools, she asserts, "we make sure that our teachers realize that they are not going to be on their own; they're going to have to collaborate with other teachers and professionals whom they may or may not like and may not agree with." The collaborative environment, "is not only difficult for many 23- or 24-year-olds to grasp, it's difficult for 40- or 50-year olds to grasp as well." This uneasy but vital collaboration, she adds, has one goal: to benefit the child.

From the training classes she has taught, Dr. Downing has learned that "the complaints by adults are mainly about other adults, not about the children."

Professionals, she observes, "come from their own knowledge base, their own specialties and everyone has their own ideas." This is especially true in the realm of multiple disabilities "where there are many people, not just a few, on each child's team." Such teams, she points out, can consist of occupational therapists, physical therapists, speech therapists and paraprofessionals, AT, behavioral and visual specialists "and lots of family members." Everybody involved, she says, "comes at it from a different perspective; there are lots of philosophies."

Chaos can reign, she notes, "which is why I ask those coming into the field if they are

capable of working with others with whom they don't necessarily agree." A collaborative effort, she declares, is often at odds with a teacher candidate's vision of how she intends to conduct her class and her relationships with students. "Young teachers sometimes tell me, 'I just want to be in my own classroom teaching kids with mental retardation or other disabilities.' I tell them, 'Pick another profession.' Others say, 'I don't want to work with general education kids; they annoy me,' or 'I just want to work with special kids.'" To those, as well, Dr. Downing says, "That's not going to happen."

## **A Constant Challenge**

The most interesting aspect of the field that Dr. Downing long ago chose as her life's work "is that it is constantly challenging." She says, "I'm always working with children, no matter how many years of experience I have, who pose an initial challenge." With each new child, she adds, "I have to pause for a second or two, catch my breath and then brainstorm intensely with other professionals to get my bearings so that I can move ahead."

When working with children, and teachers, who are attempting to become familiar with assistive technology, she explains, "the trick is not being afraid to try new things." Professionals and children with multiple disabilities, she points out, "lose nothing by trying. You have to give it a good, fair try, realizing that the learning rate is much slower for kids with multiple disabilities and that it's okay for them to fail." When failure occurs, as it inevitably must, she notes, "You try again; that's the key to everything, to any success you are going to achieve with that child."

The point, she insists, "is to make it known that no single device is going to be the one solution for a child with multiple disabilities." Such a child, she notes, "may have many devices, aids, supports and services in order to make his or her life as meaningful as possible."

## The Future: When Inclusion Is No Longer a Bad Word

Looking ahead a decade, Dr. Downing says, “My hope – and this is extremely optimistic – is that inclusion will no longer be a bad word” and that its benefits for all children will be acknowledged and generally accepted. She predicts that the proliferation of studies supporting inclusive programming will help make that acceptance a reality.

As evidence that her hope may eventually be realized, she cites a recent study extolling the benefits of inclusion for students *without* reading and writing disabilities when those students were in inclusion classrooms rather than in a general education environment. More articles of this stripe, she asserts, will continue to support the inclusion concept “so that parents will no longer have to urge support; support will come naturally.” When inclusion does indeed become accepted, parents will automatically recognize that “of course your child will be placed in his or her neighborhood school in an age-appropriate classroom with peers who do not have disabilities.” She readily acknowledges, however, that full acceptance is unlikely in just a decade’s time. Realistically, she concedes, “I am more hopeful and expectant that we will have made very significant progress toward that goal.” She bases her optimism, she says, “on the progress we’ve already made and on the doors that we have opened that had been closed.”

As far as assistive technology and its use by children with multiple disabilities, the future, a decade hence, she says, is difficult to imagine, the possibilities endless. “We’re going to make it so that we can link up to what the child is actually thinking and bypass the physical need for the child to have to access a computer.” The field, she insists, “is already part way there.” To provide “hands-free technology” to children who do not have use of their extremities will require a great deal of thought and training.

Access to information about what a child with multiple disabilities thinks and needs “will help us improve our teaching.” She emphasizes that she has more faith in this development “than in anything else, at this point.”

What encourages her most, as a university professor, “is that I am getting people into the field who experienced inclusion when they were attending school.” Seeing an influx of these teacher candidates, she declares, “makes it clear to me that we are letting kids know that having a disability is not horrific, that it’s not something to be feared or shunned and that exposure to children with disabilities may be a gift for those without disabilities and may even encourage them to enter the teaching profession in the future.”



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### Best Practice Models: Family Centered Assessment

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*Kari Jaehnert,  
PACER Simon Technology Center*

The Individuals with Disabilities Education Act of 1990 (IDEA) and the subsequent reauthorization of IDEA in 1991 mandates that assistive technology (AT) must be considered when developing individualized education programs (IEP) for children with disabilities and specifically identifies AT as a service to be provided for every child with an IEP as appropriate.

Although families have often been included in the “best practice” model for AT service delivery, the passing of IDEA legally mandates that families are included in the decision-making model. The degree to which families are involved is typically unique to the school, and/or family. Some families are included via telephone or quick in-person updates provided by the school, while other families are actively involved in

the entire process from beginning to end and play a key role in the assessment and decision-making process. Students who have families that are actively involved and included as a part of the team are more likely to have successful long-term outcomes with assistive technology.

Families involved in the selection process tend to take ownership and responsibility for technology that they've helped select for their child resulting in increased use and success for the child.

Selecting the right assistive technology (AT) can be an overwhelming process for both families and professionals. The selection process typically consists of meetings with teachers, therapists, vendors, as well as trials with a variety of possible AT solutions. Most students will go through some type of formal assessment or informal consultation to try software or hardware and allow professionals and parents to get an idea of the best solution. The best and most successful consultations or assessments are ones that involve a team of professionals and caregivers who contribute to the process.

Families can offer crucial information about their children such as their likes, dislikes, interests and daily schedules and assist professionals in identifying situations that the child participates in outside of school. This information can help ensure communication and participation takes place in all environments. Families can also contribute opinions or preferences in regard to funding, technology maintenance, and training. If a professional or school selects a software program that is too expensive or complicated for the parents to use at home it likely will not be used outside of the classroom and therefore not be very effective for the child. Technology should be selected based upon input from a variety of sources and used in all environments. A multidisciplinary approach is the most efficient and effective method of assessment. This type of assessment encourages all professionals and caregivers to get together to observe and evaluate the child at one time. The assessment or

consultation could involve people from all aspects of the child's life- teacher's aids, occupational, physical and speech therapists, and other community members who interact with the child. This type of format not only saves time, but also facilitates open discussion and sharing of goals, and helps parents better understand the therapists' point of view.

The key to a family-centered approach is to encourage openness and cooperation among the professionals and family members on the team. All team members should be given adequate time and opportunity to voice their opinions and concerns. Families, professionals, and the student should have an equal amount of input when making decisions. Another key principle is to assign roles and responsibilities among the team so that the bulk of the responsibility is not left to one person. Roles should be assigned to team members such as: who is responsible for gathering assessment data, training, and maintenance of the assistive technology. There are several great resources available for parents and professionals to use when planning for assistive technology. Several states have designed models for developing family-centered decision-making when considering and implementing assistive technology; these models will vary among states but have similar foundations and ideas. The following are a few resources and examples of models that you can adapt and modify to ensure that your school is following a best practice procedure. The Minnesota Department of Education has designed a that provides information on legal statute and best practices for consideration and evaluation of assistive technology in special education. The Manual includes definitions and explanations of the federal law regarding AT consideration as well as forms and checklists for both parents and professionals to complete during the process. The Minnesota Assistive Technology Manual can be downloaded at: <http://education.state.mn.us/content/005769.pdf>

The Quality Indicators for Assistive Technology (QIAT) Consortium is a nationwide grassroots group that includes hundreds of individuals who provide input into the ongoing process of identifying, disseminating, and implementing a set of Quality Indicators for Assistive Technology Services in School Settings. The QIAT Consortium provides an exceptional network of professionals to share experiences and resources on a national level. [www.qiat.org](http://www.qiat.org) SETT Framework was designed as an organizational tool to help collaborative teams foster the educational success of students with disabilities. The SETT Framework is built on the premise that in order to develop an appropriate system of assistive technology devices and services, teams must first gather information about the student, the customary environments in which the students spend their time, and the tasks that are required for the students to be active participants. The SETT Framework was designed by Joy Zabala ([www.joyzabala.com](http://www.joyzabala.com)) and is also available at: <http://atto.buffalo.edu/registered/ATBasics/Foundation/Assessment/sett.php>.

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## RESOURCES

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### ARTICLES

*Technical Assistance for Motor- and Multiple Disabled Children – some Long Term Experiences.* Paul Panek, Christian beck, Stefan Mina, Gottfried Seisenbacher, Wolfgang L. Zagler. Vienna University of Technology (Austria), Research Group on Rehabilitation Technology. 2003. [http://www.fortec.tuwien.ac.at/reha.d/projects/autonom/download/Autonomy\\_ICCHP2002\\_reprint.pdf](http://www.fortec.tuwien.ac.at/reha.d/projects/autonom/download/Autonomy_ICCHP2002_reprint.pdf)

This paper describes the application of a technical assistance system, called AUTONOMY, developed by the Vienna University of Technology. The paper

focuses on ways to provide new means of support to children with severe and/or multiple disabilities. The goal is to enable these children to have more autonomy and independence while exploring the children's material and social development. The article outlines information and experiences collected during the practical application of the AUTONOMY system in the "smart room" of the Austrian Support Center for Disabled Children in Vienna. Based on the encouraging results of the authors' research, the system they have developed is now in use in other institutions, in private homes and in higher education.

Using Assistive Technology For a Student with Multiple Disabilities. *Holly Cooper, Ph.D.* Texas School for the Blind and Visually Impaired (TSBVI) Outreach. 2003. <http://www.tsbvi.edu/Outreach/seehear/spring03/tech.htm>

Via a question and answer interview format, Dr. Cooper documents her relationship with a young vision-impaired woman named Alyssa and Alyssa's family. Alyssa is a high school student in Dallas who also has cerebral palsy and is speech-impaired. Initially working with Alyssa as her itinerant vision teacher and as a member of Alyssa's school district's assistive technology team, Dr. Cooper continued the relationship while serving Alyssa's family and educational staff as a consultant.

The author writes: "Readers may think of technology for students with visual impairments as screen reading applications (JAWS and the like), computer screen magnification software, computer braille translation, braille note takers and video magnifiers (CCTV's). This type of technology is widely used with students with visual impairments across Texas and other areas. However, there are many more students who are visually impaired who have additional disabilities and do not benefit from access to all the amazing braille and

low vision technology. There are currently a number of computer programs that teach switch use with simple cause and effect activities, but for blind and visually impaired users who are more advanced, finding useful software and devices can be a real challenge."

Dr. Cooper concludes: "Technology has made great strides since Alyssa was born. It has made a real impact in Alyssa's life. I expect that there will be similar improvements. One thing that will be a big help for Alyssa will be when speech recognition programs get to the point where they can recognize speech that is as inconsistent as Alyssa's. She would no longer have to dictate, and could control the computer with her voice. I think there will be improvements in technology that I can't even imagine that will greatly improve Alyssa's life."

*Deaf Children With Multiple Disabilities.*

Gallaudet University Laurent Clerc National Deaf Education Center. 2002.

<http://clerccenter.gallaudet.edu/InfoToGo/141.html>

The author writes: "The combined effect of hearing loss and an accompanying disability presents a unique and complex problem to professionals and parents. Multiple disabilities create a pattern of problems, different from the problems usually associated with any disability alone. A review of the literature yields surprisingly little specific information on educational programs for such children. The fact that there are many differences among children with multiple disabilities adds to the difficulties of providing appropriate programs. However, there ARE things that can be done."

*Coping with Multiple Disabilities.*

WebHealthCentre.com. 2000.

[http://www.webhealthcentre.com/general/cp\\_multi.asp](http://www.webhealthcentre.com/general/cp_multi.asp)

This article focuses spastic children, many of whom, the author states, must cope with two or more disabilities: "A spastic child has disorder of movement and posture. As cerebral palsy affects the brain, it is possible that apart from motor functions other functions may also be impaired. It is not uncommon to find children [with cerebral palsy] with poor vision, hearing, speech problems, or learning disability. These disabilities must be attended to early and if permanent solutions are possible, they must be sought. If this is done, the spastic child is given a better chance of empowerment." The article provides tips for understanding and helping spastic children when they are at home.

**BOOKS**

*Educating Children with Multiple Disabilities, A Transdisciplinary Approach, Third Edition.*

Fred P. Orellove, Ph.D., & Dick Sobsey, Ed.D., with invited contributors. 1996.

Paul H. Brookes Publishing Company.

Ordering information at:

<http://www.pbrookes.com/store/books/orellove-2460/>

Widely respected in its two previous editions, this textbook presents updated strategies for transdisciplinary teams that work with children who have mental retardation or motor or sensory impairments. The guide includes expanded information on developing an inclusive curriculum, integrating health care and education programs, utilizing AT, planning transitions and families' concerns about their children's education. This edition enables undergraduate and graduate level special education students to effectively provide services.

## **PUBLICATIONS**

### **National Braille Press**

The NBP is a comprehensive collection of software tutorials and guides, Internet accessibility instructional materials and keyboard command guides aimed at facilitating computer accessibility and understanding.

<http://www.nbp.org/comp.html>

### **FREE SERVICE VENDORS**

*rehabtool.com*

This information technology company develops and markets state-of-the-art hardware and software and integrates them into AT solutions that help individuals with disabilities and special needs. The website offers a personalized product and search referral services that help AT users select appropriate equipment. It also publishes a quarterly newsletter and provides access to an AT links library. For more information contact:

rehabtool.com

P.O. Box 572190

Houston, TX 77257

Phone: (281) 531-6106

Fax: (281) 531-6406

<http://www.rehabtool.com/>

### **FACT SHEETS**

*Severe and/or Multiple Disabilities*. National Dissemination Center for Children with Disabilities (NICHCY). January 2004.

<http://www.nichcy.org/pubs/factshe/fs10txt.htm>

This five-page fact sheet defines and describes the incidence, characteristics, medical and educational implications of various disabilities and provides lists of resources and organizations that focus on multiple disabilities.

*Multiple Disabilities*. Texas School for the Blind and Visually Impaired (TSBVI). 2003.  
<http://www.tsbvi.edu/Education/infant/page5.htm#main>

This compact fact sheet compares the human body to a submarine: "When operating 'on instruments' (sonar, radio, periscope), the captain must rely on what his instruments tell him about the surrounding environment. His periscope give 'straight ahead' visual information (or side vision, if the periscope is turned); the sonar tells what might be 'out there' at a distance; the radio antennae permits incoming verbal information (receptive language) or allows out-going responses (expressive language). The motor mechanisms allow the captain to maneuver his submarine ahead, make turns, stop, reverse, rise or descend. The captain must take all of the information given to him, make sense out of it and make decisions that affect the whole submarine and its crew. Survival may depend on the experience, knowledge and data processing ability of the captain."

Multiple disabilities in an infant or young child require the coordinated efforts of multiple experts (one from every identified disability area), the fact sheet continues. "Because of the interactive, multiplicative effects of multiple disabilities, it is essential that intervention and/or programming efforts be focused cooperatively on functional tasks. Whenever possible, intervention should be aimed toward minimizing or preventing developmental delays. Since there seems to be an ever-increasing number of infants and young children with multiple disabilities, the cooperative approach to early intervention seems to have the best potential for enhancing the potential of these children."

4Woman.gov. National Women's Health Information Center. 2004.  
<http://www.4woman.gov/wwd/wwd.cfm?page=79>

This information sheet provides several online resources on severe and multiple disabilities from a women's perspective.

*Residential Programs in New York State for Children with Multiple Disabilities.* New York Special Education Department. 2004.  
<http://www.vesid.nysed.gov/specialed/private/schools/resmdpr.htm>

This online resource lists – and provides links to – residential programs for children with multiple disabilities in New York State.

*Yahoo Education Directory: Special Education; K-12 Schools.* 2004.  
[http://dir.yahoo.com/Education/Special\\_Education/Schools/K\\_12/](http://dir.yahoo.com/Education/Special_Education/Schools/K_12/)

This online directory provides links to schools nationwide that focus on children with multiple disabilities.

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## KNOWLEDGE NETWORK MEMBERS

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### **The Accessible Book Collection**

The Collection provides high interest/low reading level, low-priced digital text to qualified individuals with disabilities. Readers are individuals with learning/reading disabilities and those with vision impairments or with multiple physical disabilities that can prevent them from holding books or turning pages. If a reading disability is the result of a learning disability, certification can be obtained from a school learning disability specialist, school psychologist, clinical

psychologist or a doctor of medicine or osteopathy. In cases of blindness, visual handicap or physical disability, certification may be made by doctors of medicine or osteopathy, ophthalmologists, optometrists, registered nurses, therapists, professional staff at hospitals, institutions and public or welfare agencies. In the absence of the above certifiers, professional librarians may provide certification.

Although The Collection's primary subscribers are government and non-profit schools, eligible individuals may also subscribe. Subscribers also include government or non-profit rehabilitation centers, hospitals or related non-profit facilities whose main mission is to provide specialized services related to the education, training, adaptive reading or information access needs of the visually impaired or otherwise disabled.

For additional information, contact:  
The Accessible Book Collection  
12847 Point Pleasant Drive  
Fairfax, VA 22033  
Phone: (703) 631-1585  
Fax: (360) 252-8072  
Email:  
[customerservice@accessiblebookcollection.org](mailto:customerservice@accessiblebookcollection.org)  
<http://www.accessiblebookcollection.org/>



### **Texas Deafblind Project**

Administered under the auspices of the Texas School for the Blind and Visually Impaired (TSBVI), the Project provides information and training about deaf/blindness to families and to the professionals who aid them. Subcontracted through the Texas Education Agency, the Deafblind Outreach team provides technical assistance designed to meet the needs of children from birth through age 21 who have both a vision and hearing impairment. The project compiles demographic data on the state's deaf/blind population for

inclusion in the Federal Deaf/Blind Census. Outreach services are available statewide through schools and regional Educational Service Centers (ESCs). In addition to its census activities, the Project:

- Acts as a central source for information about deaf/blindness in Texas
- Consults with families, educators, related service personnel, community providers and others through onsite visits
- Sponsors and administers regional workshops, biennial statewide deaf/blind symposiums and topical workshops related to deaf/blindness for families and service providers
- Provides training that guides families through a transition planning process and aids them in developing preferred adult lifestyles for deaf/blind family members
- Develops a secondary transition planning process model and disseminates supporting materials for families, schools and service providers that address the challenges related to the transition of deaf/blind young adults
- Trains the staff of service providers employed by the Texas Deaf-Blind and Multiple Disabilities (DB-MD) Program for young adults age 18 or older as well as other community providers
- Runs a series of leadership training events for family members
- Expands the involvement of Texas families participating in distance learning through Project Sparkle
- Supplies financial assistance to enable families and professionals to attend training
- Doubles the number of interveners supporting deaf/blind students
- Links with state higher education programs to offer undergrad coursework on deaf/blindness to interveners

- Trains 20 regional deaf/blind specialists located at each of the state's ESCs
- Develops and distributes a quarterly newsletter, SEE/HEAR and other materials about deaf-blindness on trends and issues impacting children and young adults with deaf/blindness
- Directs census activities to maintain accurate demographic information on children with deaf/blindness in Texas for program planning and evaluation purposes

For more information, contact:

Texas Deafblind Project  
Division of Special Education Programs and Complaints

Texas Education Agency  
1701 North Congress  
Austin, TX 78701-1494

For administrative issues, call Marty Murell,  
Project Director at (512) 463-9362

For programmatic issues, call Cyral Miller,  
Project Coordinator at (512) 206-9242,  
TTY: (512) 206-9188

<http://www.tsbvi.edu/Outreach/deafblind/index.htm>



## Assistive Technology

### Educational Network of Florida (ATEN)

ATEN provides information on assistive technology to Florida students, family members, teachers and other professionals. The ATEN professional staff includes educators, speech/language pathologists and occupational therapists.

The network offers workshops at its Sanford, FL center and elsewhere throughout the state. The workshops are free to Florida public school system employees, students and students' family members and caregivers and feature practical hands-on exploration of AT devices and software. Continuing education credits are available for workshop participation. The ATNET Resource Lab in Sanford houses an array of AT for hands-on demonstration

purposes. The lab includes voice-and-print-output devices, low-tech hearing and vision devices, adapted toys, computer adaptations and environmental control systems. The lab is open daily for scheduled appointments. ATNET supports four additional regional labs in Tallahassee, Tampa, Palatka and Ft. Lauderdale, all of which offer a sampling of AT options and provide regional training support.

ATEN's Resource Library contains books, magazines, journals, conference proceedings, catalogs, videos and other AT-related material. A short-term loan library offers AT devices and computer adaptations for AT assessment and trial use with students. Equipment borrowed from the loan library is intended for use by students in all settings and is packaged into customized kits.

ATEN print resources include a newsletter, Keyhole Communiqué. ATEN's website, <http://www.aten.scps.k12.fl.us> features timely information about the organization, including the ATEN training schedule and its AT databases, downloadable newsletters and device tutorials.

For further information, contact:  
Assistive Technology Education Network of Florida (ATEN)  
1207 Mellonville Avenue  
Sanford, FL  
Phone: (407) 688-2201, ext.231  
Fax: (407) 688-4593  
Contact: Diane Penn, Regional Facilitator  
[Diane\\_Penn@scps.k12.fl.us](mailto:Diane_Penn@scps.k12.fl.us)  
<http://www.aten.scps.k12.fl.us>

### **Boston College Eagle Eyes Project**

The Eagle Eyes Project at Boston College has developed two technologies enabling severely disabled children and young adults to gain computer access. The first technology, Eagle Eyes, helps children and young adults who cannot speak, and who have no voluntary muscle control below the neck, to control the mouse pointer on the screen by using eye movements. Eagle Eyes works through five electrodes placed on the user's head. The second technology,

Camera Mouse, helps the user control the computer through head movements. The Camera Mouse operates via a video camera or web camera connected to the computer. Both access technologies function as standard mouse replacements in Windows systems by using standard Windows application software. The project has also developed several application programs, including on-screen keyboard programs, games and a browser, compatible with Eagle Eyes and Camera Mouse, that are available for free download or on a CD.

The Eagle Eyes Project is housed at Boston College and is a joint effort involving the school's computer science department and Campus School. The project also encompasses other institutional participants, such as the Holly Bank School in Yorkshire, U.K. and several schools in Northern Ireland. The Camera Mouse technology is licensed to Texas-based CM Solutions, which distributes the technology commercially.

A new Eagle Eyes projects aims to provide individuals whose voluntary movement is limited with the opportunity to communicate via computer. The project focuses on developing customized software that visually recognizes patterns in movement, translating those movements into computer commands.

For further information, contact:  
Boston College Eagle Eyes Project  
460 Fulton Hall  
Chestnut Hill, MA 02647-3808  
<http://www.bc.edu/schools/csom/eagleeyes/>

For technical information, contact: Professor James Gips at (617) 552-3981 or e-mail: [gips@bc.edu](mailto:gips@bc.edu)

For information about curriculum, assessments, and licensing, contact: Dr. Philip DiMattia at (617) 552-8424 or e-mail: [dimattia@bc.edu](mailto:dimattia@bc.edu)



## California Children's Services (CCS)

CCS is a state and county program that provides occupational and physical therapy services to children up to age 21 with lifelong physical disabilities. Therapy services are free regardless of the recipient's financial status. CCS can authorize and pay for specific medical services and equipment provided by CCS-approved specialists. The California Department of Public Services manages the CCS program while larger counties in the state manage their own programs while smaller counties share operation of their programs with state CCS offices in Sacramento, the state capital, San Francisco and Los Angeles. The program is funded with state, county and federal tax monies, along with fees paid by parents. If parents or a child's physician believe the child may have a CCS-eligible medical condition, CCS may pay for or provide a medical evaluation to ascertain whether the child's condition is covered. If a child is eligible, CCS may pay for or provide the following services:

Treatment, such as doctor services, hospital and surgical care, physical therapy and occupational therapy, lab tests, X-rays, orthopedic appliances and medical equipment

Medical case management to help obtain special doctors and care for a child when deemed medically necessary and referral to other agencies, including public health nursing and regional centers

A medical therapy program that can provide physical therapy and/or occupational therapy in public schools for children who are medically eligible

Medical conditions covered by CCS include the following:

Endocrine, nutritional and metabolic diseases (thyroid problems, PKU, diabetes

Serious birth defects  
Disorders of the sense organs (hearing loss, glaucoma, cataracts)  
Disorders of the nervous system (cerebral palsy, uncontrolled seizures)  
Disorders of the musculoskeletal system and connective tissues (rheumatoid arthritis, muscular dystrophy)  
Disabling conditions or poisonings requiring intensive care or rehabilitation (including severe head, brain or spinal cord injuries)  
Complications of premature birth requiring an intensive level of care  
Medically handicapping malocclusion (severely crooked teeth)

For additional information, contact:  
California Children's Services  
(CCS)/Children's Medical Services  
Branch Office

MS 8100

P.O. Box 997413

Sacramento, CA 95899-7413

Phone: (916) 327-1400

Fax: (916) 327-1106

<http://www.dhs.cahwnet.gov/pcfh/cms/ccs>



The Children's Center of Monmouth County offers educational services, training in adaptive living and pre-vocational skills for students ages 3-21 with multiple disabilities or a diagnosis of autism and pervasive developmental delays. The Center provides each child with a functionally based academic curriculum, as dictated by the child's IEP. Included in a functional curriculum are skill needed to participate in the community.

The Center's staff employs a collaborative model for service delivery. The related services therapists – speech, occupational and physical therapists – and teachers work together to develop and implement a child's IEP. The model allows for natural

generalization of skills and hands-on training for all staff members on specific strategies.

In addition to an academic program, the Center provides extracurricular activities that include art, music and physical education under the direction of a specialist in each area. An AT specialist provides computer services for all students, including equipment adaptations. The average ratio of student-to-staff is 2-1 in the autistic, pre-school and lower functioning multiply disabled classes and 3-1 in the functioning multiply disabled classes.

The Center's program also includes:

- Fully equipped recreation center and gym
- Fully equipped treatment rooms for occupational speech and physical therapy
- Adaptive living skills rooms (fully equipped kitchen, laundry and apartment)
- Outdoor recreation and play facilities

For more information, contact:  
Children's Center of Monmouth  
1115 Green Grove Road  
Neptune, NJ 07753  
Phone: (732) 922-0228  
Fax: (732) 922-8133  
<http://www.ccprograms.com/default.asp>



### **Harvey County (KS) Special Education Cooperative**

The Newton, Halstead and Hesston school districts in Harvey County, KS have united in a cooperative effort to provide for children ages birth-21. The combined districts serve 5,400 students, of whom 700 have been diagnosed with disabilities. There is no charge for services. The co-op utilizes a continuum of service levels from total general education integration to

placement in a separate facility. The cooperative emphasizes community based training as an integral element in its services for children who are moderately to severely disabled.

The co-op offers the following support services:

- Adapted physical educators
- Audiologist
- Occupational therapists
- Physical therapists
- School psychologists
- Social workers
- Special ed nurse
- Speech and language pathologists
- Consultant service for visually or hearing impaired children

For more information, contact:  
Harvey County Special Education Cooperative  
116 W. 7<sup>th</sup>  
Newton, KS 67114  
Phone: (316) 284-6582  
Fax: (316) 284-6237  
Contact: Natise Vogt [ck]  
[nvogt@newton.k12.ks](mailto:nvogt@newton.k12.ks)  
<http://www.newton.k12.ks.us/sped/>



### **Heartspring**

Founded 64 years ago in Wichita, KS, Heartspring is a residential school for children with a range of disabilities. The facility, which consists of Heartspring School, The Growing Place and The Hearing Center, attracts students from Wichita and from states nationwide.

The Heartspring School, in conjunction with the sending school district or agency, designs IEPs delivered through an integrated team approach that includes residential school, psychology, therapy and medical staff. Heartspring School students receive the help they need to communicate

with the world around them via an interdisciplinary teaching approach that involves teachers, paraprofessionals, residential treatment providers, psychologists, medical staff, nutritionists, speech/language pathologists, physical and occupational therapists, a developmental pediatrician, child psychologist, child neurologist and each student's parents. The school's goal is to transition students to a less restrictive setting at home, in a group or in a public school. Heartspring provides short-term evaluations where students from around the U.S. are assessed by a team of professionals who develop a customized program for implementation in a student's home and community.

The Growing Place provides outpatient physical, occupational and speech language therapies, hearing services, behavioral intervention and educational testing for children. Diagnostic clinics are available for autism, ADHD and developmental delays. The facility also provides free developmental screenings to families concerned about their child's development.

The Hearing Center receives hearing testing and support from a staff of audiologists experienced in hearing loss in individuals from birth to adulthood. Their range of services includes diagnosis as well as fitting, repairing and supplying hearing aids and assistive listening equipment.

In 1998, Heartspring moved from its original location to a new \$14.5 million campus that places all staff members in a single location that connects the school, its community services center and administration building in order to promote collaboration between instructors, therapists and administration.

For more information, contact:  
Heartspring  
8700 East 29<sup>th</sup> Street North  
Wichita, KS 67226  
Phone: (316) 634-8700; (toll free) 1-800-835-1043

Fax: (316) 634-0555  
Contact: Jennifer Tribue  
[jtribue@heartspring.org](mailto:jtribue@heartspring.org)  
<http://www.heartspring.org>



## Project Sparkle

Project Sparkle is a program of individualized learning aimed at aiding parents of deaf/blind children in nurturing their child's development. The project enables parents, in their own homes, to access information, training and resources via DVD technology that is supported by a Parent Guidebook and the Sparkle website.

The program focuses on:

- Deaf/blindness
- Vision
- Hearing
- Touch
- Concept development
- Intervention
- Communication

The child profile is a database program that supports the family in the collection of data and information unique to each child. Parents utilize what they have learned to develop a profile specific to their child and can then share this profile with the child's educational team, service providers, medical personnel and others. The Sparkle website features a Family Room component where parents access an evolving collection of family stories that provide information and support. The Family Room also features a section entitled "R Kids" that highlights individual deaf/blind children and celebrates their activities. In addition, the project provides a Listserv where parents interact with each other to share ideas, information and encouragement. The Listserv spotlights deaf/blind topics for ongoing discussion. Each participating Project Sparkle state is assigned a State Facilitator who provides

information, guidance, support and resources to families on an as-needed basis. The Sparkle website features a video library where parents view presentations by deaf/blindness professionals, a glossary of terms and a resource section containing links to related websites.

For further information, contact:

Project Sparkle  
Utah State University  
6500 Old Main Hill  
Logan, UT 84322-6500

Phone: (436-797-5800; (toll free) 1-888-800-1487

<http://www.sparkle.usu.edu/About%20Us/S-PARKLE/sparkle.asp>



**We invite you to register for the Family Center’s 2004 Online Summer Institute.**

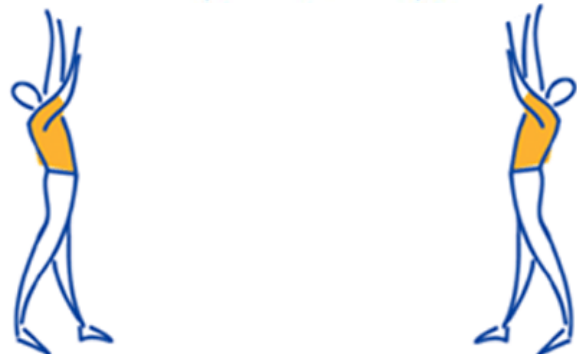
**This year’s topics will include:**

- **Assistive Technology Funding**
- **School Rights and Responsibilities for AT**
- **Results of the FCTD’s National AT Information Needs Assessment**

The Institute will take place in July. For three weeks you’ll have the opportunity to interact with professionals like yourselves, who work with families of children with disabilities. Share best practices and receive current information on AT topics that will help you better serve your audiences. You’ll have the opportunity to problem solve collaboratively and to strengthen your professional network. The Institute is free – supported by the U.S. Department of Education’s Office of Special Education Programs (OSEP).

For more information and/or to register, please call FCTD Director Jackie Hess at (202) 884-8217 or send an e-mail to [jhess@aed.org](mailto:jhess@aed.org).

We look forward to seeing you online!



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