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Family and cultural issues in assistive technology

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FCTD 2005 Summer Institute
Family and Cultural Issues
in Assistive Technology



Family and Cultural Issues in Assistive Technology

EXPERT'S CORNER

- **Expert Bios** (pg. 2-3)
- **Additional Summer Institute Faculty** (4-6)
- **Expert Perspective** (pg. 6-7)

CONFERENCE

- **Conference Transcript** (pg. 7-65)
- **Recommended Resources** (pg. 65-70)



EXPERT'S CORNER

Expert Bios

Dr. Phil Parette



Dr. Phil Parette is Kara Peters Endowed Chair in Assistive Technology, and Director of the Special Education Assistive Technology Center, Department of Special Education, at Illinois State University. On graduating from the University of Arkansas in 1976 with dual certification in elementary and special education, he worked as a 4th grade elementary teacher, an Educational Diagnostician for the Department of Social and Rehabilitation Services, a special education teacher in the Department of Correction educational system, and as an early intervention teacher. He completed a Masters degree in Learning Disabilities from the University of Arkansas in 1978, and an Ed.D. degree in Special Education (Multidisabilities) from the University of Alabama in 1982. He has worked as a Research Associate in the Department of Family Medicine at the University of Arkansas for Medical Sciences, served as the

Americans with Disabilities Act Coordinator for the Arkansas Easter Seal Society, and taught special education at several institutions of higher learning, most recently at Southeast Missouri State University (1993-2003). Between 2000-2002, he served as Dean of the School of Graduate Studies and Research.

Dr. Parette has published more than 200 scholarly works since 1982, with the preponderance of his work in the field of assistive technology (AT). In recent years, his work has focused on cross-cultural, family-centered AT applications. He was a primary co-author of the Arkansas Technology Access Program, one of the first nine states funded under the Assistive Technology and Related Assistance Act of 1988 (Tech Act). He has also developed an innovative CD-ROM, Families, cultures and AAC, that has received six major film and media competition awards. He currently serves as Editor of the new on-line journal, Assistive Technology Outcomes and Benefits, a collaboration between the SEAT Center and the Assistive Technology Industry Association. Dr. Parette's current research and development activities at the SEAT Center focus on the development and implementation of an outcomes-based, national assistive technology coalition, that synergizes best practices created at Illinois State University with partners nationwide—vendors of AT devices, education entities, government, and not-for-profits including a successful Illinois AT coalition serving 415 school districts.

Joan Breslin Larson



Joan Breslin Larson has provided assistive technology services for over 20 years. She combines a common sense approach, a commitment to collaborative decision making and a passion for enabling people to be empowered through appropriate assistive technology.

Joan currently focuses her work on assisting educators and related service providers in developing and honing skills in assistive technology and providing supports to support effective decision making and implementation. She is an active member of the QIAT Consortium and speaks nationally on collaborative decision making in assistive technology.

Additional Summer Institute Faculty

Jackie Hess

Jackie Hess is the director of the Family Center on Technology and Disability. She is the author of the publication Distance Education Primer for Special Educators and recently co-authored the Family Information Guide to Assistive Technology. As director of the National Demonstration Laboratory for Interactive Educational Technologies at the Smithsonian Institution, the Library of Congress, and the Academy for Educational Development, Ms. Hess taught thousands of educators about the role of technology in education. She co-chaired the 1993 White House Working Group on Digital Resources for Education and Training. Ms. Hess has been involved in education since 1972 when she authored omnibus education legislation for the House of Representatives. She has served as editor of academic publications for the Close Up Foundation, producing books and other curriculum materials for use in high school and college classrooms.



Dr. Brian S. Friedlander

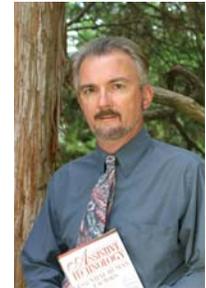


Dr. Brian S. Friedlander is a licensed and certified school psychologist with expertise in the area of assistive technology. Dr. Friedlander maintains an assistive technology practice, which provides assessments, workshops and individual training in the area of assistive computer technology. He is an Assistant Professor at the College of St. Elizabeth and an adjunct faculty member at Lesley University, where he teaches courses in educational technology. Dr. Friedlander is also the co-author of Engaging the Resistant Child Through Computers: A Manual to Facilitate Social Emotional Learning, Maurice J. Elias, Ph.D., Brian S. Friedlander, Ph.D and Steven E. Tobias, Psy.D; New York: National Professional Resources, 2001. Dr. Friedlander is the Publisher of Inclusion Times, a nationally distributed special education newsletter which is published by AssistiveTek, LLC (www.assistivetek.com). Dr. Friedlander is featured in a recently released video: Assistive Technology: A Way to Differentiate Instruction for Students with Disabilities, on VHS and DVD from National Professional Resources. He also moderates the Assistive Technology eGroup which can be accessed by going to <http://groups.yahoo.com/group/attechnology>

Dr. Friedlander is a frequent presenter on the topic of assistive technology at National and State Conferences. Dr. Friedlander can be reached at brian@assistivetek.com.

Dr. George Peterson-Karlan

Dr. George R. Peterson-Karlan, Ph.D. is an Associate Professor in the Department of Special Education at Illinois State University. He is licensed Director of Special Education and previously served as a special education administrator with the Fort Wayne (IN) Community Schools (1997-2002) where he coordinated the Assistive Technology Services team, and co-led the Autism Support Team. Dr. Peterson-Karlan previously served on the faculties of University of Illinois (1987-81) and Purdue University (1981-1997) where he developed the first university courses at both the undergraduate and graduate levels in assistive technology offered in Indiana. During his tenure at Purdue he was co-PI or PI on a number of research and training grants in the area of augmentative communication and assistive technology, including a 3-year, 2-state research study of professional development in AT.



Russ Holland



Russ Holland has been involved in the field of assistive technology for the past 25 years. As a classroom teacher, the founder and director for nine years of Techspress (an ATA Center in upstate New York), and an independent consultant, he has been involved in advocacy work, training and consulting directed at eliminating barriers faced by people with disabilities. He is co-founder of Adirondack AccessAbility Inc., an ATA Affiliate, and currently serves as the Program Director of the Alliance for Technology Access.

Much of my success has come outside of school. I believe strongly in extracurricular, hands-on experience. I've been an artist, a potter, a rock climber, a car mechanic, a teacher, a software developer, and more. All of these experiences have helped me see the difference between my learning disability and my intelligence.

Janet Peters

Janet Peters is the Coordinator of PACER's Simon Technology Center. She has worked extensively in developing technology trainings for parents and consumers. She has also worked with hundreds of individual families and adults through assistive technology consultations, utilizing the latest devices



and software. Recently Janet co-authored the publication *Family Information Guide to Assistive Technology*. She has a degree in Computer Science and Organizational Communication, an MBA Non-profit management certificate, and has completed graduate course work in education.

Expert's Perspective

Dr. Phil Parette
Director, Special Education Assistive Technology Center
Department of Special Education, Illinois State University

To ensure effective assistive technology (AT) decision-making for children with disabilities, families should ideally be actively involved with education professionals in making decisions about AT being considered for their children. A family-centered approach is recommended practice for AT decision-making--a process that involves careful gathering of information needed to address the family's strengths, needs and priorities, and to match the AT decision-making process with the family's cultural and linguistic background. It also involves matching the characteristics of the child with a disability to the environments, tasks, and features of devices.

An evolving issue in family-centered practice is the role of cultural and linguistic issues that may influence the participation of family members in AT decision-making and subsequent implementation of and support for devices and services. Culturally and linguistically-based values may wield strong influences on family perceptions of AT, and successful implementation of AT solutions agreed upon by team members.

Hopefully, our discussions in the next two weeks will address issues related to identifying and developing an understanding of family perspectives about family goals and expectations for AT that are often very different from the perspectives of professionals. A range of cultural and linguistic values will be explored--both of education professionals and families--with emphasis on how such values may affect AT decision-making. It will also explore acculturation issues, including generational differences, in an effort to better understand how these influences affect AT decision-making.

Joan Breslin Larson
AT Specialist

I have always been a strong advocate for the use of technology for persons with disabilities, I have worked to show that technology allows for possibilities. One lesson I have learned (sometimes the hard way!) is that we need to be planful in how we choose and use that technology. Careful consideration must be given to what a person needs to do, where he needs to do whatever is needed, and what strengths and skills are brought in using the technology. Another lesson is that what is great technology in one setting is not necessarily right in another setting.

Thus, we need to look across a user's life and world, choosing frequently a range of solutions to meet a range of tasks. This can be daunting, but is a doable task when many voices contribute to a discussion about what is possible.

Particularly when we are looking at technology for a student, the many voices need to include school staff, the family, peers and most importantly, the student. Each voice adds a new perspective and adds to the richness of the discussion. Will there be a perfect outcome to that discussion? Perfection is, of course, hard to reach, but there can be a great outcome when we work collaboratively to benefit a student.

I am very excited to kick off this summer institute, and urge you to talk about some of those times your voice has been heard in the discussion about positive outcomes for a student about whom you care.

CONFERENCE

Conference Transcript

- **Welcome and some questions** by **Joan Breslin Larson** on Jul 11, 2005
I am very excited to participate in this discussion this summer. The focus on family and cultural issues in AT is interesting to me. Here is some of what I have thought about as I prepared for this institute... Feel free to use these points as a jumping off point, or let's talk about what is important to you!
There is a unique set of demands on families of children with disabilities. In many ways, there is a "culture" unique

to these families that requires awareness and attention from professionals. I remember talking to a friend who has a daughter with significant health issues- she said she lives life ALWAYS waiting for the next crisis- even when things look smooth. This comment gave me a whole new awareness of her life. And- provided me with a level of understanding when she did not think the cool new technology I presented for her daughter's use was as cool as I did... She had much bigger priorities.

I have also thought about the changing demographics in our country, and the different way some cultures think about disability and technology. I will have a story or two to share if there is an interest to go in this direction. AND- last (for now at least...) what is the impact on the use of technology in a family? How do we support the use of devices in the family? How invasive is it to go into someone's home and start re-engineering their environment? When we are educators, what is our responsibility to support the use of technology at home? What are the differences when it is educationally necessary technology vs. life enhancing (but not educationally necessary) technology.

Lots of questions, and hopefully we will develop answers as a community of learners.

I look forward to the discussion.

Joan Breslin Larson

Summer Institute Faculty

- o **Re: Welcome and some questions** by **Chris Wethered** on Jul 12, 2005

Emotional Free Fall

You mentioned that families of disabled children often have 'much bigger priorities' in mind. In addition, they are often in a long-term emotional free fall, mourning the 'loss' of their imagined normal child. At every milestone (that other children experience, but their child doesn't make), that is another 'death' of the normal child, that they didn't have. There could be an ongoing depression over this continued loss experience.

Your news on the reasons, or even your AT 'solution'; while shining light and hope on the situation, could represent another missed milestone to the parent.

- **Re: Welcome and some questions** by **Joan Breslin-Larson [SI Faculty]** on Jul 13, 2005

Thanks, Chris. That is an important point. And, for those of us who are professionals, a point that we need to keep in mind. I appreciate your comment.

Joan Breslin Larson

Summer Institute Faculty

- o **Re: Welcome and some questions** by **Paula** on Jul 12, 2005

Dear Joan (and all the participants)

I work at a state department of education on the development and implementation of Universal Design for Learning (which incorporates AT and technology in general to give all students access to the general education curriculum). One direction that my colleagues and I are working toward is to what extent and how to support given technologies at school, but also at home. Your questions give me a different direction to think - how invasive will it be for family members? Typically it would be a laptop with text-speech and other similar tools. How well will family members accept a possible change of doing homework using technology rather than texts and paper? What upfront work should we do to "sell" the concept of UDL in the home as a statewide initiative?

Any comments, thoughts, suggestions, questions would be appreciated.

Paula

- **Re: Welcome and some questions** by **Joan Breslin-Larson [SI Faculty]** on Jul 13, 2005

Paula-

One of the really intriguing things I am thinking about a lot this week is how differently each family will look at this issue, based on their familiarity with technology, acceptance of doing things in a new way, ability and willingness to take on something new, ability to have technology in their home- lots of issues!

I have a friend named Joy, who, when asked about what AT works best for an individual will respond with "It all depends." And I think that's the answer to your first question- each family will have their own unique situation, and it will all depend on that situation.

Having said that...

There certainly will be a need to help some families to cross the digital divide to have access to appropriate technology in the home. Perhaps there is a something like Computers for Schools in your state, or the Cristina Project which will support getting technology into the hands of those at risk.

The federal government used to sponsor PT3 grants for schools. They had a component in those grants to help families at risk acquire the skills to be technology savvy. I heard the funding for those programs was at risk. Does anyone have up to date information on that?

I am also faced in my state with the upfront work to "sell" the concept of UDL. I attended a summer institute at our Department of Education focusing on this topic, and was so excited to see the energy generated. My intent is to work with higher ed partners to get educators skilled in this prior to getting into the classroom, finding administrative advocates who will work with state leadership teams, and a cadre of "true believers" who can act as the front line. It will be exhausting and fun.

What strategies are others using? We can use all the good ideas we can get!

Joan Breslin Larson
Summer Institute Faculty

- **Re: Welcome and some questions** by **Linda** on Jul 14, 2005
Sign us up for the "True Believers Cadre!" Our ATA Center, in addition to providing AT demonstrations, info dissemination, trainings, lending library, and evaluations, etc. runs a computer refurbishing/recycling project (small scale, to be sure!) Readying and placing the computers is very time-consuming, but the amount of initial training and technical support that is needed by the recipients overwhelms us. For that, we try to utilize community volunteers, but still we are barely scratching the surface. Also, I am sorry to say that in the last five years, only one computer went to an English Language Learner's home, despite wonderful support from the local Hispanic media. We have so far to go! When working with schools, we are trying to find ways to join the regular ed folks with the EC folks, and of course, the high incidence population is the best route; however, regular ed is sorely behind in utilizing technology as well! It is still seen by many as "cheating" or taking the easy way out.

- **Re: Welcome and some questions** by **Annie Czapp** on Jul 14, 2005
Joan,

When researching the PT3 grants status, it appears that grants are no longer being issued. According to the Department of Education website (<http://www.ed.gov/programs/teachtech/index.html>), they have not been appropriated any funds since the fiscal year 2003. However, from looking at their website (<http://www.pt3.org/index.html>), it looks as if the program is still there, but not issuing grants. The program is still providing information about the use of technology by teachers and strategies for getting that technology into the classrooms. They are still active, and recently held a conference at the beginning of this year with the grantees from 2003, 2001, 2000 and 1999.

There is a lot more information on both of these websites about the purpose of the grants and the status of the recipients of the grants.

- **Re: Welcome and some questions** by **Linda** on Jul 12, 2005
I am very interested in hearing the "story or two" regarding your experiences with "the different way some cultures think about disability and technology."

Something tells me it will have very little to do with the language difference...

- **Re: Welcome and some questions** by **Joan Breslin-Larson [SI Faculty]** on Jul 13, 2005

Linda-

I told a few stories further down the stem under "different strokes" but let me tell one more (I love telling stories!) that I have told in an FCTD forum before.

A few years ago, I was an AT consultant. I had a referral to see a young child from a family recently arrived in the US from Southeast Asia. This youngster was blind, deaf, had profound cognitive disabilities, and was at great risk for injury due to his great spirit of exploration. A social worker, the child and both parents came to my office to see me. I knew a little about the child before he came, so I was prepared (I thought) for the visit. I greeted the family and social worker and gave them a place to sit. Since the child was young, and learned through sensory input, I wore pants so I could sit on the floor with the youngster, playing with him and getting him used to my touch and input. I asked the Mom questions about the family, strategies she used with her boy, and things he liked. After about 10 minutes, the Dad stood up, and abruptly left. His wife collected the boy and followed. Consult over! The social worker called me a few days later. She was very sheepish, and explained that I was perceived as incredibly insulting. I wore pants. I talked to the Mom and not the Dad (the head of the family.) I did not act like a professional- I sat on the floor. All in all, I did nothing right.

Time for a new strategy. The social worker talked the family into returning. I went to an advocacy organization for refugees, and learned an appropriate greeting in the family's language. I wore a dress. When the family returned, I greeted the Dad first, then the Mom. (They were amused but very polite at how I mangled their language.) I addressed all questions to Dad, who had Mom answer. I asked permission to hold the boy and work with him.

After a little while, we established trust- the family appreciated that I was trying to be respectful and they knew I had skills that would help. I was able to work ongoing with them (and was able to wear jeans and sit on the floor, and talk to Mom once they knew I was OK).

From that experience, the center where I worked developed a library explaining issues regarding many cultures that were new to our community, including what was appropriate dress, phonetic versions of greetings, etc. It helped a lot to establish the trust necessary in many cases.

Joan Breslin Larson

Summer Institute Faculty

- **Re: Welcome and some questions** by **Linda** on Jul 13, 2005

How wonderful that you persevered, and changed, to affect this outcome. And how lucky that

the social worker had the knowledge and took the time to explain the situation to you. I wonder how many times situations like that have occurred and no one ever knew why? Your library idea is excellent...in fact, we have an organization here, International House, who would probably be able to assist us in getting something like that going here. Perhaps we could share resources amongst our Institute participants!

- **Re: Welcome and some questions by Jackie Hess, SI faculty** on Jul 14, 2005
Joan, I had the same thought as Linda. Your "cultural sensitivity" document sounds like an excellent resource and I'm wondering whether you would be able to share portions of it with Institute participants. If it's not in electronic format, we'd be happy to scan it here. Thanks.
- **Re: Welcome and some questions by Phil Parette [SI Faculty]** on Jul 13, 2005
I agree w/ Joan on this point. We have had many such experiences working w/ families across different ethnic groups. For example, we had to be sensitive to 'colors' worn in neighborhoods in inner city LA communities (gangs view colors worn in very unique ways and one can certainly get sideways with these individuals if one is not sensitive to the values of gangs in neighborhoods). We had both Hispanic and Asian families who were more amenable to working with us if we included a food activity prior to a formal meeting to give/get information. When working with other families, we learned to identify extended family members who were sometimes the primary decision-maker (e.g., a grandmother is sometimes a revered and important decision-maker w/ African American families). In working w/ Asian families, it was sometimes helpful to identify a respected member of the community (in one instance a well-known Vietnamese physician) to serve as the liaison between the school and the family. This served to establish rapport and build trust. So the bottom line is that it is imperative to try and understand the values of a particular family and the community in which they reside before we initiate intervention efforts. This can go a long way to communicating respect for others and optimizing buy-in from the families.
- **Re: Welcome and some questions by Linda** on Jul 14, 2005
Of course...FOOD! All cultures seem to share the "breaking bread" philosophy. I'd like to hear more about some of those activities, if you have time and are willing to share.
 - **Food bridges cultural chasms...** by **Phil Parette [SI Faculty]** on Jul 14, 2005
When we worked with a group of families in a Hispanic neighborhood, a focus group

moderator conducted three focus groups at the school site. An interpreter was present during all three focus groups. The moderator and interpreter were aware of the need to be culturally sensitive during each of the 1 - 2 hour interviews which were arranged at times and locations convenient for family members. Several of the families took off work, viewing the interviews as important and allowing for as much time as necessary. Two graduate students assisted the moderator in audio- and video-taping the interviews. One of the graduate students was a Hispanic male who also assisted in the translations and interpretations as necessary during the interviews. The interpreter assisted the participants with the completion of questionnaires and consent forms. Special ethnic foods were served. All families received a small stipend and gifts of food for their participation.

In working with Asian families, family members desired a shorter interview that started on time and was focused on the task at hand. Researchers were respectful of the time, space and reciprocity issues for each ethnic group. All families received a small stipend or gift certificate for food which was immensely appreciated.

So food is certainly a 'focal point' that can bring people together. Remember all the food movies that have come out in the last decade? I'd certainly highly recommend this as a mechanism for bringing down the chasms that may exist between cultural groups before getting down to the business at hand.

- **Re: Welcome and some questions** by **Melissa** on Jul 12, 2005
I just finished a summer course on collaboration and families. We talked about the cultural differences and how difficult it is to address the issues, when we don't even know what the issues are. We must be very careful not to assume too much or too little about how cultural issues affect our dealings with families. We looked at one case study about a child who was being encouraged to finger feed and finally, the family asked the therapist to stop because that practice was negatively perceived in their culture. Even though it was a practical skill for their daughter, their cultural views took precedence. The family didn't speak up for awhile, though, because their culture also did not feel it was right to challenge the experts. I think very often when parents don't follow through with our recommendations, we assume it is because they don't care and we couldn't be more wrong.

Melissa

- **Re: Welcome and some questions by Phil Parette [SI Faculty]** on Jul 13, 2005
Melissa:

This is a very poignant example--there are deeply held cultural values that may be diametrically opposed to what we feel is important from a white cultural perspective (I use 'white' vs. Euro-American and Anglo-American because some of the textbook publishers are now leaning toward this, and there is no consensus on terminology). We have talked with families that strongly encourage and support dependence of the child on the family, while the education professionals at the school place emphasis on independence and yet don't understand why the child fails to comply or why family members don't 'try harder' to help their child be independent. We've spoken with families who have had many negative experiences with the schools (and the government) and have developed a sense of 'distrust' for representatives of the government (and schools). And then we are left wondering why the families are reluctant to comply with our recommendations, much less to participate. These are just a few examples of what can happen if we fail to recognize the importance of strongly held values that families and children bring to the decision-making table.

- **Re: Welcome and some questions by joycewaggoner** on Jul 23, 2005

Now that the Institute is over, my internet is finally up and running. That has been my challenge for the 2 weeks! I have been a very interested lurker however.

I do have a comment on technology in the home. I work with a student that uses a switch to scan a very complex board using Auditory cues. She is very successful at school. When trying to have it go into the home, I have run into many roadblocks from Mom. I had to take a step back from what I thought was best for her child, and think what would work in her home setting. We are using a lower tech device with auditory scan at home. This device can reside in her backpack on her chair. This eliminates a need for a mount. This device also looks much less scary since it is not like a computer. I hate that the student is limited in the amount of vocabulary that is available at home, but it is at least a foot in.

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- **Welcome from Janet Peters by Janet Peters [SI Faculty]** on Jul 11, 2005

Welcome to the Family Center on Technology and Disability Summer Institute. I am honored to be able to take the next two weeks to discuss some very important issues in assistive technology. The participant list shows the range expertise you all have and I anticipate learning from all your experience.

PACER is a parent advocacy organization and many of the parents that utilize our services are very pro-active and

energetic families who (for the most part) are enthusiastic about the potential of assistive technology, yet at times overwhelmed with the options, technical aspects, or funding barriers.

I would like to pose a starter question on how as a community of leaders in assistive technology, can we broaden the capacity for families not at the stage or ability to be as advocates. How can we truly raise awareness effectively? Are the traditional means, usually written information, reaching low-income and non-English speaking families?

I look forward to the next two weeks exploring these themes with you.

Janet Peters,
Coordinator of PACER Simon Technology Center
FCTD Summer Institute Faculty

- **Re: Welcome from Janet Peters** by **Linda** on Jul 12, 2005
It is unclear to me whether we are not being successful at raising awareness or are too many other issues in their lives preventing that awareness from being a priority?
 - **Re: Welcome from Janet Peters** by **bfujinuma@renewalunlimited.net** on Jul 13, 2005
Good point:)

-
- **Welcome by Jackie Hess [SI Faculty]** on Jul 11, 2005
I'm sorry to report that we're starting with a few technical problems - hopefully they'll be resolved shortly. If you have trouble posting this morning, please try in another hour or so.

As we launch this discussion of family and cultural issues, I'd like to suggest that we think about some of the assumptions we make about family life in the United States at the beginning of the 21st century. Most of us generally assume:

1. Education leads to broadened horizons, better jobs, and a better life.
2. Through public schools, students from families on any part of the economic spectrum can get a quality education.
3. Children can and should receive regular medical care (annual physicals, etc.) from competent physicians.
4. Medical personnel and teachers are qualified to identify the majority of disabilities that a child may have.
5. Parents rely on doctors and teachers for information about disabilities and assistive technology.

6. Education and medical professionals are aware of a range of appropriate assistive technology services and devices.
7. Public libraries and the Internet are sources of information for families.
8. Any parent who truly loves his or her child will recognize a disability early in its (the disability's) development and will immediately begin a search for information and intervention.

Although I've painted these assumptions with a rather broad brush, it seems to me that, generally, our society operates as if they are true. During the next two weeks, we'll discuss families who live according to different assumptions. To work effectively with them, and to reach their children with appropriate AT, we need to understand how the world looks to them.

I hope you'll take some time each day to read one of the excellent articles that have been posted in the resource section of the Institute website.

And hopefully our technical problems will be resolved soon.

-
- **Generational Differences** by **Phil Parette, SI Faculty** on Jul 11, 2005
An important cultural factor that may often not be considered during AT decision-making are the generational differences that exist across stakeholders. Baby Boomers and Gen Xers are typically in decision-making roles on AT teams (as family members and education professionals) while the children for whom AT is being considered are Millennials (born after 1978-82), and have very different perspectives of technology as well as use patterns. We as informed 'experts' bring our experiences, values, and understanding of technology into the decision-making processes, while children may have very different perspectives and preferences (especially those children with mild disabilities). Have any of you had experiences in which abandonment occurred because AT chosen was not 'cool' or was inappropriate from the child's perspective because we may have ignored consideration of his/her preferences and use patterns?
 - **Re: Generational Differences** by **annette cerreta** on Jul 11, 2005
As an AT consultant, I see that the individual preferences of the student really trumps all the best intentions and ideas of the "professionals" on AT teams. This just underscores the importance of including the student in the AT decision-making process from the very beginning. By doing so, abandonment of devices that don't appeal to the student, for whatever reason, can be minimized.

- **Re: Generational Differences by Joan Breslin Larson** on Jul 11, 2005
 Annette- You are so right about involving the student from the first stages. I have had a student refuse to use a device because it was the wrong color (Green Bay Packers green and yellow instead of Vikings purple.) Until I was able to find a team neutral device, we were gridlocked! Was the original device able to complete the desired tasks? Absolutely. Was the team neutral device as able to complete the same tasks? Actually not, but it could do nearly everything, and worked for the student. It became desirable useful.
 I will be posting some further thoughts soon on the culture and family issues strand, as those additional thoughts will be more appropriate there.
 Joan Breslin Larson
 Summer Institute Faculty

- **Re: Generational Differences by Lisa Snyder** on Jul 11, 2005
 Along with this idea is that sometimes you really need to "sell" the device/software to the target student. As a planning team, we have had to implement the AT through a teacher who used it with the whole class. For example, using an alphasmart as a whole class writing activity before a student would warm up to the idea of using it for other activities as well. It has surprised me sometimes that there is more work that goes into the planning and set up than for the actual training and implementation.
 - **Selling the idea by Phil Parette [SI Faculty]** on Jul 12, 2005
 Lisa, I agree with you that we often have to 'sell' the idea of certain AT to students and their families....but is the selling based on the cultural values of us as education professionals? WE feel that students may need certain devices, but does this selling take into consideration what the student wants and/or prefers? While some students don't know what they need, and thus professionals step up to the plate to help make these decisions, are we circumventing values, experiences, learning styles, and other background variables of the child and family when we 'sell'?
 - **Re: Selling the idea by Janet Peters [SI Faculty]** on Jul 12, 2005
 I think this question is a good point. What if we are trying to sell an individual on the AT because it meets a goal we need, such as an educational outcome. But that goal is not meaningful for the student? There are family values that differ, is the IEP team meeting the best place to work those ideas out. Or is it fair for the school

(especially with NCLB) to have some basic requirements that they have to make understood to the family?

Can anyone share strategies they have used to build this collaborative understanding?

- **Re: Selling the idea** by **Lisa S.** on Jul 12, 2005
I would like to think that we are taking into consideration values, experiences, learning styles etc.... Whenever I do an evaluation I take into consideration ALL environments and even discuss options with the student and ask for feedback. Many times I just get the answer that they don't want to be different. However, the majority of the time that we are called in for AT evaluations, the student is failing with accommodations or modifications in place, student is NOT able to access their curriculum like their peers and with the high incidence students, are falling way behind. Many times, if we can "sell" the AT product, success breeds content and acceptance. Based on the feedback of the student, we may have to adjust or rethink the intervention. My point is that you only really know if the AT is tried and then watch and get feedback from the student.
- **Re: Selling the idea--acculturation** by **Phil Parette [SI Faculty]** on Jul 12, 2005
I agree totally. Professionals in special education have historically expected families to adapt to the expectations of the broader, mainstream school culture which typically reflects white, middle class values, such as individuality, control of one's environment, and a value of the future. When a family member or person with a developmental disability from a cultural background has different values (e.g., values group behavior versus individuality, harmony with the environment rather than control over it, and a value of the past or present rather than the future), substantive problems may be anticipated both in seeking and receiving educational services. Such contrasts between belief systems may be observed during AT team decision-making intervals. For example, families may be encouraged to assume AT advocacy activities such as funding and information-gathering for their

children. They may also be expected to participate on teams and advocate for their children if effective AT decision-making is to occur. Finally, they may be expected to use AT in the home and other community settings. While each of these expectations may be communicated or encouraged from the perspective of the professional within the dominant culture, it does not necessarily mean that the families will agree to or assume these presumed responsibilities, especially if stigmatizing effects are perceived by the family or fears that use of AT will delay the acquisition of important developmental milestones. Therefore, professionals may need to become familiar with such issues and may wish to develop alternative strategies for presentation and implementation during team decision-making.

What we have wandered into is the realm of acculturation...this has been defined in many ways, including giving up "old ways" and adopting "new ways" and the "extent to which ethnic-cultural minorities participate in the cultural traditions, values, assumptions, and practices of the dominant White society".

- **Re: Selling the idea--acculturation by Lisa S.** on Jul 12, 2005
Very interesting point! This leaves a lot to think about!
- **Re: Selling the idea by Chris Wethered** on Jul 19, 2005
'Selling the idea' isn't only about AT. Special Educators frequently even have to 'sell' parents on the need for specific IEP goals. Whether the target skill is to improve the student's academic progress, or to help him in later (post-school) life; the parents and teachers need to have a shared vision on 'what is best' for their child's future.

The big problem with trying to sell ideas, goals, or AT technology is that the parents may feel that the teacher doesn't value the parents' ideas, and wants to 'push' his/her ideas on them.

It's essential to establish a dialogue between the parents and teacher. Less 'selling' will be required, with more advance communication on the student's abilities, and needs.

- **Re: Generational Differences** by **Joan Breslin Larson** on Jul 11, 2005

Annette- you are so right! Without student buy in, we are asking for failure!

The Minnesota Department of Education has an AT consideration framework (based on Joy Zabala's SETT framework) that guides all members of an IEP team through a discussion of the need for AT to support academic tasks. The student has a form dedicated to his or her use, that he can fill out independently or with support of a neutral person. I have heard that there can be real surprises with what students have to say on occasion.

I want to think out loud a little about students who have more significant disabilities and cannot verbally express their needs and opinions. What can we learn from observation? Some lessons I have learned include...

- 1- These red switches clash with my pink wheelchair and don't look pretty, so I won't use them.
2. I've been doing this same darned activity for 3 weeks and I am bored. I'm not going to hit the switch until you give me something new to do!
3. Sometimes my head hurts and I don't want to shred paper. If you won't let me take a nap, I'm going to throw this switch away.
4. I like using my device to talk, but I'm a 15 year old boy. Why does it have my teacher's voice on it? Get me a boy's voice and I'll use it a lot.
5. I have serious sensory issues, so don't give me colored switches. Give me the black one and I'll do lots of activities.

Some of these lessons took LOTS of time to learn, and required lots of patience from the students with whom I worked until I got what it was that they were communicating so well.

Even the best technology is useless unless it allows the end user to do something they want to do with some autonomy in how it happens.

Joan Breslin Larson
Summer Institute Faculty

- **Re: Generational Differences** by **Lynne P.** on Jul 11, 2005

I couldn't agree with you more re; your last paragraph - not only should technology allow the

end user to do what they want to do, but also that the task is meaningful and there's a payoff to it (recognition or engagement, food, a desired object, etc) Too often I see tasks that are there purely to fill time (match a picture to a picture) when the individual could be taking that picture of the computer over to the computer to get some play time on it. We need to recognize the dignity of students with significant impairments and let technology build independence and enjoyment and fulfillment in the tasks they do.

- **Re: Generational Differences** by **LauraH** on Jul 12, 2005

As a parent of a child who is non-speaking and at this point, doesn't sign much, I want to say I appreciate these considerations. I wish more teachers would think about these things--reasons why students with disabilities don't comply in some areas. I am hoping to learn about AT so that I can talk with my daughter's speech therapist and special ed teacher about trying some kind of device. There doesn't seem to be much support from the local (public) school in this area.

Laura H, parent

- **Re: Generational Differences** by **Kim T.** on Jul 11, 2005

I agree. We have an evaluation center and find that the more members of the team that we can get on the same page, the better. So many times our evaluation time is really the first time that all of the professionals working with a student or individual get together to solely discuss how technology will be implemented.

As to the "cool" factor, we have on many occasions hit that barrier up front. One individual that we worked with had a rare genetic disorder and had lost the ability to speak. He was 21 years old and was able (for the first time during our evaluation) to type that he thought many of the devices that he had used in the past and indeed some that we presented were "not cool!" so he had no desire to use them.

- **Re: Generational Differences** by **Joan Breslin-Larson [SI Faculty]** on Jul 11, 2005

What strategies have worked when a student will not use certain technology? Sometimes you KNOW something is just the right thing, and when the student refuses, it is frustrating.

How have people coped- either parents or professionals? Any good strategies or suggestions?

Joan Breslin Larson

Summer Institute Faculty

- **Re: Generational Differences** by **Maury E.** on Jul 12, 2005
This is my question as well - I have a student with a hearing impairment (age14) but refuses to wear his hearing aids because they are not cool.

Any suggestions?

Maury E.

- **Re: Generational Differences** by **Phil Parette [SI Faculty]** on Jul 12, 2005
M:

My question would be what is it about the hearing aids that are not 'cool'? Do they stand out and draw attention to the child's hearing impairment? We know that there are many devices that are quite small and don't attract much attention. However, I see kids all the time with earplugs walking around listening to music, so the idea of having an earpiece is not the real issue. The issue may be that undue attention is drawn to the disability...any suggestions from our participants on how to minimize the visibility of the disability in this case?
- **Re: Generational Differences** by **kostie** on Jul 12, 2005
Will the teacher use an amplifier? The class that I work in also uses a microphone that the students use or go to when they have a question and it is passed around during discussions- all of the students benefit from this technology.
- **Knowing the right thing** by **Phil Parette [SI Faculty]** on Jul 12, 2005
I would suggest that many times when we think we 'know' what a student needs, and there is a failure to use/accept the AT solution, the dissonance is a function of our inclination to impose a culturally based value on the child (i.e., our perception of what someone else needs without considering the full array of background variables that might influence the child's response to the recommended solution). I don't say this in a negative way, but it could be that there are subtle, yet powerful values and experiences that lie in the background that would contribute to the non-acceptance of the AT. For example, we might readily choose a particular AAC device with the idea that the child would use the device at home, and assume that family members should be willing to implement the device and be glad that the child could have something to help him or her communicate

with others. However, if the child comes from a particular cultural background in which family members rely on one another for support, live with one another across the lifespan, interpret the child's communication efforts (and thus don't require 'words' from the child), and independence is not emphasized, there might be less value placed on this AT solution and the team recommendation for home implementation.

- **Re: Knowing the right thing by Kim T.** on Jul 12, 2005
I agree! We have run into many situations where teams have a set idea in their head but are running into barriers into implementation. Often the barrier is a cultural issue. For example, one adult needed a static picture based system and the residential staff had borrowed a Tech Talk from the local lending library. The therapy staff did not realize that the residential staff did not like to change the overlays and did not make use of the levels on the device. So we went back to the drawing board and found a system that will automatically change levels based on barcode reading. The residential staff was accepting of that and now the device is being used!
 - **Re: Knowing the right thing by Phil Parette [SI Faculty]** on Jul 12, 2005
Cool! This is an excellent example of acculturation, or adaptation to the values of a particular group of individuals who may be using devices. Since we each have different experiences with technology, coupled with varying perceptions, such minor changes are often all that is needed to have a different group of persons become accepting of AT solutions.
- **Re: Knowing the right thing by kostie** on Jul 12, 2005
I have found the family and choice to be integral parts in the decision making process- in one case the student would have benefited greatly from using an Alphasmart (which others in his class were using) but vehemently refused- so we gave his mother pictures and information on other note takers and he was able to chose one that he was willing to try- the family will all be practicing with it the summer- in another case I was sure that my student would benefit from using a Dynamyte- so we brought the vendor and family in and looked at a bunch of options- ultimately the family was too uncomfortable with the idea of using equipment- it is very disappointing but I keep trying to introduce assistive

technology through software and picture symbols- it's all we can do within their comfort level.

- **Different strokes by Phil Parette [SI Faculty]** on Jul 13, 2005
You know, the whole concept of acculturation suggests that each of us can have different responses to cultural forces at any moment in time. We may choose to accept totally the 'sell' being made (and thus the values/preferences of others, i.e., assimilation). We may choose to maintain some of our values/experiences/preferences while accepting some of what is 'sold' to us (use the computer for games because typical peers do, but choose not to use it for writing since handwriting is deemed important by the family). We may choose to have a very low level of interaction with the dominant culture while clinging strongly to the cultural value system of the family/ethnic group (e.g., ignoring impetus of school personnel to encourage independence using AT when dependence [and interconnectedness] is a strongly held cultural value of the family, i.e., separation). Finally, we might simply be marginalized and ignored because our values are so different from that of the prevailing school culture and professionals in that culture.

- **Re: Different strokes by Joan Breslin-Larson [SI Faculty]** on Jul 13, 2005
Phil-
Your posting has made me think that the process of acculturation resembles a dance- moving forward a little, moving back a little, some side steps, and more that one person balancing their actions based on another. It isn't always pretty while we learn the steps, but the end product can be outstanding!
Some stories about my experiences with new cultures...
I remember one family with whom I worked several years ago. They were new to the US, and were (in my mind) curt and short with me. I was getting pretty discouraged since I clearly wasn't making my usual connection with the family. An advocate from a support agency called me, and indicated that the family was aware that I was becoming uncomfortable. They were concerned that I would not work with them anymore. The advocate told me that due to the culture from which this

family came, there was no word for "thank you" and so what I regarded as rudeness was simply the family being themselves. The advocate and I talked strategy, and both the family and I modified our behavior a little. The combination of understanding a behavior change made a big difference, and the family and I could connect and develop a workable plan for the student with whom I was concerned.

Second story-

I was working with refugees from a southeast Asian country. One individual had held a position with great responsibility and respect in his country before he was forced to flee. After we worked together a few weeks, he told me "You are so smart. If you were a man, you could be very important." I took it to be the compliment it was intended to be.

I think the point of my morning ramblings is that we must be aware, when working with people from varying backgrounds, that to make things work, sometimes we have to dance- and that learning the dance for both participants might be hard, might take some work, but the end result will be worth it.

Joan Breslin Larson
Summer Institute Faculty

- **Re: Different strokes by Phil Parette [SI Faculty]** on Jul 13, 2005
Joan:

Nice imagery--let's use this expression more! A dance is certainly a fine way to envision the acculturation process. I know I take a step forward when learning about some new technologies, and then take steps back when values/circumstances/resources and other factors come into play. Children and families have their own unique dance steps that are often different from we professionals. Ideally we would like everyone to look like a chorus line on Broadway, but even

with well-synchronized dances there are slight variations among the dancers.

- **Re: Generational Differences** by **bfujinuma@renewalunlimited.net** on Jul 13, 2005
In a middle school one thing that I did with a non-verbal student who had friend she liked to be with, we asked their opinion also on what they thought would be "cool". This is the short version, but it helped and we got her a smaller purple switch and even though it was harder for her to make contact with physically, she did so more accurately because her friends thought it was "cool".

Beth

- **The cool factor and how to consider** by **Phil Parette [SI Faculty]** on Jul 12, 2005
So what is it that we as education professionals need to consider if, in fact, students with whom we are working are very aware of an array of technologies that others are using (through observation, TV, and other sources), yet we don't even understand what typical peers are using on a daily basis and how their learning approaches are different. For example, all of us are aware of students (who are Millennials) that multitask. Our faculty colleague, George Peterson-Karlan, shared a story with me a while back about watching his son in his room one day after school. While the music was playing and TV show blaring, he was working in Microsoft Word on a paper, instant messaging, Googling, and interacting on his cell phone. I see this kind of behavior in the college classroom quite routinely when we are in a computer lab--multiple technologies are being used simultaneously to be 'connected' and learn. This is a very different learning style from what Baby Boomers and Gen Xers may have been accustomed to, and my question is whether or not we really understand these generational differences and the effects they have on students (and education professionals). Do we really understand students' desires for technology, and what's cool? Or do we continue to rely on our professional judgments that are based on unique experiences, values, etc. that may be markedly different from what our students bring to the classroom?
- **Re: The cool factor and how to consider** by **Alana Collins** on Jul 12, 2005
What is cool changes so rapidly, I am not sure us baby boomers can keep up with what's cool. My son can do some things on the computers I am still wondering what is was he did but when required to something using a tool that would help him "no way" and that's where I think values and "buy in" come in play.

- **Re: Generational Differences by Phil Parette [SI Faculty]** on Jul 12, 2005
Student preferences are indeed important, and all too often little consideration is given to student learning styles, likes/dislikes, etc. before decisions are made Re: AT. One of the participants indicated the importance of 'selling' the student on the need for AT. This notion of 'selling' gets into the realm of acculturation--that is, influences that we are all exposed to over time that affect our values, preferences, and view of the world. Some people don't want to be sold, just as we tune out on telemarketers and door-to-door salespersons (whoops, showing my generation upbringing now), or discard promotional materials (either on email or paper format). I think that often our students are the same way. They may or may not respond to our 'sell' if what we're selling does not meet their needs and preferences at a particular moment in time.
 - **Re: Generational Differences by Janet Peters [SI Faculty]** on Jul 12, 2005
Some extremely good points have been made in this discussion and ring true when we look at the abandonment issues of assistive technology. What are the practical strategies for getting the student feedback. The cool factor is one point, an understanding family and cultural values certainly is key, but assistive technology is not in a vacuum. The point being AT can help accomplish a task, and thoughts about that task can be as influential as whatever AT is tried.
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- **Working with Students and Families from Diverse Backgrounds by Phil Parette, SI Faculty** on Jul 11, 2005
One of the biggest challenges for education professionals currently is to best understand the perspectives of multiple stakeholders in AT decision-making processes. For some years we have systematically examined the varying perspectives of families and education professionals, and the array of variables that should ideally be 'considered' in AT decision-making is daunting. However, ultimately for each of us involved in team decision-making it comes down to a relatively simple question: At a particular moment in time when I am considering a child's needs for AT, what factors might affect the decision that I (and others) make about AT solutions for the child?

We acknowledge that AT must be considered (as mandated by IDEA '97), though we all too often move this process placing primary emphasis on our 'expertise' as professionals, or the expertise of one or others on the team, while failing to consider a multiplicity of vary important variables that may influence the success (or failure) of any AT solution. How many of us really think about the child's 'preferences' for technology in the context of what typical peers like and use? How often do we really attempt to understand the family's comfort with and preferences for technology, and the resulting responsibilities that they may have in implementing a solution that is agreed upon by

the team? These and many other questions hopefully will be explored in our discussion in the days ahead.

- **Re: Working with Students and Families from Diverse Backgrounds** by Janet Peters [SI Faculty] on Jul 13, 2005

These are thoughts on this topic from the American Indian Project Coordinator here at PACER.

I am not sure if this will help but one of the issues I see in my community is that many of my families don't have access to computers, in large part due to income barriers. Many don't even know what "e-mail" is. I do realize that AT goes beyond just computers. I would also be concerned about how much support the student (s) would be getting from home. I find in many cases that the parent is real passive, at times not even involved.

I think it is very important to understand a person for who they are and how they identify. I have had many people ask me if I am American Indian or Native American. I simply reply that I am Indian. However, some people take offense to being called one or the other. Another concern that I would have in the Indian community is that you have to build a rapport with the person and/or family. This does not come easily because there is a lack of trust when it comes to dealing with professionals. And then there is the issue of parents needing their info given to them in a manner they can understand, we are a community that does not necessarily have a paper trail of our history- that is what we have elders for. They share with us, orally, what our history is and who our families are. I had an experience in college where we were given a paper to write on Leonard Peltier, a political prisoner. There was a guy that came to class and was very belligerent saying that "Indians don't have no history". After about 5 min., I raised my hand and explained as I just did to you, that we are oral people. We had a nasty exchange and I then produced some of the articles that I found on Leonard by visiting some of the metro area Indian organizations.

I have many parents share with me, after a rapport is established, that they cannot read and/or write. Being illiterate, how would you help your child with home work?
Let me know if you have other questions.

Lucy

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- **What is culture?** by **Phil Parette [SI Faculty]** on Jul 12, 2005

We seem to have waded into discussions of cultural issues without discussing exactly what culture is...I'd like to hear some of the perspectives of our participants--if someone asked you on the street to define 'culture' what would your response be?

- **Re: What is culture?** by **Jackie Hess, SI faculty** on Jul 12, 2005

Although I won't try to answer your question directly, Phil, I'd like to contribute some thoughts on working with people from other cultures.

Much of the work we all do with respect to AT involves information - looking for it, finding it, reading or listening to it, integrating it into both general and specific contexts. When we work with people from other cultures, their approach to information is often different and can be frustrating to us. A few things I try to keep in mind are:

(1) Public libraries are rather unique to the continents of North America and Europe. In much of the world, public libraries do not exist. The majority of public schools in those countries do not have libraries either. This greatly influences the way in which people view information and its acquisition. They bring those attitudes about the availability of public information to the U.S. when they come here.

(2) The majority of people in the world do not have access to the Internet. Even those who do, see it primarily as a means of communicating with distant friends and relatives, not as a source of information. Those who do look for information on the Web find that 95% of it is in English.

(3) People are not born knowing how to process written information. I'm not talking about reading. One has to be taught how to identify source bias; to distinguish between fact and marketing claims; to recognize

unstated assumptions that may make the information irrelevant to your particular situation; to extrapolate from general claims to specific applications; and on and on.

(4) The elite in other cultures treat information as a valuable commodity, and often prefer to hoard it rather than share it widely as we do as a matter of course in this country.

What I've found in working with non-Anglo families is that their styles of dealing with information are greatly influenced by these things. Whenever possible they will prefer getting information orally, rather than being handed paper. They'll value the information if they respect the person from whom it's coming. Unfortunately we tend to be a society of paper-based information. In the school with which I work most closely, we're trying to set up "human information pyramids and chains" to break the reliance on forms, reports, advertisements that only go to parents on paper and usually only in English.

- **Re: What is culture?** by **Phil Parette [SI Faculty]** on Jul 13, 2005

J:

I agree wholeheartedly to each of the points noted above. Your observations are certainly valid in discussing the 'culture' of individuals from non-white backgrounds. If we move beyond ethnicity, or various racial groups, however, I was curious how our participants define culture in a broader context?

- **But what is culture--still not defined!** by **Phil Parette [SI Faculty]** on Jul 13, 2005
OK, we still haven't had folks wade and define culture. I suspect there are many differing views. Focusing on the definition of the word culture is a useful starting point. Unfortunately for professionals working with students with disabilities and their families, there is wide variability in the definition of culture. For example, an early work by Kroeber and Kluckhohn (1952) identified more than 200 definitions of culture. Culture has been broadly defined as a common set of beliefs, values, behaviors, and communication patterns that are shared by a particular group of people and learned as a function of social membership. It has also been described as a lens through which individuals see themselves in relation to others and the world. One author has noted that whenever we are talking about culture, it involves 3 components: 1. what people think, 2. what people do, and 3. what people produce.

So the question is, how does such a broad definition affect your thinking about culture when it is used in conversation, and more importantly, when you are working w/ families and children with disabilities?

- **Re: But what is culture--still not defined!** by **Linda** on Jul 14, 2005
 That broad definition, " a common set of beliefs, values, behaviors, and communication patterns that are shared by a particular group of people and learned as a function of social membership," really struck me with the fact that ALL of us belong to several "cultures" then, don't we? The operative word here, to me, is 'learned.' It takes time, but is so worth doing, to learn (and respect) any given culture's parameters. Too bad that the only thing we all seem to have less of than money is time!

- **Re: But what is culture--still not defined!** by **Phil Parette [SI Faculty]** on Jul 14, 2005
 Yep, we indeed belong to many cultural groups, or microcultures within the broader 'macroculture'. For example, in the US we might all agree that there are certain values/concepts that are reflective of being an American. These might include individual rights/freedoms, productivity, democracy, etc. (I know there might be issue taken with these by many, though there are core values held by most). Once we move away from these core values, we start seeing marked differences along urban/rural, socioeconomic, linguistic, ethnic, experiential, religious, gender, and other features that define microcultures. And then within these microcultures we begin to see differences. For example, a group of female individuals within a small rural community may share similar values related to regional influences (i.e., they grew up in a small town and were influenced markedly by those experiences) but differ because one person has traveled more (and thus been exposed to many other ways of life), another has more financial resources (because the family has done well), while another has had a child with a disability for many years and has had to be an advocate for the child with many agencies/groups over time. The point is that culture is very complex, and even when we feel that we have a lot in common with any group of individuals, we may have far less in common along other important background variables that may come into play at certain points in time across the lifespan.

- **Re: What is culture?** by **lesleydianet@gmail.com** on Jul 13, 2005
 I think about this question all the time. I'm a grad student from a small rural community that might as well be a million miles away from the suburban world that most of my college students know.

Attitudes on disability are very different in the culture I grew up in. Anyone with a learning or behavior disorder simply needed to get over it, apply themselves, maybe learn some discipline; nothing is to be expected or demanded of a child with severe disabilities because she/he is "a child of god" and it's cruel to push them. Why potty train a sixth grader that will probably live in a group home anyway?

As a teacher's aide, I'll never forget the frustration and absolute rancor in the voices of the middle school teachers when I would eat lunch with them. They weren't discussing "their kids." They were discussing "our kids", the included ones, and were frustrated and exasperated that they would even be asked to deal with the paperwork and the hassle of inclusion. They had heard everything there was to hear about ADD and weren't buying it -- Steven just had to learn to stay in his seat and that was it. Doctors in the town that were known for treating children with ADD or behavior disorders were spoken about with scorn and called "crack dealers." It was a sobering reminder to me that attitudes in educational theory might have changed, but the people in the trenches are very much products of the local environment, which was dismissive.

I'm happy to say that things in that school are getting a little better since I've left.

But it really reminds me that before technology, before diagnoses, people took it upon themselves as a community to make sure a kid who was having trouble would succeed by pushing him extra hard and making him work (thus instilling structure). They feel that they are no longer allowed to do that and are angry at what they see as a culture that is too accommodating. Their discontent was rooted in the idea that after years of teaching, they were being told that their ideas didn't matter or weren't worthwhile.

I don't agree with their attitudes, but I realize they came from a very valid place.

- **Re: What is culture?** by **Phil Parette [SI Faculty]** on Jul 13, 2005
Wow! This is a great story and clearly illustrates the variations that we see even within a white culture Re: perception of disability. More often than not many individuals in this cultural group see disability as something that is 'fixable' or 'treatable'. We go to the doctor and get some pills; we fix the problem. Or we go to a surgeon and get the problem removed. Other cultural groups see disability in very different ways as we realize. Some families will see disability as a result of divine intervention, or a gift from the divine. Others will see the child with a disability as punishment for the sins/misgivings of

ancestors. The point is that these strongly held values will affect the way that the family raises a child, their expectations for that child, as well as their expectations of the education system in working with the child.

And who are we to judge them? As the case above illustrates, the position of these persons is valid to them, but given that the experiences and perceptions of others are different, the validity may be questionable.

- **Re: What is culture?** by **bfujinuma@renewalunlimited.net** on Jul 13, 2005
These have been some great comments on culture. I was so glad to hear people comment on culture differences that do not have to do with differences in race. We need to remember this is true in all races. Culture has many many factors to be considered. Rural/ urban, low-income/ high income, a high degree of education/ a more basic education, the list goes on and on. I am amazed at what I learn each day in my own intercultural marriage. Not only are we from different parts of the world, we are from very different socio- economic backgrounds as well. As we talk about issues in the field of disabilities it is very enlightening and makes both of us really think and be better at all of our relationships. I am now so much more aware of what and how I communicate things to anyone I come in contact with and have seen much more openness with the families that I work with.
- **Re: What is culture?** by **Jackie Hess, SI faculty** on Jul 14, 2005
As we've all acknowledged, we have to remain ever aware of our own assumptions re: other cultures. So much of our work with children with disabilities involves expectations - ours of them, their family's of them, and their expectations of themselves. In the television production, Freedom Machines (in which the Alliance for Technology Access was heavily involved), we meet an incredible African-American teenage girl named Latoya Nesmith. Latoya is from a single-parent home with limited financial resources. She has very significant physical disabilities. Most people, seeing her for the first time, would hardly expect her to have the following goals (as she expressed them in the program):

"I would like to do something with language, like translating songs into all different languages. I want to come up with a Polish opera. They have Italian opera, and French opera. I want to see if I could pull off a Dutch or Polish or something other

than romance languages because the Slovak languages are nice too."

Latoya is a remarkable young woman who, by the way, is still struggling to receive appropriate assistive technology from her school system. My money is on her, though.

- **Re: What is culture?** by **Phil Parette [SI Faculty]** on Jul 14, 2005
This is a great example of substantive cultural differences that mesh the culture of disability, people's perceptions of disability, and the values of the community in which this young woman lives. Latoya has goals and aspirations that are not in synch with the expectations of others which can present great challenges. We can all hope that the values and expectations of those whose lives Latoya has touched will be modified, and the necessary supports provided to help her become all that she can be...we all benefit whenever this can be accomplished.

-
- **Knowing the Right Thing - The "Cool" Factor** by **brendascott** on Jul 12, 2005
This is an interesting and important area to consider with AT and students. I believe one of the courses I took called it "cosmesis" (stemming from cosmetics) and it has to do with the student's perception about the appearance of a device or technology that they are using. If they don't buy into it from the appearance sake, they won't use it. The other issue I face constantly is the "high tech is the best tech" one. Many times a teacher or parent will tell me that they have seen voice recognition demonstrated on a notebook computer and that is what will fix their child's disability. It helps that I am a voice reco. user, so I am very familiar with the technology and have it readily available to try. In one case, against my own initial judgment, I actually consented to a trial period, trained the student for 8 sessions, after which he realized how hard it would be for him to do it, and then he decided he wanted to quit. But this was a necessary (and good) learning experience for him and he's now happier using much less sophisticated technology!
 - **School culture--a disconnect?** by **Phil Parette [SI Faculty]** on Jul 12, 2005
It would be interesting to know how many others try things out for a while to see if they will work prior to purchase...while this is described in the literature as 'best practice' we all recognize the constraints of time that education professionals must contend with each and every day. This is a function of the school culture. There is a cost associated with trying things out, as well as a cost associated with abandonment if AT doesn't

work out.

But the example shared above is a good one--it illustrates a disconnect between the world outside of the school culture and that of the culture of many work settings. Voice recognition is often used in the workplace, along with an array of technology tools that are not frequently promoted in school settings (often because of costs associated with their purchase, training, and support). So we are faced with a dilemma of trying to sell the AT, as was mentioned earlier, because we KNOW certain tools are important in the work world, or valuing and giving great credence to the preferences of students and families for lower tech solutions that are easier. As a result we may see children sometimes being grossly unprepared to be productive when they attempt to enter the world of work.

- **Re: School culture--a disconnect?** by lesleydianet@gmail.com on Jul 14, 2005
Currently, I don't work in the school environment; I'm a direct care provider on weekends and after my classes. I work with a wonderful 20 year old learning to live independently. Her right arm is paralyzed so as a result, her writing is slow and shaky. One of her independent living goals is learning how to balance her check book and write checks. Standing in line at Wal-mart while everyone is waiting on her to do a check is so nerve-wracking for her -- she does it but is almost in tears and is shaking afterwards. She also stands there and records the check in her register.

I have suggested that she buy checks with the duplicates attached and then record the purchase immediately after, or, better yet, give her a debit card. At the very least, she could use an ATM card and pay with cash if they are afraid a debit would be "too easy" and not visual enough. Most adults hate writing checks too. I've also suggested some bookkeeping software. However, her parents and my boss are against the idea because they are afraid she'll lose the ability to write and record checks.

I don't understand why we make things harder for the very people that technology could help. We use the same bank and I know for a fact that it offers online account access and bill pay. She might never have to write a check again. Or she might be able to get check printing software for bills and only have to write checks at places that don't accept debit.

I think it might be a generation gap. I think her parents and my boss aren't really comfortable with banking online. But I can't help but think how much more confident she would feel if she didn't have everyone looking at her as she struggles with her checkbook. (Try to tear a check one-handed and

you'll see how hard it is).

Has anyone run into this where people with disabilities are denied access to technology the rest of us use every day? The above comment about workplace technology made me think of this girl and her struggles.

- **Re: School culture--a disconnect?** by **Phil Parette [SI Faculty]** on Jul 15, 2005
This is indeed a generational and acculturation issue--it is generational in that there are many of us Baby Boomers (and perhaps some Gen Xers) who are more resistive to using technology. I run into people who simply refuse to use a computer as they've always done things using pencil and paper and got along just fine. I've also met many from these generations who are quite adept at trying and using all the latest gadgets. It seems to me that this again focuses on the issue of us understanding students who are Millennials (born since 1978-82), and their technology preferences and use patterns. But it may be that the key question that should be asked is what is the outcome that we are concerned about for the student? If the outcome is to use a checking account, a debit card seems far more appropriate to me (I write a check only 2-3 times a year now) coupled with on-line banking. If the issue is computation of mathematical facts, technology is available to assist the student do this. However, if the outcome is handwriting, this becomes a different issue--but we have to ask why handwriting is deemed so important any more. Most of us use a word processor in lieu of writing things in longhand. We can use a recorder to take dictation, or use voice recognition technology (they do in business settings). So I agree with you wholeheartedly that this is a cultural issue reflecting a value placed on handwriting by persons for whom this was important in their lives, and feel that it should be important for all others as well. The reality is that WRITING is important, and can be accomplished without use of traditional handwriting. This is an issue that I think is being addressed in the other strand re: AT and mild disabilities.

Thanks for this observation.

- **Re: School culture--a disconnect?** by **Lesley T** on Jul 17, 2005
Thanks :)

I am having trouble finding the thread that you refer to.

(and I am pleased that I am almost a Millennial, but not quite. I had never heard the

term before).

I think the people in charge of this girl's goals simply are afraid that things will become less concrete for her if we "make it too easy to spend money." However, right now, checkbook management is a huge obstacle to her independence because she hates the time it takes to balance the checkbook. (those spaces on the register are TINY).

- **Re: School culture--a disconnect?** by **Alana Collins** on Jul 18, 2005
Isn't there an electronic checkbook that is the size of a checkbook that does all the functions of a checkbook and you carry with your checkbook-checks. So when you need to write a check instead of using the paper register you do it electronically.
 - **Re: School culture--a disconnect?** by **Lesley T.** on Jul 18, 2005
oooooh.... I'd like to look at that!
- **Re: School culture--a disconnect?** by **Joan Breslin-Larson [SI Faculty]** on Jul 18, 2005
I personally agree with the thread that seems to indicate that perhaps access to using new, more efficient ways to manage money are worth investigating. However, let's also look at the low tech solution to check book registers being hard to handle. I googled large print check register and came up with several commercially made registers, made for persons with low vision.
Joan Breslin Larson
Summer Institute Faculty
 - **Re: School culture--a disconnect?** by **Lesley T.** on Jul 18, 2005
I had been trying to make a register on my computer that would be letter-sized and fit in a binder. I'll google large print registers.

I guess I was using this client as an example that although many professionals in the field are drawn to the "high tech is the best" way of thinking, where I've lived (South and Midwest) the opposite is true -- people are so tired of abandoned solutions or so scared that they might have to pay for it that they resist experimenting.

- **Re: Knowing the Right Thing - The** by **Alana Collins** on Jul 12, 2005
Thank you for your post I think you stated the right word TRIAL PERIOD with the availability for so many different devices and programs and then the diversity of "abilities" no one thing fits all and we need to have devices and companies willing to let there be Trial periods. And for some trial periods will be months but usually only thirty days is given.
 - **Re: Knowing the Right Thing - The** by **Kim T.** on Jul 12, 2005
Here in NY, many times insurance will require a "rental" period of devices. We recommend this all the time. The other option we have to take advantage of is the TRAIID lending library. This is a technology lending library where people can actually check out equipment before purchasing.

When doing an evaluation, we will present many, many options and discuss the pros and cons of each. I agree that the first solution seems to always be high tech (and yes, everyone thinks that voice input is the solution!) We also will do an intro to the software and have people see how it works. But we also discuss its shortcomings- the time to train, the environmental constraints, etc.
 - **Re: Knowing the Right Thing - The** by **faith** on Jul 12, 2005
I think that the team needs to make the best use of the 30 days that is given. I think that actually would be enough time to decide (in most cases)if the family and student want to use this device or not. It does not mean that the student needs to acquire a particular level of expertise in the 30 days to make a decision to go with it or move onto another option. The team just needs to make a decision about moving on with that particular device or method etc.
 - **Re: Knowing the Right Thing - Cultural reciprocity** by **Phil Parette [SI Faculty]** on Jul 13, 2005
I totally agree that a decision should be made. But I would add the caveat that a decision should be meaningfully made, i.e., it is thoughtful and sensitive to the values of all stakeholders. Maya Kalyanpur and Beth Harry advocate the use of 'cultural reciprocity' in team decision-making, and we have advanced this approach for AT decision-making. Basically, it is a 4-step process:

Step 1. Identify the cultural values reflected in the education professional's interpretation of the family and/or student's needs or in the recommendation for service. This step essentially requires the professional to ask "why" a specific perception is held. For example, an Hispanic student with a developmental disability acts out when competitive classroom activities are conducted that pit students against one another. Despite discussions about the importance of individual excellence and achievement in the classroom, the student displays a perceived inability or unwillingness to participate in such activities. At this point, the professional should ask him/herself why 'competitiveness' is deemed important. If the professional is from a white cultural background, the perception may simply be that this is a strongly held value in the mainstream and necessary for success in the workplace.

Step 2. Determine whether the family recognizes and values these assumptions, and if not, how their perception differs from that of the education professional. In this second step, the family is approached and the professional presents his or her perception of the "issue" to the family. This can become problematic in working with some families given the need for an interpreter for interactions with school personnel to occur. When interpreters are used, some families are uncomfortable discussing family matters in the presence of others. They may also feel that probing questions from professionals are intrusive. Once appropriate contact is made with the family, the professionally held perception should be presented in a culturally sensitive way to the family for their consideration and response. In this example, the family may reveal that they see nothing wrong with the child's behaviors and that cooperative activities (vs. competitive) in the family and other settings is typical.

Step 3. Acknowledge and provide specific respect to any cultural differences identified, and fully explain the cultural basis of the education professional's assumptions. In this step, the professionals should explain to the family their assumptions and beliefs and how they are different. In the previous example, the education professional would clarify that competition is important for some learning tasks and activities to provide the practitioner with a means of evaluating the student's progress. Further, the professional would note that failure to demonstrate a willingness to compete with others communicates disrespect for the structure of the classroom and wisdom of the teacher. The professional must also acknowledge that the family feels that (a) competitiveness is not emphasized in their family setting, and that (b) cooperation with others is deemed to be an important way of learning and achieving targeted goals.

Step 4. Determine the most effective way to adapt education professional interpretations or recommendations to the value system of the family.

- **Re: Knowing the Right Thing - The** by **Phil Parette [SI Faculty]** on Jul 13, 2005
But how does this team come to understand what cultural values may be interacting in this decision-making process? Are there questions posed to the family to probe their preferences/values? Is the child interviewed to understand how s/he uses technology in the home? Does the team understand what technologies are available in the home?
 - **Re: Knowing the Right Thing - The** by **Kim T.** on Jul 14, 2005
Our team actually uses quite a lengthy process beginning at the first phone call made to the agency. Our intake coordinator begins with the precursory questions. We get records from all the professionals that we can and then we make a phone call before the family/child arrives. Once there, we further clarify all of the factors in their life (some are obvious, some we stumble upon.) Really, we feel the more stakeholders that are involved, the more buy in we get for what technology we are recommending. Questions revolve around use in home, school, community, leisure interests, health concern etc, and branch to more specific from there.

What are any other AT teams using?

- **Re: Knowing the Right Thing - The** by **Kelly C** on Jul 13, 2005
A student's perception of a device is a CRITICAL component to consider when determining assistive technology. I have had students flat out refuse to use a device because of the way it looked. I, personally, feel it is important to support their decision, while continuing to explain the benefits of the tool. In many cases, AT tools can be manipulated to look more mainstreamed (i.e. removing the picture toolbar from Write:OutLoud to have it more Word-like in appearance). These minor adjustments can make all the difference. With regard to the "high tech is the best tech" issue, I think that is one we all face. Parents today have access to the Internet and many come to the table with a preconceived idea of what their child needs. This is not necessarily a bad thing...I just like to remind parents that they don't get ALL the information online and the practical application of "high tech stuff" can be difficult. Overall, I agree that most teams agree that a trial period, with a careful collection of objective data, can help make AT decisions easier.

- **Re: Knowing the Right Thing - The** by **Phil Parette [SI Faculty]** on Jul 13, 2005
I agree that the preconceived ideas provide a starting place for discussions with the family, and helping them to understand our expectations of them (and their child) to effectively use the technology. Sometimes we fail to fully explain the implications of learning to use some devices, particularly those that require a lot of training and ongoing maintenance. So we have families that may expect an immediate 'fix' when their child gets a specific AT device (e.g., my child will be able to talk as soon as s/he gets an AAC device). When they are asked about their routines at home, and the team explores the available time and resources the family has to commit to training and maintenance, it may become apparent that this would not be a good solution.

- **Re: Knowing the Right Thing - The** by **Janet Peters [SI Faculty]** on Jul 13, 2005
These are some excellent points, I think in the excitement and hopefulness of "selling" the AT device to the family, we neglect the realities of implementation. Those realities have been systematic barriers because it most often takes the AT champion be that the family or professional to program, maintain, and repair the device if needed.

Some professionals I have worked with expect that level of involvement from the families, and that is most often when the device use is maximized, but how can we get that success without the family's "technical" involvement?

- **Re: Knowing the Right Thing - The** by **lesleydianet@gmail.com** on Jul 14, 2005
I stumble over this.
If a family knows that a certain gesture means "I want a cookie" it's much easier on a busy family to honor that gesture instead of making a kiddo go get the dynavox and ask it.

I've had a mom say to me "Suddenly, everything I did with my son had to be therapeutic after he was diagnosed. There are sometimes I just want to sit and enjoy being his mom."

- **Re: Knowing the Right Thing - The** by **Janet Peters [SI Faculty]** on Jul 18, 2005
I think there definitely needs to be respect for that family bonding and connection. I have also heard from adults with disabilities that they resented every vacation and spare moment with the family taken up by what they considered "therapeutic"

activities, so some down time is absolutely necessary for everyone to thrive.

That said, families can create supportive environments with (friends / neighbors) or others that might not understand the child's speech and gestures as well, and therefore they will "need" to communicate differently. It's especially motivating if it's peers that they want to talk with. A little pre-training with the peers will also go a long way to making these interactions meaningful.

- **A parent's perspective by Janet Peters [SI Faculty]** on Jul 13, 2005

From a parent I work with:

These comments are based on my personal experience as a parent who uses a "high end AAC device", and observations of my son's classmates and their families who also use AT – not a professional perspective. High end AAC devices can be challenging for even technically savvy parents as it takes a lot of time to learn, update and then maintain the equipment. What has worked relatively well for our family is the long term technical support we had from a single school district specialist in augmentative communication. The long term consistency of this professional support was key. This person provided support to us over the course of elementary school through high school. As my son matured and became more experienced with the device, he was able to take on some programming responsibilities himself. In addition, we have had consistent one-on-one support from a home health care nurse who was interested in and willing to take on some programming tasks. As many high-end AAC device users receive personal assistant services, that might be an option for some. The key was the consistency of the support we received, which I realize is not a typical experience.

Deborah

- **Re: A parent's perspective by Phil Parette [SI Faculty]** on Jul 14, 2005

Deborah...what a wonderful success story. Many times, as we are all aware, there is a lot of turnover on school decision-making teams and the team is constantly having to bring these new members up to speed w/

regard to the child's history/successes and other issues. This has been a major concern that we have heard from family members across cultural groups around the country. Parents want teams to know and understand their children, but this is difficult with ongoing turnover and you are indeed fortunate to have such an experience with a support person over time.

This is also a characteristic of school culture! Constant change (as a function of legislative mandates, personnel turnover, movement through the curriculum, lack of 'connectedness' among educators w/in the school community, etc.) is truly part of the school culture which may be at odds with the values of families who want stability and consistency across time.

- **Re: A parent's perspective** by lesleydianet@gmail.com on Jul 14, 2005
:)

The relationship between the 1-on-1 support person and the child is really a special one. I am here because I thought I'd take a job with a nonverbal child in the school setting "just for six months until I find something better." It changed my life! I've since moved, but that child and I are in close contact and my family stops by all the time to visit her.

Having worked in the trenches, I can tell you that many times, the school aides are being asked to do the work of a professional on a salary less than that a fast food worker. (I had 3 jobs -- not good when you need every bit of your patience to deal with a tantrum -- sometimes her tantrums, sometimes mine! :)) Right now, there is no SLP for the district -- only a speech pathology assistant that is doing all the work (so therefore, they won't hire a "real" SLP at SLP wages and he's too busy to finish his degree).

I am torn when I think of the job of support personnel because I loved my job so much and had such a good experience. But I also know that by being there, I enabled the other staff to continue their "hands-off" attitude. I would make sure that there is at least a few other staff members that are willing and able to program the device and get the training.

But really, there is no substitute for someone who knows the child. It's great that your child has that.
:)

- **Some resources by Joan Breslin-Larson [SI Faculty]** on Jul 13, 2005

I am sure there are some great resources developed by state Departments of Education, the federal Office and local districts. I am attaching a link to the Minnesota Department of Education, where there are many resources for culturally and linguistically diverse learners... http://education.state.mn.us/html/intro_speced_cultural.htm

Remember the IEP forms in particular are legal standard forms for Minnesota(not best practice forms- they hold the minimal information necessary, but new information can always be added. These may not meet the legal standard in another state.

Joan Breslin Larson

Summer Institute Faculty

- **Some resources by Phil Parette [SI Faculty]** on Jul 13, 2005

One of the nicest comprehensive resources that I have found that addresses a wide range of cultural issues and disability is at:

<http://www.ncddr.org/du/products/dddreview/toc.html>

While this was a 1999 publication, and thus more recent research and writings are not included, it provides a very nice guide for persons interested in understanding the array of issues that we confront in special education when working with students and families from varying cultural backgrounds.

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- **knowing the right thing** by **cjs** on Jul 13, 2005

We as AT specialists don't know the "right thing", but it is our job to listen to what they need. Our first priority should be to determine the client/family needs - And to determine a piece of equipment without visiting their environment is questionable. Sometimes we have to offer a piece of equipment that is less than what they need as a stepping stone for more. Or even more dramatic not offer them anything until they are ready.

- **knowing the right thing: funnel or sponge?** by **Phil Parette [SI Faculty]** on Jul 14, 2005

One of the characteristics of AT service delivery systems nationwide is that we rely on experts to 'funnel' information. Experts develop a knowledge base over time and across experiences, and schools (and other systems) depend on these experts who 'funnel' the information to their various constituencies. As a result, we don't develop the broad knowledge base within schools that we should ideally have. I think that we experts

perhaps should be 'sponges' and absorb as much information as we can, learn from these experiences, and then systematically squeeze as much of our knowledge out to our stakeholders as possible.

- **Re: knowing the right thing: funnel or sponge?** by **Joan Breslin-Larson [SI Faculty]** on Jul 18, 2005

Phil- Good imagery! I used to practice under the "funnel" model. It was a real boon for ego to be the person who knew everything, and decided who could get what information. Luckily, sooner rather than later, I realized how exhausting and fundamentally unfair that was.

We have been working in our state (Minnesota) to develop a broader based information sharing system. We have AT networks in each region of the state, some on the building and district level (although that is determined by the local decision makers and I can't mandate that...). Each network shares information on a regular basis with a statewide network. The state network, comprised of educators, advocates, representatives of state agencies with AT responsibilities, and related service providers, meets regularly to network plan and implement statewide initiatives, that the department of education supports. The network also provides input to the department of education through the AT specialist.

It is not a perfect model, but it does make for better communication. We learn about what is working in each region of the state, can problem solve with each other, and get lots of feedback and input from the multiple viewpoints.

The state network plans 2 large statewide conferences each year. Parents and advocates are included all activities. We try to cover at these conferences information on the law, devices and support strategies. We generally have at least one successful user of AT provide breakout sessions or a keynote session.

We began working this last year to recruit increased higher ed participation, to promote inclusion of AT more intensively into teacher preparation.

Our next big focus will be on getting "regular" technology staff to participate with us, and including more regular educators.

We are making, to get back to Phil's initial image, a bigger and better sponge.

Joan Breslin Larson

Summer Institute Faculty

- **Linguistic diversity** by **Phil Parette [SI Faculty]** on Jul 14, 2005

I think we have had a few allusions to linguistic diversity, but haven't really delved into this issue so that our participants understand the role this plays in AT service delivery. Let me get things started on this topic by simply suggesting that there are many different communication styles/patterns that we will encounter across differing families and groups that we work with. For example, some ethnic groups are 'high context' (i.e., they listen and observe and gain information from many sources in the environment) while others will come from 'low context' backgrounds (e.g., whites tend to rely on speech to get much of their information, and place less emphasis on body language and other environmental factors). Some persons prefer not to maintain eye contact in conversation as it communicates lack of respect. Others see lack of eye contact as not being attentive. Some people will nod as if in agreement (when they actually mean they disagree, though they wish to offer proper respect to the education professional).

In each of these instances, AT decision-making and relationships with families (and students) can be affected if folks are not sensitive to the nuances of communication styles. Can anyone share some experiences in which either failure to recognize (or success in being sensitive to) such variations had an impact on AT service delivery?

- **Re: Linguistic diversity** by **Lorianne** on Jul 15, 2005

I had a Hispanic student with multiple disabilities that I taught at home for many years. I loved and trusted this family and thought they felt the same way about me. I gave many hours of my life, and spent much of my own money on this child, to help the family meet her needs. They were illegal aliens, learning English and working many hours to make ends meet. Then one day, I said something about adapting a toy for the student. A few hours later I got a call from the school district. The parent asked that I never return. It turns out that she thought I wanted to adopt her child and take her away from them. I never saw my student again.

Lorianne

- **Re: Linguistic diversity** by **Phil Parette [SI Faculty]** on Jul 15, 2005

Whew! This is a powerful story that reflects the kinds of misunderstandings that can occur with oral communication with persons across ethnic groups. Not only did a miscommunication occur, but within Hispanic culture there is a 'machismo' value system that we see in many families, i.e., females are protected, and males may dominate.

Thanks for this sharing.

- **Re: Linguistic diversity by Jackie Hess, SI faculty** on Jul 15, 2005
Although we're labeling these comments "linguistic diversity," I suppose they might be considered "body language diversity based on cultural norms."

A few years ago, as a favor to a private school principal, I taught 3rd grade for 2 years. The class included a half dozen students with special needs; some of them came from Orthodox Jewish homes. When meeting with the parents to discuss AT services and devices, I was careful not to look directly at the fathers, as I knew that, because of religious proscriptions, they could not look directly at me. I believe that Orthodox Muslims have the same proscription. Although I felt uncomfortable avoiding eye contact, it was clearly the right thing to do and resulted in successful interactions.

In addition to observing the cultural norms of others, I think it's important that we try not to convey any negative judgments we may have about them. I spent two summers in Morocco training professors at teacher training colleges in technology integration. In each city, the hospitality was wonderful; we were frequently entertained in the homes of senior education officials. Unfortunately their wives were rarely included in the dinners for which they were responsible. I often asked to speak with the wives, who would make brief cameo appearances. They were usually articulate, educated women. I came to understand that this was a complex, highly nuanced culture and I had to tread carefully within it.

Whether U.S. culture is seen as a melting pot or a patchwork quilt, schools have always been the place of greatest cultural contact. People can segregate themselves in their neighborhoods, places of worship, and social gatherings, but teachers, students, school administrators and AT-related professionals will always lead the way in our efforts to live together respectfully and productively.

- **Re: Linguistic diversity by Kim T.** on Jul 15, 2005
This is an interesting topic and as I read the other stories, I realize the lack of opportunity that we have had as an department to serve culturally diverse populations. We are in a larger city, yet in over 6 years I can name a handful of individuals that we have seen for AT services that were from culturally diverse backgrounds. I guess that speaks volumes in and of itself!
 - **Re: Linguistic diversity by Phil Parette [SI Faculty]** on Jul 15, 2005
Kim, I think what lack of diversity in our community settings does is to solidify our own value systems and reinforce the tried and true ways of behaving around and interacting with others. But when we move outside of our comfort zone, it can be like running into a brick wall.

WEEK 2 THREADS

- **Family Supports and Abandonment** by **Phil Parette [SI Faculty]** on Jul 18, 2005
Different expectations that families may have of AT that must be carefully examined during team decision-making processes. These include the expectations that (a) the child will immediately be able to use the AT device, (b) the child's developmental status will change after implementing the device, (c) the child will have immediate and ongoing access to the device after it has been demonstrated and agreed upon that it is appropriate for the child, (d) the device will result in the child being viewed as being more like other children, (e) the device/service usage will lead to an ability to use other devices, and (f) usage of the device will result in greater acceptance by others in the community. In each of these instances, if appropriate supports (e.g., information, training) are not in place, abandonment of the AT device and disillusionment with the team may potentially result.

Do any of our discussants have other critical 'culturally-based' concerns that they feel strongly should be considered?

- **Re: Family Supports and Abandonment** by **Lesley T.** on Jul 18, 2005
In the post about questions to ask the family, you mentioned independence and daily activities. I think this is a huge variable depending on family and in some cases, culture. What exactly is expected of an individual? In my experience, (which I admit is limited) kids tend to rise or sink to the level of expectation placed on them.

Some families feel that any expectations at all of the child are too much and the success of the device, and really the child as well, rests firmly in the hands of professionals. If we are "doing our jobs" things will be fine.

Many of us here would hold to the idea that children with disabilities should be held appropriately accountable for decisions and behaviors as much as we believe they are capable of being accountable. If Tommy throws a tantrum instead of handing us the PEC that says "cookie", Tommy doesn't get the cookie. However, some parents would see that as being cruel. (there are moments I've wondered that too). As a result for what we sometimes see as too little accountability at home, sometimes professionals over-compensate and frustrate the child a little too much. It can be a really scary position to be in if we're not careful and very confusing for the child.

I think the questions you have posted are good ones. Constant communication (with all that spare time we have!) between the team and the family hopefully will help prevent the above situation. We were once shocked on Grandparent's Day to see the Grandma of one of our middle schoolers feeding her. Grandma did not know this child could eat on her own, and this child wasn't going to complain. Eating on her own was not a thing we had felt necessary to inform the family of because we assumed she did it at home as well. Clear communication on the child's abilities and expectations at home and at the school can hopefully help with AT use. If we're expecting Timmy to use his device independently at school, we should let home know. Maybe he's been independent at home for years, but is liking the assistance he gets at school.

- **Re: Family Supports and Abandonment by Phil Parette [SI Faculty]** on Jul 18, 2005
This comes back to the issue of cultural reciprocity, or bending of all parties toward an agreed upon solution. It will be difficult, or impossible, at times for families to accept the values that we place on independence of the child, especially when that independence carries a 'price' or responsibility that families may be unwilling to assume. Kalyanpur and Harry suggest a multi-phase process of reciprocity that seems to have great applicability to the decision-making process, while demonstrating an awareness of the cultural background variable that exist:

Consideration 1. Identify the perceptions and values underlying the education professional's interpretation of the family and/or student's needs or the recommendation for service.

Step 2. Determining the extent to which the family recognizes and values these assumptions, and if not, how their perception differs from that of the professional.

Step 3. Acknowledging and giving specific respect to any cultural differences identified, and fully explaining the cultural basis of the professional assumptions.

Step 4. Determining the most effective way to adapt professional interpretations or recommendations to the value system of the family.

- **Re: Family Supports and Abandonment by pccbar@hci.net** on Jul 19, 2005
These are terrific suggestions for being sure that there is a match between what professionals and families view as appropriate/successful. One of the problems I have seen way too many times is when teams frequently define family involvement in the assessment process is their presence in the room while the evaluation is going on. Our most successful evaluations have

occurred when the family is an integral member of the team, sharing opinions and questions and being the expert on their child as far as preferences and strengths. When the team makes the effort to be sure this happens, there is less opportunity for misunderstanding as to the purpose and outcome of the evaluation.

- **Re: Family Supports and Abandonment by Lesley T.** on Jul 21, 2005
I often see lines being drawn (being a paraprofessional and in home helper, I get to see both sides of the fence). There often is a "well, we can't do it if the family won't help" attitude on one side and a "they think they know everything" attitude on another side. Yet, neither side actually outlines the expectations of the other or actually says anything about their frustrations.

Clear expectations can work wonders. Asking the family "What exactly are your dreams for this child" as a starting point works wonders. Then, everything is on the table and we can figure out who is responsible for each part of the plan.

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- **Team questions for consideration by Phil Parette [SI Faculty]** on Jul 18, 2005
In working with families, teams should have a series of basic questions that may potentially be posed to families to facilitate information gathering and subsequent decision-making. Here are a few:

Question 1: What is the Family's Expectation for Child Independence?

Although continued dependence may be a preference for some families, many others will clearly be supportive of nurturing their children's independence.

Questions that team members should ask include the following:

- Will you use AT in community settings outside the home?
- What skills or commitment will be required of others in the community for your child to be able to successfully use the AT device?
- Do you want your child to perform routine daily tasks, or do you or other family members expect to do daily tasks for the child?

Question 2: To What Extent Does the Family Want the Child Accepted by Others?

Questions that team members should ask include the following:

- Are there reasons not to use the AT outside the home?

- Will AT make you or your child feel self-conscious or cause undue attention if used in public settings?
- How will people around you and your child feel if AT is used outside the home?

Question 3: What Are Family Expectations Regarding Immediacy of Benefits?

If family expectations are not considered and the device fails to live up to those expectations, the child and/or family may opt for abandonment of the device in family and community settings.

Questions that team members may ask during AT planning include the following:

- What do you think the AT device will do for your child?
- How will you and your child use the device?
- What benefits can you expect?
- Do you expect benefits to be immediate?
- What training will be needed?
- How will you pay for the device?
- How often will your child use the device?
- Will your child need assistance?
- Who will provide the assistance?

Question 4: What Are Family Resource Commitments to AT Implementation?

Questions that team members should ask include the following:

- Are there reasons why you wouldn't want to use the AT device at home or in the community?
- How do you think the AT device will affect your child with a disability?
- How do you think the AT device will affect your home environment?
- How do you think the AT device will affect your children?
- How do you think the AT device will affect your spouse?
- How do you think the AT device will affect other family members?

- **Re: Team questions for consideration by Lesley T.** on Jul 18, 2005

Wow. Good questions.

With ACC, I find the issues of convenience and maintenance to be the most daunting. Considering who is going to carry the dynavox and charge it up, or who is going to replace the PECS that get lost are huge issues that lead to abandonment.

I also would consider how will reward use of the device in areas where the child has already formed a pattern

of getting needs met. (either appropriately or inappropriately). If the child can get his/her needs met by other means in familiar settings but will need to device for non-familiar settings, will we try to encourage device use all the time, or simply out in the community?

- **Re: Team questions for consideration by Phil Parette [SI Faculty]** on Jul 18, 2005
We often hear from parents that transportation of devices across settings, as well as convenience (e.g., size, ease of use, low maintenance) to be critical factors affecting family acceptance of devices.

With regard to getting needs met, we sometimes assume that using the technology is a good and desired thing to do to realize an outcome. However, expediency, self-determination, and choice-making are important elements to consider with regard to the child. Would I expend far more effort in a process that takes a lot of time when the same outcome could be achieved in a fraction of the time? Should others dictate to me what choices I make (when there are consequences to any choice made)? I think we make value judgments about people that what is efficient (or a good choice) for one person may not be what is best for that individual. With regard to AAC I do think that we need to teach children to use devices (and strategies) in non-familiar settings with others, but they should also have the freedom (if preferred) to use other modes of communication in familiar settings.

- **Re: Team questions for consideration by Joan Breslin-Larson [SI Faculty]** on Jul 18, 2005
Phil-
I have been thinking about your questions all morning. What important issues you raise. And, what I have just realized is that there is no right answer- answers for my child or family will be very different than what is right for another's. Each family has a different dynamic in how they care for each other. When we begin factoring in the issues with how various cultures view supporting and including family members with disabilities, the number of right answers increases dramatically.
Another thought is that as important as helping teams to get answers to these questions, we also need to allow team members time to figure out what the implications for the use of AT in multiple settings might be. There may be a big difference between what happens at home vs. at school, or at Grandmom's or in the church- all of which may be of essential importance for a child.
I know this conversation is making me think very hard- and I wish someone would hand me an answer on a platter. But- obviously it all gets back to that ambiguous quote from Joy Zabala that I think I used last week-

"It all depends..." We just have to narrow down- for each individual child- what it all depends on!
Joan Breslin Larson
Summer Institute Faculty

- **Re: Team questions for consideration by marimoo** on Jul 21, 2005
As I read posts from last week and this (I have not read all of them), it seems like there is an assumption that cultural difference only refers to someone from a country other than the US or who does not have English as a 1st language.

I work in Virginia and there are vast differences between far SW and NoVA.

- **Re: Team questions for consideration by Linda** on Jul 19, 2005
Phil wrote: "In working with families, teams should have a series of basic questions that may potentially be posed to families to facilitate information gathering and subsequent decision-making." These are excellent questions!!! We always have the standard question, posed to all involved with the student: "What do you hope to see technology enable your child/student to accomplish?" However, we never really spend the time to delve into all of those essential aspects, and I think we should.
Also, it may go without saying, but I do believe in posing many of those questions to the child. We have noticed that sometimes parents are surprised at how their child perceives his/her disability and how technology might impact it. We need to begin instilling self-advocacy (and understanding) early on!
- **Self-perception by Phil Parette [SI Faculty]** on Jul 19, 2005
This area is still relatively misunderstood in education. While there is literature Re: the effects of stigma associated with a label of disability, we know little of what children think of themselves and "how technology might impact it." As was noted last week, we really don't fully understand a whole generation of children who have grown up in a world that, for many, has always had computers, VCRs, video games, and a wide array of technologies that have markedly influenced the ways in which they think, process information, and many other aspects of development. We see children multi-tasking and wondering how they can be involved in 5-6 activities simultaneously and be learning from the experiences. We do know that they are learning, though their understanding of relationships between things, and their expectations resulting from such experiences and learning patterns are quite different from those of their teachers. Point is, we have much work to do...and I still think there is a huge disconnect between what we are emphasizing in education currently and what is expected in the world of work.

- **Re: Self-perception** by **marimoo** on Jul 21, 2005
I agree that too much of what is taught and tested in school is not used in the "real world". How much algebra does an electrician need? How much geography does a carpenter need? I am reading Ready or Not Here Life Comes, and Dr. Levine makes a good argument for rethinking schools and parenting.

- **Re: Team questions for consideration** by **Kelly C** on Jul 19, 2005
I think Phil's list of questions should be addressed at every AT assessment! As an AT consultant, I perform assessments in the child's/adult's natural environment---often more than one environment. I am always amazed at the difference in needs! When addressing communication, it is especially important to assess not only the child, but their potential listeners. A group of 5-year-olds in a Kindergarten have different abilities to repair communication breakdowns than adults do. We need to be comprehensive in our assessment of the WHOLE child and ALL of their environments.

- **Re: Team questions for consideration** by **Kim T.** on Jul 19, 2005
I agree! One of the biggest issues that we find is that many children, in their changes of environment have many changes of positioning- which very often affects access. Direct access in a fully supported seated position is certainly different than in side lying or in a supine stander. Additionally, the issue of mounting a device securely is often not considered, and many wheelchairs do not have "neat" places for securing a device... especially one with some weight/size to it.

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- **Home teaches school to use AT** by **Jo** on Jul 19, 2005
I am an AT Specialist as a result of my disabled child. My views about AT have changed as my son has changed. I continue to grieve over the child I did not "get", but when I discovered AT, I became very excited about the chance for him to participate in all domains of life to his fullest extent. I WISH someone had come into my home to assess and tell me about all the alternatives available. I had to learn about communication devices and teach the school. I also had to learn about various AT that would allow him to complete his school work. I found the staff very reluctant to learn about AT. I received the standard rones; "we can understand him well enough" (that's usually what FAMILIES say!) or "we don't have time to learn how to use that" and "if we get it here, it cannot go home". So, I decided he would go to school, but use AT at home to complete his homework thereby demonstrating his capabilities. This intrigued the staff because it was non-confrontational. Unfortunately, even though the school did acquire many forms of AT for his use, there was no one to learn, teach and implement. I do not think this is uncommon. As he advanced in age, the school work just became too difficult for him cognitively. We gave up almost

entirely on him doing his work independently because it just took too long. We were both killing ourselves. So, we regressed to using me as the AT while he answered yes/no questions. He had demonstrated he could use AT, but reached the point where it was more of a hindrance than help. Now, we use the least amount of AT as possible. He is happier and so am I.

- **Home teaches school to use AT by Phil Parette [SI Faculty]** on Jul 19, 2005
This is an excellent example of the fact that AT can be both a blessing and a hindrance. If the implications are not fully explored with families (e.g., what will the school do? what will families need to do? what does child want? what does family want? what supports are in place to make family/child hopes/aspirations a reality? etc.) this outcome may be a reality for many families. Of course, we all experience these same kinds of decisions on a daily basis--we opt NOT to use technology either through lack of information, burdens imposed due to learning curve, cost, etc. and are more comfortable with low-tech or no-tech strategies to do things in the world around us.
 - **Re: Home teaches school to use AT by Shellie E** on Jul 21, 2005
I was wondering if there were different experiences from home school families?
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- **The Democratic Ideal by Phil Parette [SI Faculty]** on Jul 19, 2005
Ah yes...several of the last postings acknowledge the complexity of culture and its implications for all of us as decision-makers. Multiple forces, if you will, are constantly at work that influence our decision-making. We like to espouse the democratic ideal that all members of our society should have the opportunity to grow, become, and participate in our wonderful system here in the U.S. But this participation is influenced by oh so many factors. On the one hand, we have the culture of the school and its inherent values that draw on the surrounding community's experiences, hopes, expectations, demographics, etc. We also have the culture of teachers within that school cultural system, each with varying orientations re: child development, teaching strategies, philosophies, etc. which all add to the 'richness' of the school culture. But that culture is embedded in numerous microcultures (e.g., ethnicity, geographic, socioeconomic, religious, and linguistic) that are also embedded within a macroculture (e.g., the U.S.). So the immensity of our challenge in working with children and families from diverse backgrounds is truly daunting, and I agree with Joan when she notes that there is no best strategy that works with all.

We used to use the expression, "it depends" when asked questions about the ADA and implications for specific

businesses or government entities. It really is a case-by-case basis, and the best we can do is to have a reasonable knowledge base re: an array of approaches for working with families (e.g., cultural reciprocity), and trying these out using as much information (that is sensitively acquired) as possible at our disposal. I think we are beyond the point when we as education professionals can assume the comfortable approaches that we use w/ our friends, family, and other members of the culture with whom we identify with other people that we work with in the education system-- people who may come from very different backgrounds. What is especially interesting about this challenge is that more often than not, we all have children's interests at heart, though the way we address those 'perceived' interests can be markedly different.

- **ESL--so what do we do?** by **Phil Parette [SI Faculty]** on Jul 19, 2005
In the discussion of the Corazon family, several folks have mentioned students with disabilities who have English as a second language and the unique needs of this group of students (and their families) during AT decision-making. Since we've talked about acculturation, and recognize that each person responds in different ways to acculturation influences (assimilation, integration, separation, marginalization), what specific strategies do we use when working with these children? What questions do we ask ourselves before we can successfully provide services to children and their families? What have you found effective?
 - **Re: ESL--so what do we do?** by **Kim T.** on Jul 19, 2005
Interesting that you should ask this. I recently began thinking about it from a slightly different perspective in that my sister is a Spanish teacher in a school with little resources for technology, but almost half of her class had IEP's or 504s. At a conference I recently attended, I began to ask about computer programs having different languages and was very pleased to find that many of the newer software programs do have spanish/english conversion and voices! I realize that this is in a different frame of reference, but it is nice to know that manufacturers are now considering this factor in the making of their products.
 - **Re: ESL--so what do we do?** by **Phil Parette [SI Faculty]** on Jul 20, 2005
Yes, it is a good thing. However, there will always be the issue of dialectal distinctions and how appealing these speech differences may be to potential users. For example, would an English-speaker from Boston like hearing a narrator w/ a deep Southern drawl (or vice versa). Similarly, there are such variations in language inflections within other languages as well, so the nature of how it is used will have to be considered. For example, an inner city African American child who uses an AAC device (or computer with voice features) in public settings, and which has a different dialect may potentially draw undue attention to the child (and family) and be rejected at some point in time.

Just something to consider.

- **Re: ESL--so what do we do?** by **Kim T.** on Jul 20, 2005
Unfortunately we have not come that far... so long as a computer is doing the speaking, we will never be able to take into account all of the different dialects.

What do you recommend doing?

- **Re: ESL--so what do we do?** by **Phil Parette [SI Faculty]** on Jul 20, 2005
I think that the best we can do is be sensitive to whether this may be an issue with families. Admittedly, we all have to live and work with people who bring their varying dialects into our spheres of work activity, and community life; however, for some families the difference may be important to consider. It reminds me of one story in which a Hispanic family that we were working with saw their child (who was non-verbal) use an AAC device during the evaluation, and for the first time heard their child say, "Mommy, I love you." The mother cried and we talked about the fact that the child might sound a little different if she used the device around her family, but for her the potential for this child to have a voice--regardless of what it sounded like--was far more important than any dialectal differences. We worked with one Navaho family in Las Cruces, NM, for whom Navaho inflections were extremely important for the child to be accepted by his grandparents, and in the absence of pre-programmed Navaho speech, the family opted not to use the device outside of the school setting. There is no solution to the problem other than making families aware that the child might sound a bit different (and allowing them to hear what it will sound like), and simultaneously exploring the possibilities: If you go out to a restaurant and your child brings his/her device to use, will the difference in 'voice' make a difference to you? Will it affect how you feel about using the device outside of the home? If you use it at home, and there are extended family members who may be interacting with the child, do you think it might make a difference to those family members?

I think you get the idea--making people aware that you recognize that this might be important and trying to get their input is what is particularly important. But this has to be balanced against what the child wants and thinks about the device as well. Sometimes the

family's values will trump the values of the child's peers (and thus what may be seen by the student as 'cool') and what an individual student wants. So that brings us back to the issue that has repeatedly come in our various threads--no one solution fits all scenarios and family situations have to be explored on a case-by-case basis.

- **Re: ESL--so what do we do?** by **Mguillerault** on Jul 21, 2005
I work with adults in a vocational setting, not children- but the voices I have heard have been mechanical enough that the important thing was WHAT was said, not the inflection. I admit that inflection is very important in all languages -some more than others, but why would the ability to express a need or idea be discarded simply because it is not perfectly articulated? It seems the child has enough problems that this assistance in expressing ideas would be accepted with joy. If you can't "speak" perfectly, you should be mute?!

- **So what do we do? Acknowledge and be sensitive** by **Phil Parette [SI Faculty]** on Jul 21, 2005
Oops, it seems that the wrong message was interpreted here. My position is that voice quality MAY be an issue for some families, and if it is, we should be aware of it and work with the family to help them understand our perspective and the benefits that may be realized (as well as the expectations for the family's involvement, others in the community, supports that will be provided, etc.). I agree wholeheartedly that the ability to communicate is critical for all human beings--in fact, ISAAC has been working on a position statement for the United Nations this past year re: communication being a basic human right. The form of communication, however, that is accepted by people however will vary markedly, especially when the variable of disability enters into the equation. Some families may foster dependence on the part of the child due to lowered expectations for communication (and other) skills, and reinforce dependence on the part of the child for the family's ongoing involvement and support for basic communication. If the family's perception of disability is one that involves some degree of shame/doubt, or if their cultural background is one in which persons with disabilities are less valued, or if there is a strongly held value that the care and upbringing of the child is solely the responsibility of the family (and not others) there may be the potential for 'voice quality' to make

a difference. For many families, this won't be an issue. For others it may.

So in response to your question, the best we can do is to try and understand if 'voice' may be a concern, just as it behooves us to best understand the array of hopes, expectations, concerns, supports, etc. that every family brings to the decision-making arena. If not, then we have an array of decisions that can be made. If it is, then we have a responsibility for understanding why it may be of concern to the family and helping them to understand our perspective and why the issue of voice may not be a concern to most others that the child communicates with.

- **Re: So what do we do? Acknowledge and be sensitive** by Lesley T. on Jul 21, 2005

This might be a good time to ask someone with more experience in the field than I have just what exactly are the obstacles to more natural-sounding computer voices, or using a human voice on the high tech dynamic display devices?

I understand that some things, such as the readouts when someone types letter-by-letter, HAVE to be done using phonetic rules. But could a person's voice make all of the sounds and have that loaded into the database? I would love to see choices that are geographically and culturally appropriate with inflections and accents.

One mother told of trying to get the word "divan" programmed out of her device and replace it with "sofa." Where I'm from, that would be a "couch." And the word "creek" rhymes with "stick", just so you know! :)

Some people I know like the computer sounds because that helps signal to other people that this is a little different of a communication experience and the communication partner might have to use different "rules" in order to make it work. Others, obviously, don't like the computer voice at all.

Also, it may have to do with the severity of the disability. If a person is literate and can make needs known through pencil and paper, that might be enough as far as some parents are concerned, without using a distracting device. However, for a child that is non literate and nonverbal and can't communicate any other way, I think the voice quality won't matter as much as long as the child is successful.

Or is this assuming too much?

- **Re: So what do we do? Acknowledge and be sensitive** by **Phil Parette [SI Faculty]** on Jul 22, 2005
I agree--but again, our own cultural values slip into perceptions of what should occur in decision-making, e.g., "I think that..." vs. "I feel strongly that..." and "recognize that you feel strongly that..." so what can we agree on that is in the best interests of the child.

It is the recognition of the family's perspective, and including this in our decision-making considerations that is especially important!

- **Re: ESL--so what do we do?** by **Jenzi** on Jul 20, 2005

Hi Phil and everyone --

Actually, I'm looking at this while still thinking about your suggested questions to ask the child and family, during AT assessment meetings. I agree those are great questions that should be part of every AT assessment, but I'm wondering how the family's responses might be influenced if they are just learning English, and getting used to American culture and schools. I can imagine that some new immigrant/refugee families with limited English skills might not have a clue what we're asking in some of those questions, especially if they are also unfamiliar with AT, and/or have very different ideas about their child's disability than we do -- they could very well just feel overwhelmed and say nothing! A related idea that occurs to me is that some children of immigrants or refugees are especially anxious to fit in with their "mainstream" US-born classmates...and if they have a disability too, they might feel especially strongly about that. In those cases, it seems like it's especially important to see what the child is comfortable with, and taking care to connect them with AT that will not make them stand out even more.

I'd love to hear from any of you who have worked with kids from English-language-learning families, and have dealt with these issues. How have you handled them?

Thanks!
Jenzi

- **Re: ESL--so what do we do?** by **Phil Parette [SI Faculty]** on Jul 20, 2005
Listening and learning is certainly one response that we may anticipate from some families, particularly recent immigrants who want to fit in. One of the most powerful ways to 'connect' with these families is for other immigrant family representatives who have already become acculturated to the school, AT, and other important forces, and whom have developed positive relationships to the school, to be asked to be liaisons who can tell their 'stories' to new families in the community. One of the most powerful things that we have heard in talking with families across cultural groups around the country is that they prefer to have support groups, or liaisons, who represent their background to provide them with information and to assist in understanding the many complex issues that we often wish to confront them with in our efforts to have meaningful participation in AT decision-making.

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- **Looking different--calling attention to disability** by **Phil Parette [SI Faculty]** on Jul 19, 2005
So if AT can potentially call attention to children's 'differences' when families prefer to blend in and not draw attention to themselves, what are the best practices that we should employ during team decision-making to show sensitivity to this potentially strong value that may be held by families?
 - **Re: Looking different--calling attention to disability** by **Lesley T.** on Jul 20, 2005
I think concentrating on the child and what areas the child will be able to more fully participate in might help.

In a case where the student isn't being pulled from the class and read to by a paraprofessional, for instance, but has a computer with headphones, the technology allows the child to fit in better AND be less dependant on others.

In the challenge of the week, Ramon's behavior was making him stand out in a completely negative way. A hearing aid would make him blend in much better than he had been.

- **Re: Looking different--calling attention to disability** by **Kelly C** on Jul 20, 2005
I think this is one of the biggest issues facing some AT users today. I have worked with many parents who don't want their child to stand out as "different", yet acknowledge that the disability itself can sometimes have the same result. I think we need to be sensitive to this and explore and explain options that can provide support. I worked with one child who refused to use an AlphaSmart, even though he desperately needed it because of illegible handwriting---because of his concerns over what his peers would think. To try to ease his discomfort, he and I made a deal...I would provide some AlphaSmart loaners to his teacher to distribute to others in his class so he wouldn't be the only one using it. This worked out beautifully! After just one week, he was using the device daily to complete writing assignments. When the other AlphaSmarts were gone, he was "the lucky one" that got to keep his!
 - **Re: Looking different--calling attention to disability** by **Phil Parette [SI Faculty]** on Jul 20, 2005
This is a great solution--we see college students using Alphasmarts, so anything we can do to make all kids aware that these devices are 'cool' as well as being important for productivity is a positive thing. Thanks for sharing this with everyone.
 - **Re: Looking different--calling attention to disability** by **Lesley T.** on Jul 20, 2005
That was a really wonderful way to solve the problem.

Making the technology as widely available as possible has definite advantages. ALL students might like to listen to the textbook on an mp3 player during study hall, or do interactive computer programs to enhance their learning. For students who are not diagnosed with any disability, but are struggling anyway, such a policy might be a godsend.

I don't know much about the principles of UDL, but I think that's a great place to start.

- **Re: Looking different--calling attention to disability** by **Linda** on Jul 21, 2005
Lesley T wrote: "For students who are not diagnosed with any disability, but are struggling anyway, such a policy (listen to the textbook on an mp3 player) might be a godsend. "

I know some teachers who even take it to the next level and frequently allow ALL students that option, struggling or not. After all, these students LIVE with these technologies...wise teachers (gen. ed. and EC) are realizing the power (and reality) of how they can be incorporated into learning.

- **Re: Looking different--calling attention to disability** by **marimoo** on Jul 21, 2005
It is nice when a LSD recognizes that all children can benefit from technology. In some LSDs what started as a SpEd initiative is now looking like a learning strategy.
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- **The Democratic Ideal** by **Phil Parette [SI Faculty]** on Jul 19, 2005

Ah yes...several of the last postings acknowledge the complexity of culture and its implications for all of us as decision-makers. Multiple forces, if you will, are constantly at work that influence our decision-making. We like to espouse the democratic ideal that all members of our society should have the opportunity to grow, become, and participate in our wonderful system here in the U.S. But this participation is influenced by oh so many factors. On the one hand, we have the culture of the school and its inherent values that draw on the surrounding community's experiences, hopes, expectations, demographics, etc. We also have the culture of teachers within that school cultural system, each with varying orientations Re: child development, teaching strategies, philosophies, etc. which all add to the 'richness' of the school culture. But that culture is embedded in numerous microcultures (e.g., ethnicity, geographic, socioeconomic, religious, linguistic) that are also embedded within a macroculture (e.g., the U.S.). So the immensity of our challenge in working with children and families from diverse backgrounds is truly daunting, and I agree with Joan when she notes that there is no best strategy that works with all.

We used to use the expression, "it depends" when asked questions about the ADA and implications for specific businesses or government entities. It really is a case-by-case basis, and the best we can do is to have a reasonable knowledge base re: an array of approaches for working with families (e.g., cultural reciprocity), and trying these out using as much information (that is sensitively acquired) as possible at our disposal. I think we are beyond the point when we as education professionals can assume the comfortable approaches that we use w/ our friends, family, and other members of the culture with whom we identify with other people that we work with in the education system-- people who may come from very different backgrounds. What is especially interesting about this challenge is that more often than not, we all have children's interests at heart, though the way we address those 'perceived' interests can be markedly different.

- **Re: The Democratic Ideal** by **Linda** on Jul 21, 2005

Phil wrote: "...more often than not, we all have children's interests at heart..."

And that has to count for something, don't you think?!? All of the excellent, heartwarming strategies that have been shared on this topic certainly prove that while there can be numerous difficulties working with families (cultural and otherwise), if we can somehow get across our sincere interest in and respect for them, we are all on our way to winning.

- **Re: The Democratic Ideal by Phil Parette [SI Faculty]** on Jul 21, 2005
Yes, it counts for a lot...but cultural issues really do affect the way those 'interests' are demonstrated, supported, and advocated! Culture infuses so much more richness into our daily lives, and I am so pleased that so many of you have given more thought to how this impacts what we do and how we behave around our fellow educators, families, and others in the world around us.
- **Re: The Democratic Ideal by marimoo** on Jul 21, 2005
Part of showing respect for people is accepting their decision, whether we agree or not.
 - **Re: The Democratic Ideal by Phil Parette [SI Faculty]** on Jul 21, 2005
This is a big challenge for many education professionals, as we often see ourselves as the expert about a child's needs, sometimes failing to recognize that parents are experts themselves--they have lived a lifetime with their children and know a lot more about their children in many respects than we do (since we are seeing the child through the education culture's eyes vs. that of the family culture).

Good point that you have made.

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- **So what have we learned?** by **Phil Parette [SI Faculty]** on Jul 22, 2005
I'd like to ask our participants to share some thoughts re: whether these discussions have affected the way in which they think about the role of cultural issues when working with families and children with disabilities.

Many topics have been discussed the past 2 weeks, and some really good comments have been made...but ultimately the value of this experience will be demonstrated through best practices in the field. So will this experience make a difference for you personally? How?

- **Re: So what have we learned?** by **marimoo** on Jul 24, 2005
I appreciate the opportunity to read so many posts. How long would it have taken to gather so many ideas

and at what expense? As with the other "strand", I have read more than written, and learned much. Listening to those we serve and recognizing that one size does not fit all is something I have learned from this discussion.

- **Grazie!** by **Joan Breslin-Larson [SI Faculty]** on Jul 22, 2005

Thanks for a very challenging and fun discussion. Phil- you have guided us in looking at some challenging issues. I appreciate the willingness of participants to ask questions and actively reflect.

I know I will be looking at some of my assumptions and actions at work through a different lens. As our schools become more diverse, and as we become more responsive to that diversity, I am glad we have some new resources to help us in supporting students.

And, sometimes, we now will have the tools to say "Oh- I guess that isn't the best approach for this family. What else can I do"

I think the most important thing I have learned this week is to challenge my assumptions about how best to work with people, and to maybe slow down in my approaches to families. And- I have lots of reading and homework to complete in order to share some of this information with the practitioners I support!

Thanks to the Family Center in their excellent work in making this forum available.

Joan Breslin Larson

Summer Institute Faculty

- **Family Perspective** by **TomVHanley** on Jul 22, 2005

I found the reflections of family members really intriguing. I think it's clear that (1) we've made some amazing technological progress over the past few decades, but (2) we still have to do a better job of engaging families in the process, to gain their insight into what they really need and appreciate, and how we (technologists) can work more proactively with families to make sure the technology systems are really helpful!

Tom V. Hanley

Resources

AT & Ethnic Minority Populations: Community Research for Assistive Technology Focus Group Results

<http://www.atnet.org/CR4AT/FocusGroup/EthnicThematic.htm>

This article focuses on the results of a research project that focused on African Americans, American Indians, Asian Americans/Pacific Islanders, and Latinos and their experiences with the field of Assistive Technology (AT). It was published by the Community Research for Assistive Technology Project and written by Myisha Reed. The article discusses the types of AT most likely being used by each population and how that piece of technology was funded. The most interesting part of this article is the section focusing on the barriers to AT use. The biggest common barrier among these four groups was a language barrier. Other barriers varied from group to group and included geographical locations, poverty, not enough information, distrust of outside communities, fear, not wanting to make their disabilities known, etc. The article ends with suggestions from the different groups on how things can be improved.

Cultural Issues in Mediation: A Practical Guide to Individualist and Collectivist Paradigms

<http://www.attorney-mediators.org/wright.html>

This article, written by Walter Wright and published by the Association of Attorney Mediators, is a great resource that examines the difference between individualists and collectivists. The article stresses that different cultures may prefer a different type of orientation, but no culture is entirely comprised of individualists or collectivists. Mediation is a method used in special education, usually in relation to the IEP and the use of AT. This article is useful to mediators because it discusses some of the issues that may come up when dealing with an individualist or a collectivist. It also suggests how to accommodate the different types of people during the process to make them as comfortable with the situation as possible.

Cultural Factors in the Delivery of AAC Services to the African-American Community

<http://www.asha.ucf.edu/huer.wyatt.html>

This article, written by Mary Blake Huer and Toya Wyatt, focuses on Huer's AAC Assessment Model in which she described and introduced a four part protocol which outlined strategies for self assessment by practitioners, and information gathering pertaining to a consumer's communication partners, communication needs, and capabilities. It is a great resource and focuses on cultural issues, particularly in the African American community, that may play a role in AAC services. Five issues were discussed toward the goal of more appropriate service delivery: the importance of

understanding the communication partners, needs, capabilities and skills, barriers, and strategies. The information provided within this article can serve as a general guide for providing culturally appropriate services and options for AAC users within the African American population.

Effects of Acculturation on Assistive Technology Service Delivery

<http://jset.unlv.edu/19.2/parette/first.html>

This article was written by Howard P. Parette (Illinois State University), Mary Blake Huer (California State University-Fullerton), and Marcia Scherer (University of Rochester Medical Center) and was published in the Journal of Special Education Technology. It discusses the effects of acculturation on AT service delivery and stresses the importance of accommodating family/cultural values when creating an IEP that includes AT. The article describes various issues that may cause conflict during an IEP meeting, and also discusses where these issues come from and what to do to accommodate them. In addition to discussing the cultural influences on the acceptance of AT, the article also focuses on the socioeconomic status of families and how that can play a role in implementing AT in a family. The article concludes with a useful list of five specific recommendations that may be considered to assist professionals during AT decision-making processes.

Family-Centered Decision-Making in Assistive Technology

<http://jset.unlv.edu/15.1/parette/first.html>

This paper, written by Phil Parette (Southeast Missouri State University), Alan VanBiervliet (University of Arkansas for Medical Sciences), and Jack J. Hourcade (Boise State University) and published by the Journal of Special Education Technology, presents an overview of selected family and cultural issues concerning assistive technology. In addition to discussing the issues, the paper describes where the issues come from and possible solutions to overcoming the issues. The article stresses the importance of the family and the IEP team working together so that they can receive the best results from the chosen piece of assistive technology.

Family Goals Determine Ultimate Success of Assistive Technology

<http://ericec.org/osep/newsbriefs/news32.html>

This text from a News Brief from the ERIC/OSEP Special Project gives a brief overview of the issues that need to be considered by the IEP team to make sure that they are being sensitive to the family's perception of their child's disability and the use of AT.

Keys to Access

<http://www.directionservice.org/cadre/keys.cfm#>

This document, developed by CADRE, addresses the fact that there are many families out there, particularly those who identify with a culture different from mainstream American society, that do not recognize mediation as an appropriate process for help in the special education system. The document gives possible reasons why families may be hesitant to use the mediation process and also provides strategies that can be implemented to encourage the use of mediation. At the end of this document is a multiple page list of resources for further research on this topic.

Research Update: "Examining the Effectiveness of Assistive Technology & Related Services for Ethnic Minorities"

<http://www.proyectovision.net/english/news/16/cfilc.html>

This article, written by Robin Savinar, briefly describes some of the findings of a research project entitled "Community Research for Assistive Technology Project," which examined the use and effectiveness of Assistive Technology among minorities. This article shows the results of Latino participants and how they use and view the AT industry. It shows that they use a variety of AT, but often find that language barriers or fear of the outside community cause problems in acquiring AT and/or AT information. It shows the results of a Vendor and Service Provider survey, which shows that less than half of the respondents provide software, instructions, or trainings in Spanish or any other language. Further research is still being conducted.

Serving English Language Learners with Disabilities- Chapter 9: Technology for English Language Learners with Disabilities

http://www.isbe.state.il.us/bilingual/pdfs/bilingual_manual2002.pdf

This chapter of the Resource Manual focuses on Assistive Technology (AT) to aid in the classroom for everyone, in particular English Language Learners (ELLs) with disabilities. The chapter discusses how there are many software programs for students with disabilities that are offered in other languages, which can help with the learning of the English Language and also help overcome a disability. The writers discuss how AT can be used in general to teach all ELLs. This resource is good for learning about the different AT that is available, and how they can help ELLs.

Serving English Language Learners with Disabilities- Chapter 11: Developing IEPs for English Language Learners

http://www.isbe.state.il.us/bilingual/pdfs/bilingual_manual2002.pdf

This resource is directed towards residents of Illinois, but it can be applied to everyone. The chapter focuses on serving

English Language Learners (ELLs) in the special education system and the importance for the IEP team to make the IEP linguistically and culturally appropriate. The most useful part of this chapter is the case studies that are presented, which portray three students with various abilities, backgrounds, and language proficiency. The cases deal with four main aspects of the IEP: linguistic and cultural considerations, annual goals, accommodations and modifications, and least restrictive environment. In addition to the case studies, the chapter provides various options for special education service delivery to ELLs.

What Should we Expect of Assistive Technology: Being Sensitive to Family Goals

http://journals.sped.org/EC/Archive_Articles/VOL.35NO.1SEPTOCT2002_TEC_Article%208.pdf

This guide, written by Phil Parette and Gale A. McMahon, is directed towards educators and/or members of an IEP team. It focuses on the importance of making sure the family is happy with the decision concerning AT in the IEP. While discussing the family goals in AT, the authors also mention the cultural differences among families and the different expectations of AT that go along with that. The guide gives many examples of questions that the IEP team should ask when focusing on different expectations a family may have concerning AT for their child. In addition to the sample questions, this guide has two great components. The first is a table that shows Family Goals and Expectations Regarding Assistive Technology, Potential Outcomes (positive and negative), and IEP Team Responses. The second is the case studies they provide throughout the guide that relate to the various concerns that may come up when being sensitive to family goals.

Additional Resources Provided by Participants During Institute

Cultural and Linguistic Diversity Resources

http://education.state.mn.us/html/intro_speced_cultural.htm

This list of resources was compiled by the Minnesota Department of Education. The resources are meant to assist parents and special educators in working with students from diverse backgrounds who may be in need of special education services. They provide access to the English Language Learners Companion to Reducing Bias in Special Education Evaluation along with many other resources. This resource can be very useful when trying to accommodate diversity and different family views into IEP meetings and special education in general.

Department of Education: PT3 Grants

<http://www.ed.gov/programs/teachtech/index.html>

The Department of Education use to sponsor PT3 Grants for schools. This link from their website provides history of what the PT3 Grant was and how it was handled. It shows the funding and the different aspects of the grant. The Grant is currently not being funded. This website was referred to in response to a question concerning how parents should adapt

to new technology being brought into their homes for their child to use; for example, using a laptop to do homework on instead of using pencil and paper. The PT3 Grants had a component to help families at risk acquire the skills to be technology savvy.

Disability, Diversity, and Dissemination: A Review of the Literature on Topics Related to Increasing the Utilization of Rehabilitation Research Outcomes among Diverse Consumer Groups

<http://www.ncddr.org/du/products/dddreview/toc.html>

This article was referred to by one of the experts, Phil Parette. It is a comprehensive resource that addressed a wide range of cultural issues and disability. There has been further research conducted since the publishing of this article in 1999, but it still provides a lot of information for people interested in understanding the array of issues that can arise in special education when working with students and families from varying cultural backgrounds.

PT3 Grants Official Website

<http://www.pt3.org/index.html>

As previously mentioned, PT3 (Preparing Tomorrow's Teachers to Use Technology) is no longer funded by the government. However, there is still focus on the issue. This website is the main site for the program. The program is still providing information about the use of technology by teachers and strategies for getting that technology into the classrooms. They are still active, and recently held a conference at the beginning of the year with the grantees from 2003, 2001, 2000, and 1999. One day, they may receive funding again and be able to offer more help for training teachers and parents in adapting technology.