



2006 Winter Institute

FCTD

Winter Institute on Assistive Technology

December 4 - 20, 2006

Conference Booklet



Family Center on Technology and Disability
Academy for Educational Development
1825 Connecticut Avenue, NW Washington, DC 20009
202.884.8068 fctd@aed.org
www.fctd.info

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Assistive Technology Funding

Introduction

Advances in the field of assistive technology are exciting. Every year we see devices with greater capabilities, more intuitive software, smaller and lighter equipment, and materials that increasingly incorporate universal design features. Our excitement at the availability of these items, however, is often muted by the challenge of paying for them. For many, the price tags can seem overwhelming. Therefore, families, and the organizations that work with them, need to be knowledgeable about both traditional and non-traditional funding options and the processes involved in pursuing them.

Assistive technology is often paid for through a child's special education program or through a family's insurance coverage. Other times, alternative options such as AT loan programs, waiver programs, foundation support and support from community organizations need to be explored. In this discussion we'll discuss each of these funding options in an effort to help you navigate a path through what can be a very complex system.

Milissa Gofourth, of the Oklahoma ABLE Tech program and Loan Coordinator for Oklahoma's Alternative Financing Program will join Kim Moccia, of the Minnesota STAR program, in leading our discussion of assistive technology funding. We look forward to hearing about your successes and challenges in pursuing AT funding and in sharing strategies from state to state.

Learning Objectives

1. Identify national laws that impact AT funding, and describe that impact.
2. Identify the impact of including AT in a student's Individualized Education Program on the provision of assistive technology by the public school system.
3. Identify private sources of AT funding available to families of children with disabilities.
4. Identify the ways in which AT vendors can support families of children with disabilities in their efforts to secure AT.
5. Understand the role of AT assessments and evaluations on the funding of AT devices and services.
6. Understand the concept of "funding turn-around times" and their impact on AT acquisition and use.
7. Identify key issues and terms relevant to Medicare/Medicaid funding of assistive technology.
8. Identify the options that families have when requests for AT funding have been denied, by the public school system, by Medicare/Medicaid or by insurance companies.

Expert's Corner

Expert's Bios

Milissa Gofourth

Milissa Gofourth serves as Program Manager of the Oklahoma ABLE Tech program and Loan Coordinator for Oklahoma's Alternative Financing Program, Title III of the Assistive Technology Act of 1998. She is a Work Group member for Data Collection and Reporting Procedures for State's Assistive Technology Programs and a Policy Funding Coordinator. Previously Milissa served as Outreach Training Coordinator for Oklahoma ABLE Tech.



Milissa Gofourth

Milissa works with state agencies that provide assistive technology for outcomes that will reduce the barriers to the provision of and funding for assistive technology. She provides materials and reports on the ABLE Tech program activities to the State Consumer Advisory Council. She is responsible for coordinating the Alternative Financing Program and the Access to Telework Fund which includes the facilitation of all information between ABLE Tech, the Oklahoma Assistive Technology Foundation, BancFirst of Stillwater and all loan applicants. She is also responsible for completing all federal and state reporting requirements for the AFP, ATF and ATA of 1998, as amended. Her work with Oklahoma ABLE Tech program includes the development, implementation, and evaluation of the Oklahoma State Plan for Assistive Technology as directed by the Rehabilitation Service Administration.

Kim Moccia

As the mother of a child with learning difficulties, Kim Moccia has been interested in and advocated for use and funding of assistive technology for nearly two decades. She is a 2001 graduate of California State University, Northridge Assistive Technology Applications Certificate Program (ATACP). While managing People Achieving Change Through Technology (PACTT), a non-profit program that provides assistive technology services in southeastern Minnesota, Kim gained experience helping consumers navigate the AT funding maze.



Kim Moccia

An avid writer, her article A Pocketful of Miracles, appeared in the November 2002 issue of Pocket PC magazine. Kim currently works for A System of Technology To Achieve Results (STAR), Minnesota's Assistive Technology Act program. STAR recently released the 2006 edition of its Directory of Funding Resources. Kim is active in the AT community, presents at conferences and participates in a variety of AT-related list serves. She is also a member of the Statewide Assistive Technology Leadership Team, which serves in an advisory capacity to the Minnesota Department of Education.

Expert Perspectives

Milissa Gofourth

I first started working with adults with developmental disabilities in a supported employment program. I can't begin to express the many lessons I learned from that eight years of experience but if I had to pick one concept it would be "never say never" when it comes to meeting employment goals. For the past 10 years I have tried to approach funding assistive technology with the same tenacity, but you must be prepared to work at it just as hard as any job. I know there are both public and private funding sources for various types of assistive technology (AT) and it is often necessary to develop effective funding strategies to ensure you get the AT you need. The first step to finding the right funding source is to answer the following questions about the applicant to determine eligibility:

1. Age
2. Disability
3. Income (not always required)

The next set of questions should determine the primary purpose of the AT (education, employment, medical or community living). Once you have narrowed down the funding source, research the following information:

- The purpose of the program: for example, the purpose of special education under IDEA is to provide a free and appropriate public education for children with disabilities.
- Eligibility requirements: such as age, type of disability, income and resources, location of residency, etc.
- Application process: such as necessary documentation to determine eligibility.
- Appeals procedure: if you disagree with a decision of the funding source, what are your next steps.
- What AT services and devices are provided: for instance will a funding source pay for an evaluation but not the device or the device but not repairs. Another example is with the type of AT purchased: Medicare will purchase a wheelchair under certain criteria but not computer software that allows specialized access through a screen reader.
- Pieces to the puzzle: lessons learned by going through the process. If you have information on the law, waiting list, procurement rules, vendors, etc., you are more empowered to advocate effectively.

Kim Moccia

While assistive technology is becoming more user-friendly, finding funding for it isn't. This, in part, is due to:

- Variety of resources available on a national and state level, each with its own set of definitions and eligibility requirements
- Misinterpretation or implementation of laws and policies
- Failure of AT policies to keep pace with changing AT practices
- Budget constraints

Although there is no magical formula for finding funding, answering the questions below will provide you with the ingredients you need to support your request and narrow down the list of possible funding sources.

- What is the need?
- Is it a medical, educational or vocational necessity?
- Do you have documentation that substantiates the need?
- What device and/or service will meet the need?
- Do you have documentation that substantiates the need for the device and/or service?
- What is the cost?
- Are there alternatives?
- What funding sources are available?
- Is co-funding an option?

During our two-and-a-half weeks together, we will discuss how to develop a funding strategy, resources available to assist you during the funding process, as well as, what to do if funding is denied. I look forward to our discussion and hope that you will share your success stories, as well as, lessons you've learned from unsuccessful attempts at finding funding. It is in sharing our experiences that we will learn what works, what doesn't and what we need to change to improve the future of AT funding!

I look forward to guiding you through this process, so you can advocate for yourself and others. More importantly, I look forward to learning from you as you share your funding experiences.

Recommended Resources

1. Finding the Money

<http://www.infinitec.org/learn/money/findingthemoney.htm>

This AT funding guide, available on the Infinitec website, is broken up into 4 modules. The guide offers a thorough look at AT funding options for families. The guide includes sections on general funding tips; funding through private insurance, Medicare and Medicaid; school-funding of assistive technology and a list of funding Information Resources. The article calls “knowledge and research” the primary tools for AT funding in general, while strongly advising beginners to have support from professionals and helpful advocates.

2. Funding for Assistive Technology

<http://www.sc.edu/scatp/fundingfact.htm>

This brief article published by the South Carolina Assistive Technology Program (SCATP) discusses three main aspects about receiving funding for assistive technology. The first section of this article contains the nine basic steps to funding. Each of the steps includes a brief description about the actions that should be taken. Next, SCATP discusses various funding options. These funding options describe the various places you can go to obtain financial assistance, which include private insurance plans, Medicaid, Medicare, school districts, children’s rehabilitation services, and various state agencies. The final section contains information about appeals, and what to do if your funding is denied. In addition to these three sections, SCATP also provides additional resources for more information.

3. A Resource Guide to Assistive Technology Funding

<http://www.vats.org/downloads/ATFunding.doc>

This 29-page guide published by the Virginia Assistive Technology System (VATS), talks about various aspects of assistive technology and funding. VATS provides an introduction to the whole guide by describing what exactly assistive technology is. They give examples of how it can help in people’s every day lives. After the introduction, they discuss how to develop a successful funding strategy for obtaining assistive technology. They offer nine steps, each one with details describing what is to be done by the various parties involved. The third section of this guide focuses on your legal rights for obtaining AT devices. They give descriptions of each of the laws and how it pertains to your funding options and your rights. Once you have obtained funding, there are follow-up steps that need to be taken to make sure you get the right piece of AT. VATS offers tips on how to choose your AT Vendor and how to evaluate various pieces of technology to see if they will be helpful to your particular needs. Finally, they offer information about loan and recycling programs if owning the device is not an option.

4. **Assistive Technology and Funding**

http://www.atnet.org/advocacy/issue_atfunding.htm

This brief article, brought to you by the AT Network, describes AT funding now and how it may change in the future. First, they go into detail about each of the public funding sources. Many of these sources are directed towards California residents, but it can also be paralleled to what other states offer. This article also discusses AT funding in the future and possible reforms in this area. They discuss possible opportunities for significant tax relief and also various incentives for schools to perform AT assessments.

5. **Overview for Funding Assistive Technology**

<http://www.maine cite.org/fund2.htm>

This overview was published by Maine CITE. It begins with information about individuals with disabilities and how technology can help these people. It then goes into the necessity of money to obtain this technology and the services. The overview discusses the various funding strategies, how to identify a primary funder, the importance of documentation during the funding process, and how to deal with denials and move into the appeals process.

6. **Paying for the Assistive Technology You Need: A Consumer Guide to Finding Sources in Washington State**

<http://uwctds.washington.edu/resources/legal/funding%20manual/index.htm>

This manual was developed by the University of Washington Center for Technology and Disability Studies. It is geared toward residents of the state of Washington, but the majority of the information can be applied everywhere. This extensive guide contains information about many aspects of funding assistive technology. There are seven chapters in this manual, including the following: Assistive Technology Basics, Health-Related Sources for Assistive Technology Funding, Employment-Related Sources for Assistive Technology Funding, Education-Related Sources for Assistive Technology Funding, Assistive Technology Funding Sources for Special Populations, What to do when Assistive Technology Funding is Denied, and Alternative Sources for Assistive Technology Funding and tax incentives. The chapter on Education-Related Sources contains information about primary and secondary public schools, private and parochial primary and secondary schools, and post-secondary education. At the end of this manual, they also provide additional resources.

7. **Finally, Help Through the Funding Maze...Assistive Technology Funding Manual**

<http://www.iltech.org/fundingmantable.asp>

This manual, published by the Illinois Assistive Technology Program, consists of three parts. Part I is the introduction that provides general information about funding. If you are not familiar with AT funding, this section should be very helpful. Part II lists govern-

mental agencies that can provide AT funding. Also in Part II are all the private, non-profit agencies and service clubs that can help you in your search for funding. Finally, in Part III, they list resources that may be helpful in your search for funding.

8. **Assistive Technology Public Funding Source Guide**

<http://www.techaccess-ri.org/fundintr.htm>

This information was put together by the Rhode Island Disability Law Center. It is split up by subjects, which can be very useful for narrowing down your search. The topics they go into great depth about include: Medicaid, early intervention, special education, vocational rehabilitation, independent living, medicare, and veterans benefits.

9. **Assistive Technology Funding Search Tips**

http://www.ucp.org/ucp_channel.doc.cfm/1/14/86/86-86/2938

This two-page article is clearly written for the individual technology user or the family of an individual with disabilities, professionals and caregivers. It is a more concise, edited version of a longer article entitled, "Finding the Money" by Infnitec, Inc. which has been reviewed previously at the FCTD website. This article gives a broad approach to the subject of searching for funding, with some specific ideas and examples included. It is aimed at the beginning fundraiser as a plan, and could be used by those more experienced with fundraising as a checklist.

10. **Your legal rights to assistive Technology**

<http://www.uiowa.edu/infotech/Legal.htm>

This resource published IPAT Infotech talks about recourses that families have when they are denied AT funding. They discuss various different funding options including government sources, private insurance, Medicaid, medicare, private insurance and IDEA. The document is broken into three sections, AT for children, At for adults, and AT for the elderly.

11. **The Public School's Special Education System as an Assistive Technology Funding Source: The Cutting Edge**

<http://www.nls.org/specedat.htm>

This article is provided by Neighborhood Legal Services, Inc. and focuses on the public school system as an assistive technology funding source. The article discusses IDEA and the obligations of the school system in providing AT funding identified in an IEP.

12. **A Survey of Programs and Funding Sources for Assistive Technology Other than the Individuals with Disabilities Education Act (IDEA)**

<http://www.nls.org/pdf/speced.pdf>

This document outlines common funding options when assistive technology devices and services are not obtainable through the special education system. Funding options discussed are: Medicaid, Medicare, Social Security and SSI, vocational rehabilitation services, ticket to work and private insurance.

13. **Informed Consumer's Guide to Funding Assistive Technology**

<http://www.abledata.com/text2/funding.htm>

This guide breaks the AT funding process into discrete steps. It offers guidance on getting started and preparing a justification statement, and identifies keys to successful funding. A list of State Technology Assistance Projects is also provided as well as a list of additional resources.

14. **Assistive Technology Funding - Resources for School-aged Children with Disabilities**

<http://jset.unlv.edu/15.4/Kemp/first.html>

This guide discusses AT and the Individualized Education Plan (IEP). It describes the role the school may play in helping to fund assistive technology for students.

15. **Getting A "YES" From Your Insurance Company**

<http://www.iltech.org/persistence.asp>

This is a brochure describing strategies and planning for obtaining funding for assistive technology devices and service needs through family health insurance plans.

Transcript - Assistive Technology Funding

- **Welcome to the FCTD Winter Institute on AT by Jackie Hess [SI Faculty] on Dec. 03, 2006**

We're very pleased that you've chosen to participate in the Family Center on Technology and Disability's first Winter Institute on Assistive Technology. Many of you have participated in our summer institutes and know how informative and rewarding they can be. We're trying a few new things with this institute and are interested in your evaluation of their utility.

Quite a few people have, in the past, asked us for the option of being notified by email when new posts appear. We've included that feature in this institute and will be anxious to see how well it works. Please remember that it's only an option. You do not have to register for email alerts if you prefer not to.

We're also trying something new in structuring the discussion strands by "sub-topics." Each of you have received the learning objectives established for each strand. We'd like to focus the discussion within each week to certain aspects of funding and advocacy building. However, please know that you can continue to pose questions and offer comments on ANY sub-topic at ANY time throughout the next two and a half weeks. As always, you can post questions and comments on additional topics as well. We have an excellent faculty and an extremely impressive group of participants and I'm certain that the collective knowledge base is both broad and deep.

So welcome! I hope you'll check the discussions often and won't feel a bit intimidated from posting. Remember, everyone is here to help kids with disabilities and their families and we're all in this together!

Jackie Hess

FCTD Director

P.S. Please feel free to phone or email Ana Maria Gutierrez or me at any time:

jhess@aed.org; (202) 884-8217; agutierr@aed.org; (202) 884-8068

- o **Re:welcome to the FCTD Winter Institute on AT by Debbie Thompson on Dec. 04, 2006**

Hello...I just wanted to thank everyone involved for the invitation to join the Winter Institute. I am excited about spending the next several weeks engaging with everyone!

- o **Re:welcome to the FCTD Winter Institute on AT by Karen SFT on Dec. 04, 2006**

Thank you for the invitation to participate. Advocacy, defining success and funding are appropriate topics for discussion and learning in any arena. I hope that in the process of this journey I can glean information on appropriate assessment of the AT so that the AT fits the needs of the student, provides a functional support for the student when performing their daily roles and fits within the student, family and educational cultural beliefs. Being able to access AT for advanced assessment has been a struggle. I look forward to learning with this group.

- **Re:welcome to the FCTD Winter Institute on AT by Kim Moccia on Dec. 04, 2006**

Karen, thank you for being the first participant to post! Access to assistive technology is a crucial component of the assessment/evaluation process. AT Act programs recognize the importance of this and are working to improve access to and acquisition of AT. If you haven't done so already, I recommend contacting the AT Act Program in your state to discuss your options for accessing AT, including loan programs. You will find a directory of AT Act Programs at <http://www.resna.org/taproject/at/statecontacts.html>.

- **Re:welcome to the FCTD Winter Institute on AT by Laura on Dec. 04, 2006**

Hi, I visited our STAR website and learned that we have an alternative finance program that allows applicants to borrow money at low interest or extended terms for the purchase of AT, adaptive equipment, or related services. The other interesting service they offer is the device demo and short term loan which enable the user to see if they can use the particular device before they buy. This program appears to be in the beginning stages but can be found in various regions of the state so it is accessible to most residents. I look forward to our discussions!

- **Re:welcome to the FCTD Winter Institute on AT by VernaAnn Kotansky on Dec. 05, 2006**

Hi! I am very anxious to learn more through this forum. I went to the RESNA site regarding the AT Act Program. I did receive the information for Ohio - this is a VERY unpublicized resource in our area (Cleveland). Unfortunately, I can't help but be frustrated. While IDEA indicates that schools must provide services and equipment for AT, the Feds continue to neglect the funding issue behind these well meaning 'rules'. I am frustrated in my district, I can offer my assistance in any way to help a family secure funding, however can not provide an evaluation or paperwork for the acquisition of individual equipment. We do a nice job of providing what a student may need in the educational setting and make allowances for home and community use, however when all is said and done the equipment is still the school's and the families are left 'looking'. How do other districts handle the private acquisition of equipment - Medicaid, etc. grants, etc.? Thanks for the input. VernaAnn

- **Michigan Integrated Tech Supports & Universal Design by Grace F. on Dec. 11, 2006**

Hello, I work in a school system in Michigan and have been very pleased with the state AT resource, which has recently changed its name to Michigan Integrated Technology Supports (MITS). They have traveled to each ISD district to work with the AT specialists, even including the UP where I work! They have a lending library that gets equipment out as fast as it's available when requested (for a 6 week trial or more). This has been very helpful in determining what may be most appropriate for purchase. And the MI Medicaid system has been very cooperative, as well. Many of our students go through Medicaid for funding, and the turn-around time is relatively short.

(The latest focus of MITS is Universal Design for Learning - UDL. Instead of “retrofitting to meet the needs of individual students” it seeks to develop flexible goals, methods and materials that meet the needs of a broad range of students, whether they are special ed. or not.)

- **Michigan Universal Tech Supports & Universal Design by Kim Moccia on Dec. 11, 2006**

Grace, it is always a pleasure to hear success stories. Thank you for sharing what’s working in Michigan and also for mentioning Universal Design for Learning (UDL). UDL promotes and supports curriculum design that is accessible to the broadest range of students possible. Here in Minnesota UDL cadres were formed through a State Personnel Development Grant. The cadres have received a range of learning materials that support UDL including textbooks, software, and other materials. Cadre members also attend workshops, which in the past have featured national leaders in universal design, including speakers from CAST (www.cast.org), and Dave Edyburn (<http://www.uwm.edu/~edyburn/>) from Knowledge by Design Inc. (<http://www.knowledge-by-design.com/>) Perhaps Joan Breslin Larson, who was responsible for forming the cadres, will share additional information about current UDL cadre activities.

- **Michigan Universal Tech Supports & Universal Design by Jackie Hess [SI Faculty] on Dec. 11, 2006**

Do you think that the emerging focus on Universal Design will have an effect on the funding of assistive technology? If so, what impact would you predict?

- **Re:Michigan Universal Tech Supports & Universal Design by Kim Moccia on Dec. 12, 2006**

Jackie, I do feel that Universal Design for Learning (UDL) will have a positive impact on assistive technology in the classroom. A classroom that uses technology to implement UDL may provide some students with all the support they need to access curriculum, participate in learning and make progress toward meeting their goals. For example, a student who is dysgraphic and unable to take hand-written notes would benefit from a classroom that provides the class with notes in a variety of formats (audio files/whiteboard capturing, etc.). And since the UDL framework is designed to provide students with an opportunity to learn how to learn, it empowers students with skills and strategies needed to succeed beyond the classroom.

Another plus, in my opinion, is that UDL will help reduce barriers caused by the social stigma attached to using assistive technology. (We all know the student who refuses to use AT because he doesn’t want to look different.)

Of course, UDL will not address or eliminate every student's need of assistive technology but it will enhance every student's opportunity to access, participate and progress!

This brings me to another issue—providing students with computer access. In today's world students need to have, at a minimum, basic computer skills. I was at a meeting recently where there was discussion regarding school budgets and technology. If all students are entitled to computer access, should computers used by students on an IEP be paid for with special education dollars or general education dollars?

o **Re:welcome to the FCTD Winter Institute on AT by Linda Taylor on Dec. 04, 2006**

Hello. I am going to participate in this Winter Institute just to see where it leads me. I am a mother of a special child who has so many needs -- but they are being met as they are recognized. I do know that I have learned something already by going to the Tennessee Department of Human Services link that was provided, and I have the information on the Tennessee Technology Access Project. I feel like I have been "successful" already (smile) -- because having this contact is going to prove beneficial. I thank you all for accepting me, a "neophyte" into this Institute. I am a Speech Pathologist who has not been actively employed for many years, because of the demands of Jesse's care. I am ready to reenter the job market now -- and am just weighing various options. I will grab all of the information that you provide as a sponge -- And I will use it to benefit Jesse, individually, and the entire school and school system in Memphis.

▪ **Re:welcome to the FCTD Winter Institute on AT by Kim Moccia on Dec. 04, 2006**

Linda, it's nice to hear that you've already discovered helpful information and feel successful. Welcome!

o **Re:welcome to the FCTD Winter Institute on AT by LMD on Dec. 05, 2006**

Thank you for your welcome. Just sending along some general information about AT to all involved: I work with the Tots-N-Tech Research Institute, a collaborative research project between Thomas Jefferson University in Philadelphia and Arizona State University. The project has just recently developed a new tool called "Assistive Technology with Infants and Young Children: Program Self-Assessment." We are currently recruiting a national sample of professionals to complete the program self-assessment online and provide information about whether what's occurring in their EI programs supports assessment, implementation, evaluation, and system processes with Assistive Technology (AT) with infants and toddlers.

If any of you would be interested in completing the tool it would be greatly appreciated and your feedback will help TNT develop an easy-to-use program assessment tool for use by professionals to monitor the use of best practices with AT with young children in their early intervention programs. Any feed-

back using these postings would be helpful as well.

Here's the link to get you to the self-assessment and it will take you to the Tots-N-Tech website. You'll see another link on that website: <http://www.asu.edu/clas/tnt>

▪ **Re:welcome to the FCTD Winter Institute on AT by Kim Moccia on Dec. 05, 2006**

Thank you for the invitation!

o **Re:welcome to the FCTD Winter Institute on AT by CLuck on Dec. 06, 2006**

I am also very interested and excited to be a participant in the institute! I work as a Case Manager/Care Coordinator for children w/ special needs, and I will be learning more than contributing , I think. But I am definitely here so I can benefit the families that need AT.

o **Re:welcome to the FCTD Winter Institute on AT by Camisha on Dec. 06, 2006**

Hello. My name is Camisha Williams and I am a speech-language pathologist. I was on the assistive technology team in my former school district and just recently got assigned to the team in my current district. The district I currently work in is much larger so the issues that arise are much different than before. I am really excited about expanding my knowledge in the area of assistive technology.

▪ **Re:welcome to the FCTD Winter Institute on AT by Kim Moccia on Dec. 06, 2006**

Welcome, Camisha. I'm wondering if you would mind expanding upon your comment, "The district I currently work in is much larger so the issues that arise are much different than before." It would be helpful to hear how a smaller district addresses AT and funding needs versus a larger district. Do you think the issues relate to the size of the district, staff awareness of AT and funding options, or is it "something else"?

▪ **Re:welcome to the FCTD Winter Institute on AT by Camisha on Dec. 07, 2006**

My previous school district was very small so the money was tight but the students there did not necessarily require devices or equipment that cost thousands of dollars or that was not covered by Medicaid. Also, the department of disabilities and special needs was involved with many of the students so that was another avenue for assistance. Another factor was that the parents were not as informed so they did not request as much. Now, I am in a larger school district where they are faced with weighing what the parents want, versus what the child needs, along with the cost of equipment as the devices recommended are usually in the thousands. So, because of their ability to "do so much," funding has become an issue because the referrals have increased, the equipment is expensive, and the parents have certain expectations for their children. So, I do think it is the size of the district along with an increased awareness of AT along with that "something else."

- **Welcome! by Kim Moccia on Dec. 03, 2006**

Welcome to the first day of the 2006 FCTD Winter Institute. Over the course of the next 2.5 weeks we will be discussing the funding of assistive technology. This week we'd like to take time to discuss the role of the school system in funding assistive technology. What successes have you had in funding assistive technology and what role did the school system play? Have there been times when funding assistive technology meant working cooperatively with other agencies or funding sources? If so, what role did the school play in coordinating the funding process? I hope you'll share your experiences so that we may all learn and grow together!

- o **Re:Welcome! by Linda Taylor on Dec. 04, 2006**

Does the school system have a role in funding assistive technology? I am the parent of a special child, and his teacher has often stated how Jesse's insurance will need to buy him many of the technology he needs. We have never been refused by the insurance company, but there are so many other children who are not as blessed as we are. Every child who needs a communication device should have one, and that is not happening at the school. The educators should be thoroughly trained in the most effective use of the technology -- trained to the point that they are able to practice adequate use of the equipment -- to the point of being able to teach other parents and me how to effectively use the technology. I am glad I am a part of this Institute.

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- **Re:Welcome! by milissa.gofourth on Dec. 04, 2006**

Yes, the school system does have a role in funding assistive technology if the IEP team has determined that the device is necessary for the child to receive an appropriate education. Therefore, the device and service (as defined in my "welcome" post) must be educationally related and necessary. The cost of the device becomes the responsibility of the school.

Although parents may choose to use their private insurance to purchase assistive technology, schools can not force parents to fund the device particularly if there is a cost, such as co-payments, deductibles or even a life time maximum on the policy.

- **Re:Welcome! by Kim Moccia on Dec. 04, 2006**

I'd like to also add that parents might find it helpful to visit the Parent Advocacy Coalition for Educational Rights (PACER) Center at www.pacer.org. Click on National Parent Centers Alliance button on the home page to find a regional center nearest you.

- **Re:Welcome! by Debbie Thompson on Dec. 04, 2006**

Just wanted to pop into this institute also. Thanks for the opportunities.

- **Re:Welcome! by Liz L on Dec. 07, 2006**

I think a point of clarification is needed here. Schools don't need to buy the AT but must make sure it is there for the student. They could be the fundraiser or the negotiator with other funding

sources to get the equipment. Schools don't realize that difference. They could be more proactive in finding funding rather than purchasing the AT themselves.

As far as insurance goes, the parents can elect to tap that resource but schools cannot require it, especially if it reduces the lifetime limit of available funds through the insurance policy.

- **Re:Welcome! by Kim Moccia on Dec. 07, 2006**

Thank you, Liz, you bring up a good point. If parents voluntarily decide to pay for a device through their insurance, they need to be aware of potential consequences such as out-of-pocket deductible charges, possible premium hikes and/or decreases in lifetime coverage.

- o **Re:Welcome! by hollygg on Dec. 04, 2006**

I work for an Early Intervention program (Birth to Six) and we contract our preschool services with one of the local school districts. We are looking to expand our services to this school district - in fact meeting with the SpEd Director to begin discussing this, this week. We have already been told that the school district has no money - so we are having to think of some creative ways to at least start by providing support and resources that we have. This topic couldn't have come at a better time.

We have been fortunate to have great funding through grants, but this can not be our source for services as our program grows. I am excited to see how others have worked with the school district in paying for services and devices. - hollygg

- o **Re:Welcome! by Camisha on Dec. 06, 2006**

Funding for assistive technology has not been a real issue that I have dealt with. The equipment that students need is expensive and my district is now looking at the equipment that will provide the student with what they need in the most economical manner. The South Carolina Assistive Technology Project is great in that it loans equipment for trial use prior to a district or other agency purchasing the equipment. That really helps to see if the device or equipment is what the individual needs prior to purchase since funding is such a big issue. My school district has done a good job of purchasing what students need in absence of assistance from other agencies. I just attended a workshop in which it was stated that Medicaid in the state of South Carolina would no longer pay for assistive technology. I am sure that may have an adverse impact on smaller districts who are not able to fund assistive technology within their budget. I think that funding in this area has always been an issue and is just now becoming an issue in my school district.

- o **Re:Welcome! by Grace F. on Dec. 11, 2006**

Our special ed. director works closely with the Technology dept here, and I have found the AT-IT working relationship extremely helpful! As the technology people become more informed about AT, they partner with us to provide equipment that may not be needed by others, or even share their budgeted money for specific equipment. In fact, our Tech coordinator just stopped in my office with a mailing

he received on a voice recognition program. We are in the process of setting up a dedicated notebook computer with the capability to run a variety of voice recognition programs to try with students. This is coming from a sharing of our budget monies.

- **Re:Welcome! by vernaann kotansky on Dec. 11, 2006**

The AT-IT relationship is becoming a more warm fuzzy relationship in our district, as the AT team is pushing the use of technology globally faster and further in the special ed. and regular ed. populations. We still struggle with what comes out of whose budget. Unfortunately, the AT dept does not yet have its own budget - we just submit requests and keep our fingers crossed - school funding in OH is not the best by any stretch of imagination! The IT dept. continues to view AT as the 'red headed step sister' - no offense to any red headed step sisters out there :). Slowly, as we continue to move forward, the respect for what we are doing is growing. Hopefully soon, they will offer a piece of their budget to the AT dept - hopefully

- **Welcome to the first day of the Winter Institute! by Kim Moccia on Dec. 03, 2006**

Welcome to the first day of the 2006 FCTD Winter Institute. With so many experienced and knowledgeable participants, I know we are all going to learn a great deal from each other. So let's begin by taking some time to discuss IDEA and ADA and how they have impacted the funding of assistive technology.

Thirty-one years ago the Individuals with Disabilities Education Act (IDEA) was passed in 1975. At that time, the use of technology in education was limited. In fact, it's only been eighteen years since the Technology-Related Assistance for Individuals with Disabilities Act (Tech Act) of 1988 was passed. The Tech Act gave us our legal definitions for assistive technology device and service--definitions that are still used today. IDEA was amended in 1997 and in 2004; and, although it has yet to fulfill its commitment to pay 40% of the average per-student cost for every special education student, it has changed the way we educate our students.

In 1990 the Americans with Disabilities Act (ADA) was enacted. Although this civil rights bill does not address a student's educational plan it does require that school programs and services are accessible to students with disabilities.

And then there's technology itself. Thirty years ago few of us could have imagined the world we live in today.

We have all experienced the changes brought about by legislation and technology over the past 31 years. So how has IDEA and ADA impacted the funding of assistive technology? I look forward to hearing about your experiences, as well as your thoughts and hopes!

Today's quote – "The accumulation of knowledge, the discoveries of technology, our ideas, our art, our social structures, all the achievements of mankind have value only to the extent that they preserve and improve the quality of life." Charles A. Lindbergh

o **Re:Welcome to the first day of the Winter Institute! by loriet on Dec. 04, 2006**

I think this opportunity is great as well. As a teacher at a university I am always trying to get my students the best information possible about assistive technology. What better place than to be able to discuss with lots of other people that have such great and varied experiences. We talk a good bit about funding and def. make use of the lending library. We are actually a branch as well...although a very small branch:)

▪ **Re:Welcome to the first day of the Winter Institute! by Kim Moccia on Dec. 04, 2006**

Thank you for joining us. I'd love to hear more about how you provide students with information on assistive technology. Is this part of student services or course related material? What types of equipment do you loan?

• **Welcome by milissa.gofourth on Dec. 04, 2006**

Welcome,

I want to echo how excited I am to be a part of the Winter Institute. I recognize many of the participants and want to tell you how much I have learned from this group re: how to fund assistive technology. I also realize some of you may be new to this field so let me start with a basic concept; what is assistive technology as defined by IDEA?

``SEC. 602. <> DEFINITIONS.

Except as otherwise provided, in this title:

(1) Assistive technology device.--

(A) In general.--The term `assistive technology device' means any item, piece of equipment, or product system, whether acquired commercially off the shelf, modified, or customized, that is used to increase, maintain, or improve functional capabilities of a child with a disability.

(B) Exception.--The term does not include a medical device that is surgically implanted, or the replacement of such device.

(2) Assistive technology service.--The term `assistive technology service' means any service that directly assists a child with a disability in the selection, acquisition, or use of an assistive technology device. Such term includes--

(A) the evaluation of the needs of such child, including a functional evaluation of the child in the child's customary environment;

(B) purchasing, leasing, or otherwise providing for the acquisition of assistive technology devices by such child;

(C) selecting, designing, fitting, customizing, adapting, applying, maintaining, repairing, or replacing assistive technology devices;

(D) coordinating and using other therapies, interventions, or services with assistive technology devices, such as those associated with existing education and rehabilitation plans and programs;

(E) training or technical assistance for such child, or, where appropriate, the family of such child; and

(F) training or technical assistance for professionals (including individuals providing education and rehabilitation services), employers, or other individuals who provide services to, employ, or are otherwise substantially involved in the major life functions of such child.

I think the definition for assistive technology device is very broad and the definition of assistive technology service is very specific. It is important to remember, assistive technology encompasses both the device and the services necessary to use the device appropriately.

o **Re:Welcome by Linda Taylor on Dec. 04, 2006**

I, too, am learning a lot. This is great information.

• **Evaluations by school systems by Vicki L on Dec. 04, 2006**

Thank you for allowing myself to participate in the Winter Institute. I look forward to learning from this group as a professional and parent. My son, with special needs has AT written into his IEP, but I as a parent am dissatisfied with the results of his evaluation done by Early Special Education. As the parent I need resources to go to for him to get the proper AT. If you can believe it, his evaluation was done over the phone by the AT person assigned to that particular school and just by a few comments from his IEP team! I believe there are many more resources my son can tap into for his education and communication. Can I get the school district to pay for an independent evaluation?

o **Re:Evaluations by school systems by Joan BL on Dec. 04, 2006**

I would certainly write a letter to the special education director and tell him/her specifically which areas of the evaluation you challenge, and request an independent educational (AT) evaluation for your son. I would certainly include in that letter the list of requirements of an educational evaluation. The definition of an AT evaluation in IDEA includes the language “the evaluation of the needs of such child, including a functional evaluation of the child in the child’s customary environment;” which apparently did not happen in your child’s case. An evaluation done over the phone did not happen in your son’s customary environment. The district can then either choose to tell you why their evaluation was adequate, or can have an evaluation done at public expense. Please know, though, that whether the school pays for an independent evaluation, or you have it done on your own, the district is required to consider the outcome of that evaluation. This does not mean they are required to implement it.

Good luck- I hope this institute is helpful to you.

▪ **Re:Evaluations by school systems by Sue T on Dec. 04, 2006**

I’m a new parent advocate and am just learning the in’s and out’s of AT funding. I understand that an AT evaluation has to be paid for by the school if it’s written into the IEP. But doesn’t it require an evaluation to get it into the IEP? It would seem to be circular - you need to have an evaluation before you can get an evaluation paid for. What am I missing?

- **Re:Evaluations by school systems by Joan BL on Dec. 04, 2006**

Sue- This is a question I spent lots of time thinking about when I was a new state specialist. Here is what I learned, and what I share with schools in MN. At EVERY IEP meeting, the team needs to consider whether a student needs AT for a free, appropriate public education. If the child is not making adequate educational progress, it is possible that additional tools and services are necessary and AT may be one of them. If the IEP team is aware of tools to help, then they can try things out (equipment trials) or- if the team is not aware of what is available, they should have an evaluation done. So- Tim is not making adequate progress in completing written work. His work is not fluid, and his spelling is poor. The OT on his team has heard of word prediction. They try it with Tim, and his fluency increases. They include the use of computer based word prediction in his IEP.

Joe, however, does not speak. The team knows there are some machines that can talk for someone, but don't know what is available, or how to match features to need. They ask for an AT evaluation, which the school provides. The evaluation team comes up with a list of features which matches Joe's skills, and recommends several devices for trial. The school obtains those devices, the team gathers data, then reconvenes to examine the data and make an informed decision about appropriate AT for Joe. I hope this helps!

- o **Re:Evaluations by school systems by VernaAnn Kotansky on Dec. 04, 2006**

Hi! I am excited to be part of this winter institute. As the AT Specialist in a school district, I am under the impression a school district is responsible to provide an AT evaluation, as it is warranted by the IEP team. If the district does not have an AT team assigned to perform the evaluation, they need to provide one for the student. In the reauthorization of IDEA, AT must be considered on all IEP's. Have you contacted the county services or state AT services for a recommendation of where to go? Personally, I do not understand how an "AT eval" can be completed over the phone - not possible.

Looking forward to more discussion. Have a good day, VernaAnn

- **Re:Evaluations by school systems by Kim Moccia on Dec. 04, 2006**

It is nice to see such great participation on our first day!

I'd like to add that the National Early Childhood TA Center site has (<http://www.nectac.org/topics/atech/funding.asp>) information on funding assistive technology. The site also has a state contact finder that may be helpful.

- **Re:Evaluations by school systems by sandync on Dec. 04, 2006**

I am glad to be a part of this discussion. It is very helpful. Thanks. Sandy

- **Re:Evaluations by school systems by sandync on Dec. 04, 2006**

You may want to refer to the conference booklet from this institute on #11 under recom-

mended resources. There is an excellent resource called The Public School's Special Education as an Assistive Technology Funding Source: the Cutting Edge. It has lots of good information in it. You also may want to go to your state AT website. I know NC has funding information at their website at <http://www.ncatp.org/Funding.html>. There is valuable information there. Annette Lauder is the contact person. She knows lots of medicaid updates etc. as well.

- **Re:Evaluations by school systems by Kim Moccia on Dec. 05, 2006**

Hi Sandy,

Thank you for participating! It's nice to know that you've found the Institute materials helpful. And thank you for encouraging folks to get in touch with their state AT programs. Our state AT Act program here in Minnesota has extensive information regarding funding on its Web site. For instance, every two years STAR publishes a Directory of Funding Resources that can be found at <http://www.admin.state.mn.us/assistivetechology/FD2006/Welcome.htm>. In addition to the hard copies we distribute, we also have an online version in English and Spanish. The directory has helpful general information on funding including how to develop a funding strategy and how to appeal a denied request. It also lists federal, state and local resources.

The Minnesota Dept of Health annually updates a huge (currently 252 pages) resource called, "Who Pays—Taking the Maze out of Funding." This manual provides Minnesotans with solid assistance on how to navigate the funding maze including tools such as a funding flow chart, possible funding ideas, descriptions of funding programs, and possible resources for non-citizens. There are also some helpful charts that compare service eligibility criteria. Additional information and this document can be found at <http://www.health.state.mn.us/divs/fh/mcshn/finres.htm>

- **Parents Should be Included on Funding Issues by Linda Taylor on Dec. 05, 2006**

Being a concerned parent, I would like to be included in on such aspects as school funding. Maybe, as parents who are so close to the issues of funding, we could use our influences on a political level. I know I have written a few letters to congressmen concerning other issues of the special needs children's population. Such tactics seem to help. The school systems might just find that their strength in receiving funding derives from the ones such issues touch the greatest. Of course, our school board meetings are open to the public. I guess knowing when funding was going to be discussed would allow parents to choose to attend to voice their concerns about that issue. Am I making any sense?

- **Re:Parents Should be Included on Funding Issues by Joan BL on Dec. 06, 2006**

Linda- You make a great deal of sense! You bring up some issues that we have been talking about on the

advocacy side of this conversation. Jane has talked about the 10 steps to successful advocacy. Making sure the decision makers are aware of the issues is critical! Legislators, school board members, PTA boards, school superintendents all need to be aware of the presence of students with disabilities in the class, and that their needs are important. So- keep fighting the good fight! Keep talking about what is important for all kids, and be aware that sometimes (lots of times) we need to be aware that we might be told no, but not discouraged enough to not be willing to come back another time with another good request (or even the same request, perhaps with a different wrapping!)

- **Re:Parents Should be Included on Funding Issues by Kim Moccia on Dec. 07, 2006**

I agree with Joan. Keep informed and stay involved!

- **Re:Parents Should be Included on Funding Issues by Thao on Dec. 08, 2006**

I work with the early intervention population, and you don't know how much this hits home for me...on so many different levels. First of all, the initial introduction to assistive technology can be a very anxious and stressful discussion for some families. The acceptance of the need for A.T. in their child's life can be very overwhelming. Sometimes, the acceptance does not even come until after the child has transitioned from the early intervention services to part B services. (Note: this is something that all school-based therapists should keep in mind, that, if a child did not receive A.T. during the E.I. years, it is not due to the therapists' negligence; we are merely trying to support the parents' readiness for A.T.). Secondly, if a family is ready for A.T. during the E.I. years, I have seen some pretty amazing results occur. Parents can move funding and legislation like you cannot believe! I have had parents get approval for funding when I couldn't pull it off! You go, parents!

- **Re:Parents Should be Included on Funding Issues by Jackie Hess [SI Faculty] on Dec. 11, 2006**

Thao, have you noticed any pattern to the readiness of families to accept the idea of acquiring AT for their children? Do you see cultural influences at work? Is educational level an issue (perhaps even conversely)? I would imagine that the way in which families are approached would be key. - Thanks.

- **Re:Parents Should be Included on Funding Issues by Thao on Dec. 11, 2006**

Hi Jackie,

Yes, both cultural and educational factors play very important roles in the families' readiness for AT services. In addition, there are socioeconomic factors; the children's levels/degrees of disability; the families' past experiences and perceptions of AT; and the families' support circle. Most families in E.I. are still working through the grieving process, and so acceptance does not often come so quickly. You are absolutely correct about the way in which families are approached about AT. We need to be very gentle in our ap-

proaches. We need to be very respectful of the families' concerns. We need to realize that, for some families, the need for AT may mean the loss of dreams for their children... loss of the dreams for a "normal" life. This doesn't mean, however, that we can't gently help them to realize some different dreams; and that is when I feel that I have been successful in introducing AT.

- **Re:Parents Should be Included on Funding Issues by Dr. Brenda Scott on Dec. 17, 2006**

Thao, you couldn't have said this better! Parents are often in the grieving process, sometimes until way after the student goes to Part B services. They also sometimes think that if they embrace an AT device, they are somehow depriving their children of learning the skill. For example, many families do not want to embrace augmentative communication for fear their children will not learn to talk if they use it.

- **Funding turn-around times by Ann on Dec. 05, 2006**

One of the learning objectives in the Institute handbook we were sent has to do with "funding turn-around times". I'm wondering how this impacts the provision of AT by schools. I've noticed, for instance, that it can take most of a school year for a child to receive a device that was identified in an IEP at the beginning of the school year. Why does it take so long? Is there any way of expediting these purchases? Does the federal law say anything about the time in which devices are to be provided? It seems almost criminal to me when a device requested in September doesn't show up until April. Then there's training time. By then, the entire year is virtually lost. Thanks for your explanations and suggestions.

- o **Re:Funding turn-around times by milissa.gofourth on Dec. 05, 2006**

The school is responsible for providing services as written in the IEP in order for the student to benefit from a free an appropriate public education referred to as FAPE. During the IEP team meeting discuss a time frame in which the child should receive the AT device. If it is going to take longer than a couple of weeks the team needs to discuss alternative methods and/or devices to use in the meantime. If the device is not provided in a timely manner (up for interpretation) the parent can request another IEP meeting to discuss how the school is going to provide the necessary device/service for the student to reach their educational goals. If the school does not provide the device the parent can use various steps within their "Parents Rights" such as filing a complaint or going through due process.

- o **Re:Funding turn-around times by Kim Moccia on Dec. 07, 2006**

I've found that turn around times vary greatly depending upon the device needed, the funding source, and the level of experience in completing and attaching the necessary paperwork required for funding. It can be helpful to try and anticipate what the turn around time will be and discuss strategies for dealing with the delay. Strategies may include borrowing a device from a loan program or renting/leasing one

from a vendor. Vendors who rent/lease devices often times deduct the cost from the sale price.

It's also important to have a backup plan in place for those times when the technology isn't working (broken or needs maintenance) or is not available (left at home, lost, stolen).

- **School Evaluations by Marianna Bond, M.Ed., ATP on Dec. 05, 2006**

In the part of the country where I live (SW USA), the school district AT/AAC evaluations are really rather pathetic. The school districts do not, in general, see the value in AT and see it more as an “unfunded mandate” because they do not receive any special monies for providing devices or AT services.

Therefore, they take a “it's your turn this year to be the AT evaluator” approach to school evaluations for AT/AAC instead of actually getting someone in to assist who is trained and qualified. That way, if they don't find a need, they don't have to pay for a device. I am wondering how this issue is handled in other parts of the country?

- o **Re:School Evaluations by Linda Taylor on Dec. 05, 2006**

As a parent, I have found that living in Tennessee is great as far as the school system attempting to do all that it can do to nudge its special student population toward productive citizenry. There are facilities from which parents are able to draw for the borrowing or other means of acquiring AT. I am not in on the ground floor of basic decisions of where the monies will come from for such fundings. I may contradict myself, too, when I retract the above statements, somewhat, to say that the AT is outside of the school district. One school principal actually, however, had a strong facilitator conduct a two day training session on the making and use of various AT -- that was quite rewarding. I, however, did not incorporate the ideas into carry-over at home. I needed more training than two days. The principal made a great effort, however. Maybe others could do the same.

- o **Re:School Evaluations by Jeanne S. on Dec. 06, 2006**

Our school district uses a “team” approach. We have a couple core people who look at the request for a tech evaluation and then decide who we need to pull in depending on the student, their needs, and information from the IEP team. Who actually “does” the evaluation varies from speech therapist, physical therapist, occupational therapist, vision specialist, or combination of people. We also have a person that will research current technology to see what is new out there. That person also works with teachers that have students who are auditory learners to check out the appropriateness of books to tape/CD/DVD or text-to-speech (software that will speak the book/handout/text to the student). I guess I feel fortunate in that our district does not “shy away” from technology. Where we struggle is “implementing” the technology. We find what we need, we acquire it - but have difficulty making some things “work” in the school environment, particularly when we get to middle and high school and things start happening at a faster pace - and with multiple teachers involved.

- **Re:School Evaluations by Kim Moccia on Dec. 06, 2006**

Jeanne you bring up a very good point. In my previous job, I worked with schools and this was an issue I often came across. It didn't take long for me to take Joy Zabala's SETT framework (Student, Environment, Task, Tools) and convert it to what I referred to as the SETTTI framework (adding training and implementation). [Joy, hope you don't mind!]

IEP Teams would be wise to consider and discuss training and implementation needs during the evaluation process in order to ensure that once the right AT is found the student will benefit from using it!

- **Re:School Evaluations by Andre Ryssemus on Dec. 06, 2006**

One of the things that I noticed when AT is being implemented is that the student has no interest in the AT whatsoever. With all the recommendations from professionals into what device will work for the student, if the student does not buy into the technology, or shows an interest in the device then it becomes a work on futility. Nice idea, but in the end a very expensive paper weight. Once the student has an interest or buy in, the AT purchased and is trained on the device one thing that gets forgotten in the process is the teacher. Especially, if you are dealing with multiple teachers as Jean stated. Some concerns that I came across with teachers are: What are the expectations for the device? Will the device cause a distraction to the other students in class? How, do I handle the student if the device breaks down or not in use? How will I implement a back up instruction if the device does not work? Not all teachers need to know what AT is out there but a basic functionality before the semester starts can lessen the anxiety level when the semester starts. Sometimes vendors will be more than happy to give a product demo.

- **Re:School Evaluations by Kim Moccia on Dec. 06, 2006**

Andre, truer words were never spoken! This is why it is so important to include the student, as much as possible, in the evaluation process. There are many reasons why a student may not "buy in" to the device. One common reason is that the student doesn't want to "look different."

A few years ago at a conference, I heard a story about a high school that purchased Alpha Smarts. Instead of making them a "special education tool" the school took a different approach. They had the coach introduce the device to the students at an assembly. The devices were then kept in the library and any student who needed one could check it out. The students who needed it as an assistive device used it and so did students who found it cool or convenient.

Another example of encouraging "buy in" is letting students use digital media players (such as an iPod) to listen to books.

The questions your raised regarding expectations and standard operating procedures should be addressed by the IEP team (including the student) up-front so that everyone is on the same page.

- **Re:School Evaluations by kthompson on Dec. 07, 2006**

The IEP team keeps coming up as a key component in AT implementation and I couldn't agree more! What we find often, however, is that the evaluation we provide is sometimes the first time since the IEP meeting that the whole team actually gets to talk with the family and the child together! What are some strategies that people use to help facilitate the teaming process?

- **Re:School Evaluations by Joan BL on Dec. 07, 2006**

When we developed the framework to help MN schools learn how to talk about AT, we adopted the SETT framework as a starting point. But- I also reflected on how it felt to be the Mom in the meeting, sitting in a meeting with all those professionals with charts and data and expert opinions about my child. And, I thought about how it felt for my child to sit and hear about himself, and not really have too much of a voice in those meetings.

We developed a voluntary (not required) set of forms for IEP teams to use prior to the IEP meeting. There is a form for educators, family members and the student to fill out, with a series of interview questions that will help all members of the team be prepared to talk about AT in a collaborative manner. We give the student the opportunity to talk about how she feels about using devices- either positive, negative or neutral. We give Mom or Dad a chance to tell about what their agenda is. I hear that these have been very helpful. Different districts use them in different ways. I have one friend who works in a district where many parents do not speak English. He makes sure he asks all the questions during the meeting of all participants, then summarizes the outcome for all. Some districts use some forms, some use none. But, when they are used, they help the conversation happen. To access the forms, please click here (See the last 15 or so pages)

- **Re:School Evaluations by Russ Holland [SI Faculty] on Dec. 11, 2006**

Here in rural upstate New York, we have been able to coordinate educational teams of people who work with each student we see through the evaluation process. Using a collaborative model, these people may include the OT, PT, SL/P, classroom teacher, aide, if there is one, and most of the time, the parents who generally 'drive' the whole evaluation in the first place. The student is always part of the process. Our experience is that, because we go to the student's site (and don't necessarily know the child that well), the student and the team that works with the student will be the 'experts'. A lot of ground work is done prior to the actual direct interaction with the AT in order to hear everyone's voice, plan what AT to use, and to design the experience to facilitate success and be meaningful to the student. The beauty of the collaborative model is that the outcome is truly a team process and is more likely to be supported cross-discipline because everyone has had input. Many times trial periods are suggested and

reviewed which has saved some expense since once the ‘honeymoon’ was over, the AT was put aside. In most cases where students are using AT, monthly or quarterly meetings of the team are written into the IEP so that ongoing communication takes place. In addition, training the ‘new’ team for the next school year starts in March or April, depending on the needs of the student, so that carryover is ensured.

- **Re:School Evaluations by Kim Moccia on Dec. 12, 2006**

Ongoing communication between IEP Team members and developing a transition/training plan to ensure carryover from one year to the next are key to successfully integrating AT. Thanks, Russ!

- **Re:School Evaluations by Grace F. on Dec. 15, 2006**

These forms will be very helpful; thank you for the link! I have often been concerned about how the student and parents feel when going through these evaluation sessions, too. Having the opportunity to complete these forms prior to the IEP is a great idea, and much less threatening (and therefore, more accurate).

- **Re:School Evaluations by Karen Dedmon on Dec. 18, 2006**

Can you share the link you mentioned in your post regarding having evaluation forms completed prior to the IEP meeting. This sounds like it may help me as well. Thanks

- **Re:School Evaluations by Grace F. on Dec. 18, 2006**

Check Joan’s Dec.. 7th entry; there’s a link near the end of her entry.

- **Re:School Evaluations by Kim Moccia on Dec. 18, 2006**

Karen, the link to the Minnesota Assistive Technology Manual is http://education.state.mn.us/mde/Learning_Support/Special_Education/Evaluation_Program_Planning_Supports/Assistive_Technology/AT_Resources/index.html. You should find the forms referenced above near the end of the manual (approximately the last 15 pages).

- **Re:School Evaluations by Linda Taylor on Dec. 06, 2006**

I thank Jeanne for that explanation of how her school incorporates AT. She should think about conducting seminars to explain this entire concept of AT to people who are not “up” on the lingo of AT. As I have stated often this week, the “implementation” stage is where the ball gets fumbled at our child’s school, also. Since that is the case, seeming, elsewhere, why isn’t more time devoted to making sure the technology is not just available but sitting useless, unused to its fullest capacity? Is there a need for a call for more AT students in such a discipline?

- **Re:School Evaluations by Kim Moccia on Dec. 06, 2006**

Linda, the short answer to your question is YES there is a need for more postsecondary training programs, as well as, general awareness training for the public. Professional training includes an understanding of best practices in assessing needs, evaluating options, and the importance of teamwork during this process. As far as the technology itself it is impossible for one person to know it all or be an expert on every device. Working with vendors, outside consultants and utilizing resources such as listservs can be very helpful.

- **Re:School Evaluations by Laurie DuBose on Dec. 07, 2006**

When we receive a referral for an AT evaluation for a student/client with complex needs at our vocational rehab center, we schedule OT,PT, SLP, and case manager to be present for the intake. This represents our core AT team. The team also includes a rehab engineer and LD specialist on a prn basis. At the intake with the student, family, and ideally, school representative and/or therapist,needs/goals are identified and the course of the evaluation progresses from there. Disciplines that are not needed, drop out at that time or are placed “on call” if needed later. Each discipline brings expertise related to the identified needs--whether seating/positioning/mobility, computer or AAC access, communication needs and so forth. This also allows staff to focus on an area of expertise related to his/her discipline and not be in a position to have to “know it all”--something that is virtually impossible to do. As a state sponsored vocational rehabilitation center, our focus is on transition from high school to post secondary education, training and/or employment. We see ages 15 on up. Schools utilize our services to help provide vocational guidance and direction as well as evaluating AT needs and potential to benefit from further therapeutic intervention. Funding options for these services may include medical insurance, Department of Rehab Services (DRS), blended funding between DRS and DOE, as well as others.

- **Re:School Evaluations by Lesley Thacker on Dec. 13, 2006**

Hi everyone! I've been lurking this past week. I'm sort of a professional observer -- I've been a teachers' aide and now I do waiver care and respite while I finish my degree. I've gotten to know some amazing people.

Many, many, many people I know have a complete block when it comes to AT because of the implementation issue. By the time I know a student or a client, he or she has usually been through the school district long enough to be a bit jaded. The parents will answer “oh, we tried that a few years ago” or something like that. I hear the story of the expensive keyboard that never got used, how “she just hates the computer” etc. etc.

In my opinion, implementation is almost a full time job. When the ball gets dropped there, it really gets dropped because it affects future interventions as well.

Right now, I do all the programming for the boy I work with. I really am encouraging his mom,

teachers, and other care providers to get involved if I program his device, it only says what I think I need him to say. (It's a graphic based communication system) I recently found out he's been going to concerts with another care provider -- that's awesome. I need to know that.

The device abandonment is also a HUGE issue.

I think if everyone on a team works hard to implement the device in the best way possible, the student and the team will be less likely to give up on it. I think it's important to choose a device or a communication method that grows with the student.

The pressure to make a device work can also be overwhelming.

"What? We did car washes for this and now you are only using it to ask me for more trail mix?" It's easy to say "oh, he's not using his device to its capacity" and leave it at home instead of letting the student take weeks, months, or even years to really feel comfortable with it.

Educators don't have weeks, months, years, typically. - They have 4 quarters. I can see where that can lead to frustration.

(Someone pointed out to me that when I got my first computer, I wasn't programming it right away. I played solitaire and made clip art print outs. No one decided it was a waste or was upset that I didn't just know it automatically. Yet we expect our kids with learning differences to just pick up a dynavox and suddenly be able to explain what is going on in their heads.)

- **Re:School Evaluations by Tasha on Dec. 13, 2006**

Lesley- you raised great points! Implementation is (in my opinion) the biggest hurdle. And one strategy to help is to make sure everyone on the team knows what their role is, and to make sure that adequate training occurs to allow them to do their role.

The youngster you work with is very lucky to have you involved in his life.

- **Re:School Evaluations by DThompson on Dec. 14, 2006**

I would have to agree with this post. I have worked in various Adult Day Centers where the majority of the population were AT users. The individuals that worked primarily with the individuals had a hard time "buying into" equipment because the individuals were not able to use the equipment as soon as they came out of the box. This is where having a lot of energy and a passion to educate about promoting self-expression, independence and self-determination come in. I have worked with many individuals for 1+ years in order to embed AT into their daily lives. IT TAKES A LOT OF ENERGY and a passion to educate!

- o **Re:School Evaluations by Kelly C on Dec. 06, 2006**

I find that this issue is handled differently even within a state...for example, here in RI there are some districts that have AT teams, others that have an OT or other therapist familiar with AT and some that

refer to outside agencies. Parents do have the opportunity to disagree with an evaluation conducted by their district and request a second evaluation at a place of their choosing. Unfortunately, all of this takes time and students can lose an entire school year in the process!

o **Re:School Evaluations by RECTanya on Dec. 07, 2006**

Hello, Where I am in the south we have a Assistive Tech Project that will give parents and schools an assessment of what may work for AT for the student. They are also available to go into schools and work with the teacher and school staff whether it's a hardware or software issue. The project is a place where parents and schools can go and try out software and hardware as well as AT toys and other devices. It is my understanding that most states have an AT Project similar to this so you may want to search out to see if your state has an AT Project. We also have a AT Expo each year where lots of vendors come together from computers to housing modifications etc. are displayed. We are currently as a state reaching out to nearby states to collaborate in the area of AT whether it's wheelchair or other equipment needed. Check out what your STATE is doing in the area of AT and share with the school districts. I used this project for help with my own child.

▪ **Re:School Evaluations by Kim Moccia on Dec. 07, 2006**

Every state and U.S. territory has an AT Act Program. The Assistive Technology Act of 1998 was amended in 2004. This Act requires that programs funded under this Act primarily focus their activities in the areas of device loan, device demonstration, device reutilization and state financing activities. The types of activities vary from state to state. I may be biased but I believe that getting in touch with your state AT Act program is important! In case you missed it, here is a link to more information on AT Act programs and a list of state contacts <http://www.resna.org/taproject/at/stateprograms.html>.

• **Try before you buy by sandync on Dec. 05, 2006**

One thing that I do with the students in our school system is to borrow many items from places like the North Carolina Assistive Technology Program before we purchase items. This works very well since so many devices are so expensive. It helps to make sure we purchase the right item many times. I believe in the "try-it before you buy-it" idea! It has helped us many times. I am thankful our state has the NCATP and several other places we borrow items.

o **Re:try before you buy by kthompson on Dec. 05, 2006**

I agree with you. We have a regional evaluation center where we have been fortunate enough to have participants/students trial devices here at the evaluation, and now, many reimbursement sources (other than schools) are requiring that a trial rental be completed to ensure good fit. When this is not an option, AT professionals can often contact vendors of a specific product directly. The vendors are more than happy to have a representative come and demo a product with a specific person. They are often very knowledgeable and will sometimes allow for a professional trial or rental of a device as well.

o **Re:try before you buy by Linda Mesavage on Dec. 05, 2006**

Loan programs and alternative funding programs are 2 of the key activities of State Tech Act Programs which exist in every state. In Pennsylvania we have two excellent programs, PA's Assistive Technology Lending Library loans equipment regardless of age or disability; PA Assistive Technology Foundation has two cash loan programs for individuals to purchase assistive technology. I encourage everyone to check out the State Tech Act Program in their state. In Pennsylvania our State Tech Act Program (PIAT, Pennsylvania's Initiative on Assistive Technology) is located at Temple University and can be found at: <http://disabilities.temple.edu/programs/assistive/index.htm>

Find your state's Tech Act Program on RESNA's web site at: <http://www.resna.org/taproject/at/statecontacts.html>

▪ **Re:try before you buy by Jeanne S. on Dec. 06, 2006**

In Ohio we have SERRCs (Special Education Regional Resource Centers) that are local and frequently have technology "libraries" that lend software. My local one, MEO-SERRC, is great at letting our district use software. They also have a tech person that I can discuss concerns/options with and often lets me know new things to consider. They have been helpful to me when I want to have a student try something. Sometimes what we as the tech team think sounds great doesn't actually work so well in a particular environment so it is nice to borrow and rule it out before spending money and time on something that just doesn't match the student.

▪ **Re:try before you buy by cpichler on Dec. 06, 2006**

Wisconsin has two resources available to children, the Wisconsin Assistive Technology Initiative (WATI) maintains a lending library of technology specifically loaned to school districts. The state tech act program, WisTech, has 8 equipment libraries located in the eight Independent Living Programs around the state, and the equipment in these programs can be borrowed by anyone. WATI has also arranged bulk purchases of some of the most popular educational technology, mostly software based, through a local vendor to reduce the cost to districts. Check out the WATI website at www.wati.org or the WisTech site at <http://dhfs.wisconsin.gov/disabilities/wistech/>

o **Re:try before you buy by Laurie DuBose on Dec. 07, 2006**

We are fortunate at my facility to have a wide variety of AT to use for evaluation purposes and the luxury of time, in some instances--depending upon availability, to evaluate the usefulness of the device/equipment over an extended evaluation period. This process allows us to make recommendations for AT with a level of confidence that what is recommended is appropriate. There are many factors, outside the evaluation setting, however, that contribute to the success or failure of use of any AT as we all know. Funding support, family and educator support, therapeutic intervention, student/client motivation for use of the device, to mention a few. An extended trial, as noted in the "try it before buying it" is highly recommended WHENEVER POSSIBLE, as it helps provide insight into each of these factors in advance of the purchase--it also provides the opportunity to change course/recommendations if needed.

- **School Evaluations by Vicki L on Dec. 05, 2006**

I want to thank everyone for their information on school evaluations for AT. All the information was very helpful. We do have an independent AT evaluator across the state where I get a lot of information but I could not get the school district to pay for an evaluation by them. I would have to come up with the dollars myself, plus travel expenses. I got the impression that even after the evaluation is completed the school district may not pay for the AT device for my son to communicate with, due to loss of language. I would possibly end up purchasing the AT on my own, or trying other funding.

What type of role do any of you believe Protection and Advocacy could play in these types of situations? Has anyone ever tried to use them to get AT into the IEP or purchasing?

- o **Re:School Evaluations by patty on Dec. 05, 2006**

It is interesting reading everyone's viewpoint on this subject. I came from a school district that had the beginnings of a very good system. There was an assistive technology team and we often called in "experts" in the field to consult with when a need arose. The school district was lucky because the county paid for most of the augmentative communication devices. Now I am in MN and it isn't nearly as easy. I am working with high school students who have autism and little to no way of communicating. The parents of the students in my classroom had no idea of the technology that was available, regardless of who pays for it. The difficult part, as I see it, is you have to prove that students aren't making academic progress. For some students that is very difficult to do and it seems rather tricky when we don't know what their capabilities are because they have no way of communicating. I am hoping these discussions will assist me in helping my new school district develop a better system.

- **Re:School Evaluations by Joan BL on Dec. 05, 2006**

Patty- you raise an interesting point and one I would like to talk about. (I am, by the way, aware of the district where you work, and actually used to be the outside AT expert for that district!)

There is a combination of folks who have responsibilities for individual student advocacy. The first, of course, is the parent. I do know from personal experience that parents are expected to do far more than is reasonable to have any one person do. Parents should not have to know the range of AT devices, but I would hope that they have exposure to the fact that there is AT that helps students with disabilities. The educators on the IEP team are another line of advocacy. Again- no one person can know all the AT that is "out there" so what I expect from teachers is that they know that AT is available, and that there are resources to help pay for it. The county case manager is another line of approach. In MN, there are multiple opportunities for funding for communication devices. County case managers are the first line of approach. If you have high school aged students, you may also have rehab counselors in the IEP team meeting to talk about transition issues.

There is a huge issue with needing to have a school system that is willing to talk about AT, and to make it a meaningful part of the curriculum. Your former district had an AT team. This is a good

approach. I have a personal goal for MN that all educators need to be aware of the potential for AT, and should be aware of at least some AT devices. I know I have not reached my personal goal, but I continue to work on it! I would be very happy to help you tie into some of the resource in MN that might help you develop resources to assist your students.

- **Re:School Evaluations by vicki on Dec. 05, 2006**

Joan,

The school district where I work does not have an assistive technology person. We contact the Educational Coop in our area with questions. I think it would be great if we had more resources available to us. Is there an assistive technology evaluation form we can use to help us along the route to finding the right assistive technology or if there is some type of technology that would help a student? I teach in MN and would love to tap into the resources you mentioned.

I am finding this institute to be a great source of information and resources already. Thanks.

- **Re:School Evaluations by Joan BL on Dec. 06, 2006**

Vicki- If I am correct, you are in a fairly rural section of MN. Here are some resources available statewide- the MN state AT listserve is full of incredibly generous practitioners, regardless of location- you can always reach a few hundred friends who share interest in AT. Contact me to join the list. There is also the statewide conference in AT which is scheduled April 23 & 24, 2007 in St. Cloud. Registration material will be out in January. There is the state AT manual which has a form that addresses components of an evaluation. The manual and information on other resources can be found here.

The MN department of education has published a video tape with Joy Zabala who developed the SETT framework, with her talking about how to think about AT. Again, contact me off the institute and I will see if I can get you a copy. We are talking with Joy about doing a new version of this on DVD this coming year.

MN also has the PACER Simon Technology Center. I believe they will be in your part of the state this winter to conduct some workshops on AT. They have a fabulous lending library with many resources. And, of course, our federal tech act program (STAR) has equipment for loan and has other resources for information on AT and in particular they have a great funding directory. Kim Moccia from STAR is acting as faculty in the funding part of this institute. - I hope this helps-

- **Re:School Evaluations by Jackie Hess [SI Faculty] on Dec. 06, 2006**

Valdosta State University has more than 60 online videos on a range of AT topics, including a 15-minute video and Power Point presentation by Joy Zabala on "Evaluation of the Effectiveness of Assistive Technology" There are a wide array of others as well

(presented by Joy and other experts), addressing both specific AT devices and general AT information. The video selection can be viewed and accessed at: http://coefaculty.valdosta.edu/spe/ATRB/Video_Tips.htm

The Georgia Project for Assistive Technology has a number of online videos as well, including: “Considering Assistive Technology in the IEP” and “Assistive Technology Evaluation” at <http://www.gpat.org/Resources%20Main.htm> While these videos take a little while to load, most of them are well worth the effort!

During the final week of the Institute we’ll discuss and re-post these resources and others.

- **Re:School Evaluations by Jackie Hess [SI Faculty] on Dec. 05, 2006**

Recently the U.S. Department of Education has been promoting a new approach - Response (or Responsiveness) to Intervention (RTI) - as a means of identifying students who need additional services, and providing those services, BEFORE they display a several-year pattern of failure. I’m going to ask Stephen Luke of the National Dissemination Center for Children with Disabilities (NICHCY) to weigh in with information about RTI. I think it may have a significant impact on the provision of AT (albeit down the road).

- **Re:School Evaluations by hollygg on Dec. 05, 2006**

I would be interested in knowing what the AT evaluations look like that everyone is talking about. I have found in our program that we are using a combined observation (in the “customary environments”) and collaboration process with the SETT Framework as our guide. The only time that I would use a formal assessment tool, for example, might be if I had some specific concerns re visual perception that might compromise a child being able to access a communication device etc... We have also video taped a child in the classroom during key activities to review later and use as a comparison later in the school year. After the discussion with the classroom staff and parents we try out some of the suggestions in the classroom, make modifications and document the changes in terms of increased independence, increased participation and other goals that were discussed. As our case load gets bigger I worry about how this will work, time wise. Thanks for the input! Hollygg (WA state)

- **Re:School Evaluations by Jeanne S. on Dec. 06, 2006**

I would be interested in knowing where AT would fit into the RTI process. Right now, AT in our district is incorporated into the IEP process. But the students who we are starting to address with the RTI process are not formally identified yet with a disability so not in the IEP process - yet providing them with AT would be a reasonable intervention. Is anyone out there providing AT to students as an intervention - before they are placed on an IEP (or 504 Plan)?

- **Re:School Evaluations by Dr. Brenda Scott on Dec. 09, 2006**

Jackie, I agree with your comment on RTI. Technology (to include assistive technology) needs a broader definition within the realm of education. Assistive technology has been traditionally viewed as “access/accommodation” for moderately to severely disabled students. However, it can also be an intervention for students who exhibit any type of learning problem. Especially when we consider the learning disabled population, there is now a plethora of strategies, techniques, low tech and high tech devices that can provide modifications to curriculum. I think the real challenge is going to be getting school systems to adopt this broad definition, given that their technology funds continue to dwindle.

- **Re:School Evaluations by Stephen_Luke on Dec. 14, 2006**

Jeanne S. and Dr. Scott present good points in discussing RTI's relationship to AT and IEPs. Clearly there are some students whose obvious or documented disabilities allow for IEPs at early stages in their school career. Given the disability, AT may or may not be appropriate, but at least it is an option. As is often the case, far too many other learners are left to struggle over a significant period of time before they become eligible for IEPs, let alone the supportive AT interventions that can be included in such programs.

The spirit behind RTI is to provide more targeted support at the first signs of struggle. Such an approach holds the promise to unify a historically discontinuous service delivery system that has emerged to carve deep divides between general and special education. As we see more and more states, districts, and schools embracing an RTI paradigm, our conceptual approaches to education become necessarily reframed. Part of this reframing must include meaningful application of AT beyond (and before) the IEP process.

It is likely this paradigmatic shift will take some time to take root. Forums such as this can only help to illuminate the complexity of issues involved. For a compilation of some useful resources on RTI: <http://www.wested.org/nerrc/rti.htm>

- **Re:School Evaluations by Dr. Brenda Scott on Dec. 17, 2006**

Stephen_Luke, thanks for the reference re:RTI. I agree, this is going to take some time for school system folks (and parents) to embrace and shift.

- **Re:School Evaluations by Kim Moccia on Dec. 05, 2006**

When we talk about the school's role in funding assistive technology it is important to remember that assistive technology purchased with school funds becomes the property of the school. For this reason it is important to take a long look at the type of AT needed. If a device is needed beyond the educational setting, such as a communication device, it may be more fitting to use other funding sources such as Medicare, Medicaid, private insurance and personal funds.

Team work between the IEP Team and professionals consulted during the evaluation process is crucial to meeting the child's needs at home and school. It can be helpful to have the support of a trained advocate. Organizations that serve specific disabilities such as UCP, Parent Advocacy Centers, and the Protection and Advocacy for AT program can help parents find the support of an advocate.

A listing of state Protection and Advocacy for Assistive Technology contacts is available at <http://www.nls.org/paatstat.htm>.

- **Role of school district by lmf2@fm1960.net on Dec. 05, 2006**

My school district gave almost no fight for a personal communication system. I met with the Spec.Ed. director privately and updated them that we had obtained our own evaluation (12 trials in 6 weeks). We explained that we were applying for funding through private insurance and the state funding mechanism. I pointed out that they would need to acquire a backup device able to support the same function (because technology fails, and because my son would not be able to progress in his IEP if the technology fails). We had to submit our Private Eval and agree to the district doing their own evaluation. They agreed to a short trial period, one month. At the IEP team meeting submitting their findings, the Sp.Ed. director asked, what would happen if they bought the back up and our funding sources did not work out. I responded that their back up would then become my son's primary device (they had no response).

I asked for the School district to coordinate a loaner device from the local education service center while we waited for our funding sources to process our requests; they did. We did receive private insurance denial one week later, but two weeks after the denial, we received our state funding voucher, and seven days after that the device was here. Louise D.F., North Texas

- **Taking school AT home by rylin on Dec. 05, 2006**

I would be interested in others' experiences with students being able to take AT purchased by school home. For my own children we have used the "needed for educational activities at home" i.e. homework, argument. I have run into greater resistance when supporting other families in their IEP's . I often hear parents voice frustration by the "waste" of resources that duplicate purchasing of equipment for a child to use in different settings represents. One of the barriers often raised surrounds who is responsible for breakage. What are others experiencing? - Rylin Rodgers

- **Re:taking school AT home by Rita Wood on Dec. 06, 2006**

This summer I sent a couple of switches home with a student so that he could access his environment at home (turn on the TV, radio, etc.). I also sent home an agreement to the parent listing the equipment, their purposes and uses, and a statement saying that the parent was responsible for reimbursement if the switches were broken or lost. This paper was signed and returned to me prior to sending the

switches home. Since I work for an educational collaborative which serves many districts, this student's LEA requested the specific agreement. The student used them all summer and returned them when he came back this September.

o **Re:taking school AT home by milissa.gofourth on Dec. 06, 2006**

I am not sure what other parents are experiencing with schools when it comes to being able to have the student take home the device, but I'm sure it runs from strong resistance to total acceptance. IDEA addresses a student's need to take AT home, "[300.308(b)] On a case-by-case basis, the use of school-purchased assistive technology devices in a child's home or in other settings is required if the child's IEP team determines that the child needs access to those devices in order to receive FAPE." So make sure the issue is addressed in the IEP. As to the schools' concern on who is responsible for breakage, I would encourage there be an open discussion of the school district's policy for any student taking any school property home, i.e. text books, band instruments etc. But remember, the school is in fact responsible for the repair or replacement of the device.

o **Re:taking school AT home by Jeanne S. on Dec. 06, 2006**

Our district usually allows devices to be taken home when they are required for IEP goals that are worked on at home and school (i.e. homework, communication skills). In some cases we have used our site licenses (when allowed) to install applicable software on the home computer so that it matches what exists at school. In another case, it was a laptop that went back and forth. So far our school district has covered the cost of breakage. There have been one or two cases where our district has been reluctant to do this because the family is seen as "transient" or "unreliable" and it becomes an issue that the IEP team has to work through.

o **Re:taking school AT home by kthompson on Dec. 07, 2006**

Although I do not work directly at a school, it appears that bringing equipment home is the exception more than a rule around here. We in fact work with families to purchase equipment on their own (with assistance of their AT team at school) so that if they change districts, schools or sometimes even teachers that the equipment goes along with them because it is in fact theirs. They also have to understand that it is theirs for the fixing as well :)

▪ **Re:taking school AT home by Kim Moccia on Dec. 07, 2006**

When assistive technology is part of a student's IEP, the school is responsible for providing the assistive technology necessary to implement the student's IEP. The school is also required to cover the cost of maintenance, repair and replacement of the AT even if the school did not purchase it. There may be exceptions if a device is used at home for non-IEP purposes.

o **Re:taking school AT home by Laurie DuBose on Dec. 07, 2006**

Responsibility for breakage is an ongoing issue without an easy resolution. Some parents take the risk

of breakage and send the student's personal device to/from school--hoping nothing will happen. Others refuse to send the device unless the school assumes liability in case of breakage. Many AT devices are "temperamental", including laptop computers, and are subject to increased likelihood of damage, loss or theft, associated with being transported from home, to school, to classes, to school events outside school etc. Being able to pinpoint how/when the damage occurred may be challenging, if not impossible, to determine. Duplication of equipment has its own challenges, however, as information recorded/stored/assigned at school, may not then get home to the equipment there and vice versa. Or it becomes lost along the way. How this question is handled varies from school district to school district and often corresponds to the size of the school district's AT budget and the level of understanding/enlightenment of those in a position to make the budgetary decisions.

o **Re:taking school AT home by Dr. Brenda Scott on Dec. 09, 2006**

Our school system allows students to take equipment home to use. We ask the parents to sign a "Home Use" form, which just states they will assist and monitor their child with the usage. With proper supervision, we believe the AT devices will be taken care of and normal wear and tear (and some breakage) is expected. We have been doing this now for the past 5 years and have been fairly pleased with the results. How can we foster independence with our disabled population if we don't allow them to use our devices in all environments?

▪ **Re:taking school AT home by croberge on Dec. 11, 2006**

I am new to my position in our school district and am my own department (Assistive Technology), so I am in the creating stage of documents and resources. If anyone has copies of "Home Use" and "Equipment Usage" forms, etc. I would appreciate guidance and examples. I have seen a few forms and have created a few, but the perfectionist in me knows there are better forms out there.
Thanks

• **Monitoring AT in the IEP by Liz L on Dec. 06, 2006**

I haven't read all of the messages yet but wanted to get this out there. I hope it's not redundant. While the schools are legally responsible for providing AT, there are always rumors (and truths!) about administrators telling teachers not to put AT on the IEP because there is no money. I know there is a lot on truth in the 'lack of money' excuse but aren't the feds allowing it to happen through their lack of follow up? In Wisconsin we count how many students have AT on their IEP but no one asks how many should have it on the IEP and no one is really checking to see if it has been provided. We assume it has because the law says we have to. If districts were held more accountable they may purchase more AT and actually find that it's cost effective! Just looking for thoughts from others.

o **Re:Monitoring AT in the IEP by Joan BL on Dec. 06, 2006**

Liz- What a great point! This is certainly also a point in the advocacy conversation. One of my biggest

concerns is that when dollars are tighter, the families that know about, and know how to ask for AT frequently get it because they are good advocates.

We work very hard to find multiple funding streams for devices. But- the bottom line is special ed can be expensive, and until there is enough pressure on Washington to fund it at the level we need, not enough will happen.

▪ **Re:Monitoring AT in the IEP by LMF on Dec. 07, 2006**

I am wondering about example goals with AAC devices. My son is a first grader starting with his communication device. We have had the device since June. An independent consultant has visited school and made some suggestions for implementation. I am concerned and would like to hear some professional opinions about:

1. The one time visit is only able to estimate and project implementation and the IEP team is trying to write one year goals off of implementation suggestions
2. Should the IEP team consider not only how to implement the device at school but also how to at home and in other settings, and what about family training for how to implement the device in outside educational setting.
3. How do some districts manage the programming time? How do programming time estimates get documented in the IEP (do they, or are they incorporated in other numbers?) How do some professionals manage the up-front programming demands?

In this situation the SLP at school recently received her C's (May 2006). I am very concerned about the learning curve and the time it will take her for programming. Not to mention her training on the MT4 is very basic. And then there is the lack of experience and the impact that will have on estimating and managing programming requirements to support the IEP.

I apologize for the long post. And would really appreciate experiences and opinions.

Cheers! Louise

▪ **Re:Monitoring AT in the IEP by Kim Moccia on Dec. 11, 2006**

Hopefully some of our participants with experience in this area will respond. In the meantime, I've forwarded some of your questions along to a listserv and I will post any responses I receive. With regard to question #2 I would venture to say that "it depends." It would be reasonable to expect the school to help program standard communication pages (greetings, feelings, etc.) as well as pages that deal with the student's educational needs and IEP goals. It would not be the school's responsibility to program personal pages such as a page used to request favorite videos. Vendors are a good resource for training opportunities and many even include online tutorials on their Web site.

▪ **Re:Monitoring AT in the IEP by Kim Moccia on Dec. 12, 2006**

I'm passing along a response from a colleague –

I think that it is important, as an extension of the SETT process, to delineate everyone's role--who is in charge of programming the device, charging it, deciding on core and fringe vocabulary, etc. In an ideal world, I think the SLP should be responsible for "creating the master plan" since SLPs have knowledge of language development, including syntax and morphology. Consistency with device programming is crucial. If a device has multiple pages, buttons should be placed in the same location on each page. I have seen too many devices where AAC users end up in "never never land"-- the AAC user can't get back to his/her main page. It is great for parents to have input, but I really think that someone who has knowledge of how kids learn language decide where buttons should be located, number of buttons on a page, etc. With kids who use digitized speech devices, it is great to have a "peer-aged voice" do the recording.

The problem, of course, is time. I have to admit, that I do the majority of my device programming at home. There simply is not enough time during the school day.

An equally important issue is teaching the AAC user to use his/her device and to provide the user with opportunities to communicate.

- **Re:Monitoring AT in the IEP by Kim Moccia on Dec. 12, 2006**

Here is another response I received to the question Louise posted above -

These are tough questions. In our district, I have seen that the devices that get used the most are those programmed at home by mom. Ideally the speech therapist does the programming and in the end the SLP is the person to communicate with Mom what they need. The SLPs are starting to do more programming but they generally don't write in time for programming. I think they should. It gets tricky because you need a point person to keep the boards consistent. In the end, it comes down to who knows the most about programming the device.

- **Re:Monitoring AT in the IEP by patty on Dec. 12, 2006**

Hi Louise,

I have had goals put in the IEP that relate to learning the programming part of a device (turning it on, volume, etc.) and ones which relate to using the device to communicate. I also include using the device in most of their academic and social goals. I think one area that is often over-looked is the programming time. I have been told by many people to try to keep the programming time down by using all of the pre-programmed tools. There have been many times when I need to program 1 or 4 devices for projects/activities for the week and have little to no time to do it. I think it is an important question to be asked at an IEP meeting "Who is going to program the device and when will it be done?" Many times it is unclear who is supposed to do the programming, the teacher, speech person or assistive tech. person. Usually the teacher is the one who needs it done, so it is assumed they will do it, with no additional time. It is a good question.

o **Re:Monitoring AT in the IEP by Dr. Brenda Scott on Dec. 09, 2006**

I agree with having accountability for AT for school systems. Because I head the AT program for our system, I keep a list of who is getting what. Each year we do a “head count” audit to determine the numbers of students in each disability category who are receiving services and our funding is based off of these audits. However, AT is considered a “related service” and is not counted, so I am never asked for my list. An exception is made for visually impaired and deaf-blind students, who are counted on a separate registry and who do qualify for some federal funds to purchase materials and equipment. But we are never going to get there if we don’t allocate funds for AT and hold systems accountable for it.

• **Implementation by LMF on Dec. 06, 2006**

We are very stuck in implementation. Creating the vision, who, what, where, when, and how. I have decided that the campus administrator (Principal) has to have a working knowledge about not only training time, but also programming and a “whole team” approach to programming.

I am curious what kind of district models there are of successful team approaches to implementing communication devices that coordinate: Token Systems, Task completion check lists, interactive “to do” lists, Visual schedules, and Visual rule scripts.

What are some experiences with this, good and bad? I would appreciate everyone’s thoughts! - Louise

• **Back up plan by sandync on Dec. 07, 2006**

RE: AT equipment/devices

This might be a little off base but I did want to share it with you all and especially parents of children with expensive AAC devices.

I just want to make a note that it doesn’t matter whether the school purchases the equipment or the equipment comes from another source; we all need to have a backup plan for our devices. Sometimes they quit working for whatever reason. I recently finished doing a presentation on Emergency Preparedness for People with Disabilities using Assistive Technology devices to the NC AT EXPO. I can’t point out enough for everyone to have a backup plan. Many times batteries die and/or the device may have to go in for repair or whatever. Use low-tech equipment alternatives like communication boards, erase off pads instead of laptops or expensive augmentative communication devices. Have a plan ready.

Be prepared. Don’t wait until disaster strikes. During Hurricane Katrina many folks were left behind without the devices they needed to communicate. I am really getting a lot out of the information presented to us thus far. I am personally hearing impaired and have to remember this myself to have “extra” batteries. Thanks.

- o **Re:back up plan by Kim Moccia on Dec. 07, 2006**

Thank you for that important reminder!

- o **Re:back up plan by JH on Dec. 08, 2006**

This is great advice. Could you share any other suggestions from your presentation? Who should have a copy of the plan? How often should it be updated (checking phone numbers for instance, for currency). In the wake of 9/11 many of us put together “fly away” bags, with essentials ready to go. What should be in an emergency kit for a child with disabilities? (This probably doesn’t fit in this sub-topic, but a little flexibility goes a long way.) Thanks.

- o **Re:back up plan by Dr. Brenda Scott on Dec. 09, 2006**

Sandy, I was in a resource room just yesterday, and they were drawing pictures on an erasable pad to work with a student whose augmentative communication device battery had failed. What a good demonstration of low tech and of having a back up plan!

- **Re:back up plan by croberge on Dec. 11, 2006**

It is interesting to see that low-tech devices can still be effective. Speaking of devices, any ideas out there on the best ways to approach with parents that the best way to start (in most cases) is with low tech first. Our school district has given away the moon and stars in some cases and then word gets out that this was done and therefore most parents want to start at the high end. In most cases it is not necessary and more importantly funding is a major issue since funds have not been allocated for AT. Thanks.

- **Re:back up plan by Kim Moccia on Dec. 11, 2006**

Device trials and data collection are an important part of documenting what is most appropriate for the student at that time. It may also help to remind parents that it is better to wait and obtain a high-end device when (and if) it is appropriate rather than let an expensive device sit and hope the student grows into it. (Not to mention that there will be something newer and better down the road!)

- **Medicaid Funding AT by milissa.gofourth on Dec. 11, 2006**

I want to provide a basic overview of Medicaid because it can be a wonderful funding source, particularly for children who qualify. Medicaid (should not be confused with Medicare) is a joint federal-state medical assistance program that provides coverage of medical expenses for categorically qualified persons with low income. Categorically qualified can be children, pregnant women, aged, blind, or individuals with disabilities. In most states individuals that qualify for Supplemental Security Income (SSI) through the Social Security Administration also qualify for Medicaid.

Medicaid covers a broad range of medical services. Some services are mandated by federal law and must be provided by every state, while other services are provided at a state's discretion. Assistive technology (AT) is purchased as Medical Equipment (ME) as mandated under a home health service. Not all AT is purchased by Medicaid, it must be considered "medically necessary" as defined by your state Medicaid program. AT devices may be available as a component of other Medicaid programs such as Early and Periodic Screening, Diagnosis and Treatment (EPSDT) or special waiver programs. Medicaid generally makes payment for covered services provided by health care providers who have entered into a participation agreement with the program. In some states, the Medicaid agency has created a mechanism for schools to be a Medicaid provider of medically necessary services such as physical therapy, speech therapy, or case management, just to name a few of a potentially very long list of services.

Are any of you associated with school districts that are Medicaid providers? What have been some of your successes in funding AT through Medicaid? What have been some of your denials? Why?

o Re:Medicaid Funding AT by Thao on Dec. 11, 2006

In early intervention in Oklahoma, we have been very successful with Medicaid funding for DME for seating and positioning. We have encountered some minor issues, at times, regarding reimbursement for trays and for tie down systems for wheelchairs and strollers. All in all, though, we have had success in E.I. A speech-pathologist I know was even successful in obtaining a communication device for a fifteen-month old in our program. In Oklahoma, we have more difficulties with private insurance funding. We have a program called TEFRA (Tax Equity and Fiscal Responsibility Act) that provides Medicaid for those families who are not eligible for Medicaid (I think primarily due to income), yet whose children are medically needy. This program allows Medicaid to pay for equipment that the private insurance would otherwise not fund.

o Re:Medicaid Funding AT by Grace F. on Dec. 15, 2006

We've had wonderful success with Medicaid here in the UP of Michigan, partly due to a working relationship with the regional AT center. We realized that Medicaid requires a Speech-Language Pathologist evaluation from a Medicaid-approved facility. Because their contracted SLP knew AT/AAC devices, and she is employed through a local hospital (an approved facility), her evals are recognized by Medicaid. Then, they closely follow the recommended procedures from the vendors (Dynavox, Prentke-Romich, etc.) for submitting all paperwork to them. The vendors take it from there and submit to Medicaid. We've had devices approved with no problems.

Also, I just finished gathering all the necessary paperwork and working with our SLP at our local district to submit for payment through private insurance. We followed the checklist from Dynavox, and worked with their MI rep who will help see this through. The family doesn't qualify for Medicaid, but after the mom called her insurance, she was told that the AAC device definitely would be covered as "an approved medical purchase." What started as a daunting task has been very manageable, especially with the help of other experienced AT people in the field, and vendor reps.

Also, I have to add that networking with other AT specialists is so helpful. Here in the UP we are very isolated, with many miles between districts. But, we make a point to meet monthly to review devices, strategies, assessment info, etc., etc. Some of our AT people travel 3 hours to get to this meeting (I travel just under 2), but we gladly do it for the support it offers!

- **Re:Medicaid Funding AT by Kim Moccia on Dec. 15, 2006**

Grace, thank you for sharing your regions successful approach! Do you think that barriers caused by traveling will have an impact on future networking meetings? There is discussion on the Advocacy strand about how to overcome the distance barrier by using technology. With the cost of gas going up and increased demands on everyone's time, non-traditional approach to meetings and trainings is on the rise.

- **Re:Medicaid Funding AT by Grace F. on Dec. 15, 2006**

Usually just a snow storm will impact our getting together! We have all just found the face-to-face networking so helpful. Also, we have been using the technology to do trainings and further networking from that site, since it's set up for distance learning. We have found non-traditional approaches to learning helpful, but generally we meet there to implement that as well. (I guess we're all used to traveling great distances for just about anything up here, so it's all part of UP life...)

- **Funding AT through Medical Programs by Kim Moccia on Dec. 11, 2006**

Medical programs may be used to fund assistive technology. Although different programs have different eligibility requirements there are common guidelines that should be followed no matter which program you approach for funding.

1. Determine the need for assistive technology. Remember that AT is used to increase, maintain or improve functional abilities. Identify and describe the student's difficulty in performing a specific task.
2. Identify the devices and services (including training) required to fill this need.
3. Provide documentation that supports #1 and 2. Examples of documentation include physician's prescription and letters of medical necessity from other professionals involved such as occupational therapist and/or speech therapist, etc. Provide data that supports your position that the device to be purchased is uniquely qualified to meet the needs of the student. Identify features (such as customizable on-screen options), device style (such as built in key guard) or hardware (long lasting battery) that contributed to the selection of this device. The more specific you can be the better. Remember that the person reviewing this claim may have little or no knowledge of the device you are requesting or how the student will use the device. It may also be wise to state why certain options weren't considered. I once heard of a claim denied because scanning wasn't considered. In this particular case, the student was able to direct select. Unfortunately, the reviewer didn't understand that considering and comparing scanning options wasn't necessary.

4. Have a clear understanding of what types of documentation the funding source requires and provide it. Be sure to fill forms out completely and accurately.
5. Establish and maintain a connection (specific person whenever possible) with the funding source and do not let long periods of time elapse (months) between communication.
6. Be prepared to appeal if you receive a denial. Some programs offer only a short window of time to appeal so know your rights and make note of appeal deadlines.

What successes have you had with funding AT through Medicare/Medicaid/Private Insurance? Do your schools utilize a third-party billing system?

o **Re:Funding AT through Medical Programs by croberge on Dec. 11, 2006**

Our school District has had some success with Medicare/Medicaid/Private Insurance funding of AT equipment according to the AT Consultants who also work for our district. At times they have been denied but through the appeal process have met with some success.

• **Community-based funding by Kim Moccia on Dec. 11, 2006**

Community-based funding includes resources such as faith-based institutions, civic groups and foundations. Many families have successfully turned to community-based groups to raise funds necessary to purchase needed assistive technology.

For instance, recently I was reading my local community paper and saw an ad for a fundraiser to help purchase AT for a child. The event was held at a local church and included a silent auction and lunch. Local fundraisers foster a sense of community and are often quite successful at raising some or all of the funds needed.

A few months ago I participated in an AT exhibit at a conference. One day of the conference offered programs for students and during session breaks students visited the exhibit hall. I had the opportunity of showing students a variety of AT during this time. Approximately three weeks after the conference I received a call from Make-A-Wish Foundation. One of the students who attended the conference had made a wish for Tablet PC and software he had seen at the conference and the foundation was contacting our program for additional information before granting the wish.

How have you successfully used community-based resources to obtain funding for assistive technology? Did you learn lessons along the way? Please share!

o **Re:Community-based funding by Kim Moccia on Dec. 12, 2006**

Don't overlook disability-associated organizations and health charities. Here in Minnesota, individuals with CP can request assistance from United Cerebral Palsy of Minnesota to help purchase assistive technology equipment.

Sometimes funding assistance is available for specific types of equipment. Gillette Children's Specialty Healthcare has a sports grant to help their patients pay for adapted recreational equipment.

Ask service providers and vendors if they are aware of resources that can assist you with funding. You may be pleasantly surprised!

- o **Re:Community-based funding by Camisha on Dec. 12, 2006**

I have never used community based funding for AT as there has never been a need to do so. However, this sheds light on a new means of possible funding as funding for AT continues to become an area of concern.

- o **Re:Community-based funding by Paula Taylor on Dec. 13, 2006**

One of the problems with parents seeking funding for equipment is that many potential donor/payment sources want you to prove that they are the funder of last resort. That can have parents running in circles, which leads to burn out, to say nothing of momentum being lost.

However, many communities have untapped funding sources that should be explored. One example in my community is that there is a TV personality, who is the parent of a child with a disability, who presents specific cases on TV, seeking money, equipment, services, etc. Another example in my community are organizations such as Rotary, Lions, etc. They often are willing to give some money towards an effort, especially if the child lives in their service area. At the high school in my district, the students have raised funds to pay for AT by asking students to drop their change into a bucket after they pay for lunch, letting them wear jeans by paying a fee or even wear hats after paying a fee. It seems like at least once per month the staff is told they can wear jeans if they pay a small fee. And finally, including the child's specific need in any annual holiday fundraising can yield results.

The other idea I have had, but have not really explored feasibility, is to develop a used AT program that lets people donate AT that they are not using or which has been replaced by other AT. This would be complicated, but with the boom in AT availability, it might be the time to implement it.

As an early-in-the-chute baby boomer, I am certain that our needs for AT as we age will change the way AT is used, funded, made available and recycled! We have changed every other aspect of society, why not AT?

- **Re:Community-based funding - AT Reuse by milissa.gofourth on Dec. 13, 2006**

Paula, there is a growing movement to develop used AT programs, many of the statewide Assistive Technology Programs that have been mentioned in other posts operate and/or support device reuse through device exchange, refurbishing and recycling activities. In addition, U.S. Department of Education, the Office of Special Education and Rehabilitative Services, Rehabilitation Service Administration just recently funded assistive technology reutilization programs through a demonstration grant. (I could not find programs that were awarded funds on the RSA site.) Reuse of AT is emerging

as one of the ways to make AT more available. To the extent that AT reuse is practiced today, it is generally done through:

- Device exchange programs in which a “seller” and a “buyer” are connected directly with each other, as with classified ads;
- Device recycling programs in which an organization accepts donated AT items and stores them until new owners are found; or
- Device refurbishment programs, which are similar to device recycling, except that the programs provide the additional service of fixing or customizing used AT devices before the new owner receives them.

Recycling and reuse of assistive technology makes common sense. Many people can't get the AT they need because they can't afford new devices and can't get funding from private insurance or federal, state or local sources. People in need of AT may turn to AT reuse programs because these programs often do not have eligibility requirements. In addition, used AT is generally more affordable, if not free. Others may choose used AT because they do not want to invest in new devices if they will be needed for only a short time. AT reuse also benefits those giving away the AT. Passing on used devices means no longer needing to store them and sparing the environment the impact of throwing them away. In addition, those who donate AT know they are helping people in need.

Hundreds of organizations around the country, large and small, are involved in AT reuse. From state agencies, to non profits, to hospitals, to churches, there are AT reuse programs in all parts of the country that meet all kinds of needs. Since many of these programs operate on a shoestring budget there is little promotion, coordination or networking of and among these programs to ensure an efficient and effective system for getting used AT into the hands of those who need it. Your statewide assistive technology program should be able to get you in contact with local reuse programs, go to: <http://www.resna.org/taproject/at/statecontacts.html>.

▪ **Re:Community-based funding - AT Reuse by Kim Moccia on Dec. 13, 2006**

The Georgia Department of Labor/Tools for Life program recently received a 5-year grant to establish a National Reutilization and Coordination Center, which has been named the Pass It On Center. This center will help programs that received funds under the grant Millissa mentioned to establish or expand reutilization programs. The center will also provide technical assistance to reuse programs and help to establish a best practices service model. In addition, it will develop a database of more than 600 reuse programs and will be responsible for a national plan for emergency preparedness to help victims of disasters quickly find wheelchairs, ramps and other types of assistive technology destroyed or damaged during the disaster. Information is available on the Tools for Life Web site www.gatfl.org.

▪ **Re:Community-based funding - AT Reuse by Deidre Omahen on Dec. 14, 2006**

You can also try a local Lekotek program. Many of our sites loan adaptive toys and equip-

ment to parents. Check out www.lekotek.org for the closet site to you. The sites are not able to mail equipment rather families join the program and have monthly sessions where they leave with toys for the month.

- **Re:Community-based funding - AT Reuse by cpichler on Dec. 14, 2006**

Wisconsin has a very successful re-utilization program called the Wheelchair Recycling Program. It not only recycles wheelchairs, but a great deal of other types of equipment as well. Most of the recycling work is done by our prison system as part of job training, so overhead is lower and transportation from one area of the state to another can often be accommodated through the corrections system. You can get more info at www.wrp.org/

One caution with using recycled equipment-unless the device is the user's primary device, such as their primary wheelchair, Medicaid and most other insurances will not cover maintenance and repairs. Many people purchase or obtain used equipment to serve as backup, or secondary mobility, etc and are surprised to learn that they have to pay for repairs. Unless warned ahead of time, many fail to budget for tire, battery and upholstery replacement, etc.

- **Re:Community-based funding - AT Reuse by Jackie Hess [SI Faculty] on Dec. 14, 2006**

The October 2005 Family Center on Technology & Disability newsletter focused on AT reutilization and featured an interview with Dave Grass, founder and director of the Northern Illinois Center for Adaptive Technology in Rockford, IL. Here's an small excerpt from that article. The entire newsletter can be accessed at: PDF version: www.fctd.info/resources/newsletters/upload/FCTD_Oct05_Issue43.pdf or HTML version: <http://www.fctd.info/resources/newsletters/displayNewsletter.php?newsletterID=10028>

"There is no reason why a center like ours can't be started in a local community. We let the local media know about what we are doing and the media are very cooperative in spreading the word. Not only do we look for equipment, we look for people. Engineers have volunteered, and they fix some of the AT that bounces back to us because it's broken. These engineers take a look at the equipment to see if it can be salvaged. For the engineers, this kind of work is fun, a challenge. They are indispensable to the recycling process.

ATEN, he adds, has established a collaboration with DeVry University, a technical institution. DeVry, he explains, was seeking intern activities that would allow its students to gain hands-on experience working with AT equipment. For ATEN, he declares, the collaboration was a perfect match. 'We also work with a junior college near us. If the kids at the JC can't fix our equipment, it's no loss because there's no cost factor.'

Local banks can play a role in establishing a recycling center, he points out. "Banks have been a big help to us. Their turnover of equipment is huge because speed is everything in banking and

obsolescence comes fast. One bank gave us automated banking centers, which use standard monitors that were touch-sensitive. The monitors worked on standard equipment. When we removed the monitors from the bank systems and put them on a standard computer we had touch sensitive screens.’

This arrangement, Mr. Grass recalls, took shape soon after he was interviewed on-air by a local TV station on the 6 o’clock news. In the interview he reiterated his assertion that AT can range from a computer to a walker to a doorknob, from the highest of high tech to the lowest of low tech. ‘Every time we get coverage, we get a couple of wheelchairs as a donation that we might not ordinarily get because people often don’t connect that kind of AT with what we offer,’ he says.”

- **Re:Community-based funding by Dr. Brenda Scott on Dec. 17, 2006**

Paula, I like the idea of recycling/reusing AT! It just makes good sense. I believe our state tech act funded organization runs a used equipment exchange site. School systems should probably try to do the same.

- **Education Foundations funding AT by milissa.gofourth on Dec. 11, 2006**

In Oklahoma many schools began their own Education Foundation, a separate entity; usually a non-profit organization run by community volunteers. These foundations do all sorts of local fundraising activities in order to provide funding for educational programs or activities that are not otherwise budgeted. For example a newspaper subscription for an entire English class, playground equipment or funds to go on field trips. Each local foundation develops a plan to distribute the funds, usually through a “request for proposal” submitted by a teacher. In years past my school district has been awarded foundation funds to purchase augmentative communication devices and other specialized equipment that was not in the budget.

- **From whose budget should AT come? by Jackie Hess [SI Faculty] on Dec. 12, 2006**

In a post in sub-topic 1, Kim Moccia asked the following question: “If all students are entitled to computer access, should computers used by students on an IEP be paid for with special education dollars or general education dollars?”

In another post, VernaAnn Kotansky included the comment: “We still struggle with ‘what comes out of whose budget?’ Unfortunately, the AT dept does not yet have its own budget - we just submit requests and keep our fingers crossed.”

So, what do you think? What would best serve both schools and students? How does it work in your district?

o **Re:From whose budget should AT come? by Joan BL on Dec. 12, 2006**

As our friend Joy Zabala says- it all depends! Is the computer used by the general student population or solely by the student with an IEP? Computers in the school computer lab can be accessed by all students, and should be paid for by general ed dollars. Perhaps there is a specialized keyboard that is plugged in when a particular student needs to use it. The keyboard is paid for by sped dollars. If the computer is used only by a student with an IEP and it is an included accommodation listed in his IEP, then special ed dollars are used.

As we move further along the path to universal design, hopefully, more computers and equipment will become accessible, and this question can disappear!

One thing we need to advocate for in schools is adequate respect for AT programs. This includes having staff in place who have a job description that includes AT, a budget and equipment. I held a meeting last week with my state leadership team- representatives of AT teams from around the state. They reported that they- to a man and woman- were swamped with too many referrals in AT. We need to support them being able to do their job well.

o **Re:From whose budget should AT come? by paula taylor on Dec. 13, 2006**

In my district in Ohio our buildings have computers which are available to everyone and they are funded through general education funds. Even the computers in rooms offering support only to students with disabilities. Based on the student population in that building, some of these computers are actually including some software we might consider to be needed only by students with disabilities. But we have found that some of it helps all students, so funding comes from general education. For students who must have some sort of specific AT or software, this would be included on the student's IEP and funded through special education. But special education funding has been tapped too, in a few cases, for adaptations that are not used by disability populations exclusively. Such things as larger monitors, an extra computer in the classrooms where several students with disabilities are getting instruction, word prediction software, etc. This is because, among other things, we don't have to use a certain percentage of our special education funds for at risk students, per NCLB.

o **Re:From whose budget should AT come? by Dr. Brenda Scott on Dec. 17, 2006**

In our district AT (including computers) comes out of special education funding. We are fortunate to have written some savvy grants that allowed us to establish an AT Lending Library, staffed by an assistant and several part time therapists (SLP, OT, & me). Our IT department supports us with handling computer issues. It's functioning for now; however, I am always worried about continued funding and I have seen another AT Lending Library that was part school system/part public funded go under this year.

o **Re:From whose budget should AT come? by speddie on Dec. 19, 2006**

In the districts where I have worked the money for computers and AT have come from Special Education funds therefore we didn't have a lot because our funds were usually used up. There was usually a computer lab in the school for us to go to but it was usually booked up by regular ed (they seemed to get priority) and if you asked the IT person for software that your students could do they didn't know much. I knew more than he did. It was very frustrating because the only computers we could get in the classroom were those that the regular ed classes didn't want anymore. I think regular ed thinks special ed has a lot of money and should pay for their own stuff but we don't have a lot of money and usually what we use could benefit the other students as well.

▪ **Re:From whose budget should AT come? by Joan BL on Dec. 20, 2006**

Although it does not have an immediate impact on the school level, I have courted and made the staff person responsible for generating the school tech plans at our state agency a champion for accessible and assistive technology. Her willingness to be aware of the needs for ALL students to be participants in learning means that when schools in MN submit their tech plans (to qualify for Rate discounts) they need to include what their plan for accessible and assistive technology. Schools are also supposed to have a special educator involved on their school tech team. This strategy is important because it does not come from the special ed world, and has a respected IT statewide leader setting the tone.

I know not every state is able to have the same access we were lucky enough to get, but I can tell you the access started by an informal visit and an invitation for coffee. And- just as we have talked about throughout the advocacy side of this discussion, telling the important story. The important thing is getting the right people involved in seeing a problem and finding the solution- on the state level if you have the ability to act on that level, on the district or building level if that is where you are. Good luck- the work you are doing is so important.

• **community-based funding sources by pccbar on Dec. 12, 2006**

One source that should be considered is the Knights of Columbus. They are a Catholic men's organization that has people with developmental disabilities as their primary philanthropic focus. You may be familiar with them as the Tootsie Roll guys who stand in front of stores giving away tootsie rolls for donations. Most of their money stays local. Try contacting your local Catholic Church and ask for the name and phone number for the person in charge. You don't have to be Catholic to benefit from them. I have had great success getting them to purchase equipment for individuals.

- **What is Medically Necessary by milissa.gofourth on Dec. 12, 2006**

I try to approach funding strategies by using the words that are used by the funding source. For example the definition of “Medically Necessary” can be very different in private insurance than it is in Medicaid. Since Medicaid is a state/federal program each state creates its own definition of medically necessary. By studying the “medically necessary” definition of the Oklahoma Medicaid program you can see how one or two words can impact whether you get funded or denied for medical equipment.

The Oklahoma Medicaid definition for “medical necessity is established through consideration of the following standards:

1. Services must be medical in nature and must be consistent with accepted health care practice standards and guidelines for the prevention, diagnosis or treatment of symptoms of illness, disease or disability;
2. Documentation submitted in order to request services or substantiate previously provided services must demonstrate through adequate objective medical records, evidence sufficient to justify the client’s need for the service;
3. Treatment of the client’s condition, disease or injury must be based on reasonable and predictable health outcomes;
4. Services must be necessary to alleviate a medical condition and must be required for reasons other than convenience for the client, family, or medical provider;
5. Services must be delivered in the most cost-effective manner and most appropriate setting; and
6. Services must be appropriate for the client’s age and health status and developed for the client to achieve, maintain or promote functional capacity.”

I have seen denials because the agency indicated that it was just a “convenience”. Yet, the same device could be for the purpose to “maintain or promote functional capacity.” Another example, it depends. Your state’s definition of “medically necessary” can usually be found on the Medicaid agency’s web site under policy.

- **Vendor Assistance by Kim Moccia on Dec. 13, 2006**

Vendors of assistive technology--especially those that make high-end communication devices—understand how difficult it can be to successfully go through the Medicare and Medicaid funding process. And, just as important, they realize that it makes good business sense to help their consumers secure funding through such programs. This is why some vendors offer assistance during the funding process (answer questions, check paperwork for completeness) and provide helpful information and checklists on their Web sites.

- o **Re:Vendor Assistance by Jackie Hess [SI Faculty] on Dec. 14, 2006**

A number of vendors do indeed provide valuable funding information and assistance. Here are some useful links to vendor sites. The links should take you directly to their funding pages.

Assistive Technology, Inc. provides funding information at <http://www.assistivetech.com/s-funding.htm> including a downloadable 30-page funding packet. The funding information portion of its website is divided into user-friendly topic areas.

Prentke Romich Company offers funding assistance at <http://www.prentrom.com/funding> focusing particularly on Medicare, Medicaid and insurance coverage.

ABLEDATA offers links to a number of funding information sources at <http://www.abledata.com/able-data.cfm?pageid=113573&top=16040&ksectionid=19326>

Technology for Education, Inc. provides a funding section at http://www.tfeinc.com/resources/funding_index.shtml including a useful resource entitled “Developing a Funding Strategy”

- **Re:Vendor Assistance by Kim Moccia on Dec. 14, 2006**

Thank you for the list Jackie!

Vendors really do play an important role in the successful funding and implementation of AT. They're on the “front lines” along with the consumer. And, from experience, know what it takes to submit an acceptable and potentially successful claim.

There is a non-profit organization of manufactures, sellers and providers of technology-based assistive devices and services called the Assistive Technology Industry Association (ATIA) www.atia.org.

ATIA works closely with Electronics & Information Technology (EIT) companies and government on matters of common interest and has a number of sub-committees including one on Medicare/Medicaid. This sub-committee is currently compiling a document on the significance of assistive technology in the productivity of people with disabilities. ATIA is encouraging its members to submit stories that highlight the successes and problems of funding devices through Medicare/Medicaid programs. ATIA holds a conference every year during January in Florida that provides an opportunity for its members to discuss matters of importance with AT professionals.

AT Act programs and ATIA are currently discussing opportunities to work together including the possibility of creating a buying cooperative. Other activities of ATIA include a joint publication of The Assistive Technology Outcomes and Benefits journal with the Special Education Assistive Technology Center (SEAT).

Anyone want to share how a vendor has helped them during the funding process?

- **Re:Vendor Assistance by Kim Moccia on Dec. 19, 2006**

Thought I'd add to the list of vendor sites that provide how-to information on obtaining medical funding –some even provide guidelines on appealing denied claims. This is merely a sampling of sites. The moral of the story here is to check with the vendor of the product you're purchasing

to see what, if any, assistance they provide!

- Easy Stand – successful funding using the team process
<http://www.easystand.com/funding/team-process.cfm>
- Words + - funding information listed by state
http://www.words-plus.com/website/news_at_a_glance/news1.htm
- Dynavox funding information designed to walk you through the funding process, and provide you with the information and forms you need to jump-start the process.
<http://www.dynavoxsys.com/Default.aspx?tabid=29>
- Rifton provides sample letters of medical necessity by product line
<http://www.rifton.com/resources/lettersofmedicalneed/index.html>

- **Schools and Medicaid by Kim Moccia on Dec. 13, 2006**

I'd like to repeat the questions Millissa asked at the beginning of the week in case some of you missed them: "Are any of you associated with school districts that are Medicaid providers? What have been some of your successes in funding AT through Medicaid? What have been some of your denials? Why?"

- o **Re:Schools and Medicaid by Joan BL on Dec. 14, 2006**

There are a variety of schools in MN which use MA funds to pay for AT devices, including AAC and positioning devices. There is rarely (only one that I know of) instance where there was a denial. This is a positive situation for kids. The biggest problem is that the district must pay up front for the device, then (at least in our state) wait for reimbursement over 2 years. However, using the formulas in special ed funding, a district is sometimes able to recoup in excess of the cost of the device (our legislature has examined this and it is not unethical) and then any dollars in excess of the cost of the device MUST be spent on special ed services.

The biggest win is that the device belongs to the child, even if the school paid for a portion of it. There is no longer the ability to debate whether it goes home, etc.

- o **Re:Schools and Medicaid by Peter.Stack on Dec. 15, 2006**

I've had the opportunity to be involved in decisions on both sides: State Medicaid and Public School Department. In RI the general working method is that a child's individual Medicaid coverage is responsible for items he/she will use in all settings. If there's an academic or school-specific item specially needed for school time and school-related goals, it is the responsibility of the school department to provide that item (which remains the property of the school department), and as to whether it can go home nights/weekends/summers depends on the particular school department's policy.

- **Re:Schools and Medicaid by milissa.gofourth on Dec. 15, 2006**

What a great example of how blending funding sources (Medicaid and IDEA) can help a student get the needed AT.

- **Re:Schools and Medicaid by Joan BL on Dec. 16, 2006**

It is great to see that kind of collaboration. I would like to state, however, that whether AT goes home nights/weekends/summers cannot be decided by the school's policy. IDEA clearly states that the IEP team, on a case by case basis, decides if a student should have access to their school owned AT outside of school for access to FAPE.

- o **Re:Schools and Medicaid by Dr. Brenda Scott on Dec. 17, 2006**

Kim,

We've been successful with getting AAC devices funded through Medicaid. I'm not sure if we have had any denials (none that I know about).

- **Re:Schools and Medicaid by Lesley Thacker on Dec. 17, 2006**

The trouble that we've had with getting devices through Medicaid is all of the steps involved -- a case manager, a doctor, an evaluator, etc. all have to do their jobs in order for it to work. Unfortunately, where we are, Medicaid paperwork goes into a black hole and we never see it again.

- **Re:Schools and Medicaid by Kim Moccia on Dec. 18, 2006**

That's great news! What do you feel contributes to such a high percentage of successful funding requests?

- **Volunteers by Kim Moccia on Dec. 14, 2006**

I have seen organizations successfully use volunteer groups of community professionals. Courage Center, here in Minnesota, has a dedicated group of engineers who volunteer their time and know-how to fabricate solutions not readily available in the marketplace.

Fabrication is another option to consider when seeking AT solutions. Dr. Therese Willkomm has written, Assistive Technology Solutions in Minutes, which is an excellent resource on how to create low cost AT solutions in 5 minutes or less. (<http://www.nhassistivetechology.org/>)

Has anyone fabricated or modified a successful AT solution?

- **Expanded community support by Jackie Hess [SI Faculty] on Dec. 14, 2006**

An additional benefit of seeking funding from community organizations is that it establishes an ongoing relationship between a family and members of the community. Often we hear about the sense of isolation

felt by families of children with disabilities. The type of support that can be offered by community-based groups often goes well beyond funding a particular device or service. There is, of course, the social support that can be provided. But there's also the possibility of free respite care, mentoring of both the student and parents, training on technology by tech-savvy community members, transportation assistance, and access to an expanded network of contacts and sources of additional support.

- **Payment Pass Through by Kim Moccia on Dec. 14, 2006**

I've seen situations occur when vendors do not accept Medicare/Medicaid payment even though the device is covered by the program. I'm curious to hear how others have handled this type of situation. Has anyone successfully setup a "payment pass through" system?

- o **Re:Payment Pass Through by Dr. Brenda Scott on Dec. 17, 2006**

I'd be curious as to what a "payment pass through" system is.

- **Why EPSDT can work successfully by milissa.gofourth on Dec. 15, 2006**

In an earlier post when I gave the definition of "medically necessary" I mentioned that each state determines their own definition. This is not true with Early and Periodic Screening, Diagnosis & Treatment (EPSDT) because it is a federally mandated Medicaid benefit for all children birth through 21 years of age. Many of the words used expand Medicaid services to children. Remember there must be a medical need, which must be clearly demonstrated on a case-by-case basis, for an AT device.

According to EPSDT "medically necessary" service means medical, dental, behavioral, rehabilitative or other health care services which are:

- reasonable and necessary to prevent illness or medical conditions, or provide early screening, interventions, and/or treatment for conditions that cause suffering or pain, cause physical deformity or limitation in function, cause illness or infirmity, endanger life, or worsen a disability;
- provided at appropriate facilities and at the appropriate levels of care for the treatment of a member's medical conditions;
- consistent with the diagnosis of the condition;
- no more intrusive or restrictive than necessary to provide a proper balance of safety, effectiveness, efficiency and independence; and
- assists the individual in achieving or maintaining maximum functional capacity in performing daily activities, taking into account both the functional capacity of the individual, and those functional capacities that are appropriate for individuals of the same age."

Additionally, the amount, duration, or scope of services to recipients may not be denied arbitrarily or reduced solely because of the diagnosis, type of illness, or condition. Appropriate limits may be placed on services based on medical necessity.

I know the word “rehabilitative” has helped therapists when they are providing documentation for prior authorization.

- **IDEA Web Site by Kim Moccia on Dec. 15, 2006**

The Office of Special Education Programs (OSEP) at the U.S. Department of Education recently launched a new Web site with information and resources on the Individuals with Disabilities Education Act of 2004. You can visit the site at <http://idea.ed.gov>.

- o **Re:IDEA Web Site by Joan BL on Dec. 17, 2006**

I also like www.Wrightslaw.com. There is a range of options there- some free, some for a fee. The information is student oriented and appears legally correct.

- **Re:IDEA Web Site by Kim Moccia on Dec. 17, 2006**

I like that site, too!

- **ADA Web Sites by Kim Moccia on Dec. 15, 2006**

Thought I'd share a few of my favorite ADA sites:

- <http://www.usdoj.gov/crt/ada/pcatoolkit/abouttoolkit.htm>
 - <http://www.access-board.gov/adaag/about/index.htm>
 - <http://www.adaproject.org/>
-

- **Final questions and comments by Jackie Hess [SI Faculty] on Dec. 18, 2006**

Welcome to the final three days of the Family Center's Winter Institute on AT. I hope that the hundreds of you who have been following the discussion silently have found the information useful. We greatly appreciate the kind comments of those who have said so via post or email.

In these final days, we invite you to post comments and questions on any aspect of assistive technology policy or practice that may be of interest to you. We'll do our best to address them.

On the administrivia front: Each of you will be receiving the Family Center on Technology & Disability's 2007 "Assistive Technology Resources" CD-ROM and an Institute Certificate of Participation. Ana Maria will be coordinating the paperwork for those of you who want to receive CEU's for the Institute. (You're eligible for 3.2 CEU's.) As always, it's been a pleasure working with all of you. - Jackie Hess

- o **Re:Final questions and comments by Karen Dedmon on Dec. 18, 2006**

At the conclusion of this AT Winter Institute, will we still have access to this site?

- **Re:Final questions and comments by Jackie Hess [SI Faculty] on Dec. 18, 2006**

Yes, you'll be able to access all of the information (posts, resources, expert perspectives, etc.) in the FCTD's online discussion archives. All links will remain active. However, the AT funding strand and the statewide advocacy strand will be archived as separate discussions. Our website structure doesn't allow us to archive the Institute as a single discussion.

All of our online discussions and institutes are included in our annual "Assistive Technology Resources" CD-ROM." We're also thinking of distributing a separate CD-ROM, available in a month or so, with the contents of just this Winter Institute.

- **Companies and Communities by Kim Moccia on Dec. 19, 2006**

In addition to providing support during the funding process, companies sometimes take a lead role in elevating awareness of assistive technology and its ability to empower people with disabilities. For example, you'll find research, accessibility solutions, business resources, case studies, tutorials and training and more at www.microsoft.com/enable. And, of course, Apple provides Mac accessibility information <http://www.apple.com/accessibility/>.

Many companies conduct philanthropic initiatives. Here are a few examples:

- <http://www.meaf.org/>
 - http://www.dell4k12.com/program_detail.php?pi=4
 - <http://www.adobe.com/aboutadobe/philanthropy/commgivingprgrm.html>
 - http://www.att.com/gen/corporate-citizenship?pid=7736&DCMP=att_foundation
 - <http://foundation.verizon.com/>
-

- **Final Question and Comments by suzann mcknight on Dec. 19, 2006**

I want to thank the Institute for giving me the opportunity to participate in the on-line course. I have gained a lot of knowledge through the sessions. Everyone who responded to the discussions had information that I enjoyed reading about. Again thank you for this opportunity.

- **Free by Kim Moccia on Dec. 19, 2006**

And, what about free? Depending upon the student's need you may be able to utilize freeware/shareware software. Here are a few sites –

- Click N Type virtual keyboard - <http://www.lakefolks.org/cnt/>
- Dasher – innovative text-entry interface for PC - <http://www.inference.phy.cam.ac.uk/dasher/>
- Read Please – text to speech - <http://www.readplease.com/>

- Universally Accessible Chess - <http://www.ics.forth.gr/hci/ua-games/ua-chess/>
 - And then there's <http://www.onlineconferencingsystems.com/at.htm#top> which has a listing of over 200 free AT software applications.
-

- **by Brice on Dec. 19, 2006**

Many thanks for great insight and sharing. I have benefitted greatly from this information.

- o **Re: by mknebel on Dec. 19, 2006**

I too would like to thank everyone for their valuable information. It is overwhelming at times to try to retain it all and then retrieve it at the time it is needed. Does anyone have a good system for this?

- **Re: by Kim Moccia on Dec. 19, 2006**

Here are a few strategies I use –

First – put it in a folder!

If it's a link to a site I immediately put it in a sub-folder in my Favorites folder. I create topic specific sub-folders for easy retrieval AND I backup my favorites folder just in case!

I do a great deal of cutting and pasting and creating files of information that I put in folders named by topic (all my IDEA info is in a folder called IDEA). If I don't have time to read information right away I create a task or calendar entry in Outlook that I link to the file. That way not only do I remember to read the file I know how to find it!

I love Microsoft OneNote <http://office.microsoft.com/en-us/onenote/FX100487701033.aspx> and use it constantly.

I also love the free Microsoft Reader and utility that allows easy conversion of Word documents to e-book. Once I convert my info into an e-book I can easily highlight, annotate and bookmark information. There is also a free text-to-speech utility so I can listen to my e-books. (<http://www.microsoft.com/reader/downloads/default.mspx>)

Hope this helps!

- **Final Comments by Paula Taylor on Dec. 19, 2006**

Just as last year, I have learned many new and thought provoking things from participating. I work directly with families and support them in their efforts to work collaboratively with our school district. Having this “pot” of new information and ideas will make my assistance to families even more effective. Thanks to everyone who posted either questions and/or answers.

I also want to add an observation as a parent who has been in the disability business forever! My son is 41 years old and really only benefitted from IDEA and its forerunners for a short time in his educational career.

Way back then even getting an adapted writing instrument was a major project. Does anyone remember using the pink foam from hair rollers to improve grasp? Look how far we have come.

- **Moving Forward by Kim Moccia on Dec. 20, 2006**

During the Winter Institute I read posts that said, “I am wondering...” “How do you...” or “What do you use to...” The outpouring of participant suggestions, ideas, and sharing of experiences and resources posted in response was, to me, inspiring. And, I will continue to be inspired every time I refer back to the Institute materials and visit the resource links posted. Thank you!

The progress we’ve made—and we have made significant progress—happened because of dedicated folks like you. So now it’s time to put the knowledge we’ve gained to work as we continue to promote the benefits of assistive technology and the need for funding.

Even if each of us acts upon only one new piece of information gained from this Institute, we will move all of us one step closer to further success! Or as Kahlil Gibran once wrote, “A little knowledge that acts is worth infinitely more than much knowledge that is idle.”

Endeavor, Enlighten and Empower!

- **Some last thoughts by milissa.gofourth on Dec. 20, 2006**

I want to thank everyone for their participation, I have learned a great deal. Thank you Paula for reminding me of the pink foam rollers we used as pencil grips, because it does prove we have come a long way. Just think Medicare now will fund AAC devices, which is really big when you consider all other private insurance companies use Medicare as their standard for determining medical necessity.

I think our discussions covered some of our greatest funding challenges, the need for; (1)a quality evaluation, (2)training on the device must be provided not only to the child but to teachers, aides, parents and therapists, and (3)the importance of team work throughout the process.

I think that we must realize this is an emerging field, in which technology is changing so rapidly it is hard to keep up. We will make mistakes, but that is okay because in the world of assistive technology I have to remember what Beverly Sills once said,

“You may be disappointed if you fail, but you are doomed if you don’t try.”

Additional Resource Links

1. AT Act Programs

- State AT Programs Contact List - <http://www.resna.org/taproject/at/statecontacts.html>
- State AT Programs - <http://www.resna.org/taproject/at/stateprograms.html>

2. Universal Tech Supports and Universal Design

- CAST – Universal Design for Learning - www.cast.org
- Dave Edyburn’s Homepage - <http://www.uwm.edu/~edyburn/>
- Knowledge by Design, Inc. - <http://www.knowledge-by-design.com/>

3. Invitation to Tots-n-Tech Research Project - <http://www.asu.edu/clas/tnt>

4. Parent Information Centers

- PACER (Parent Advocacy Coalition for Educational Rights) - www.pacer.org

5. Funding Sources

- National Early Childhood Technical Assistance Center – Funding Sources
<http://www.nectac.org/topics/atech/funding.asp>
- North Carolina Assistive Technology Program – Funding
<http://www.ncatp.org/Funding.html>
- Director of Funding Resources for Assistive Technology in Minnesota
<http://www.admin.state.mn.us/assistivetech/FD2006/Welcome.htm>
- Minnesota Children with Special Health Needs: Financial and Other Resources
<http://www.health.state.mn.us/divs/fh/mcshn/finres.htm>
- Vendors
 - i. Assistive Technology, Inc. - <http://www.assistivetech.com/s-funding.htm>
 - ii. Prentke Romich Company - <http://www.prentrom.com/funding>
 - iii. ABLEDATA - <http://www.abledata.com/abledata.cfm?pageid=113573&top=16040&ksectionid=19326>
 - iv. Technology for Education, Inc.
http://www.tfeinc.com/resources/funding_index.shtml
 - v. Assistive Technology Industry Association (ATIA) - <http://www.atia.org>
 - vi. Easy Stand - <http://www.easystand.com/funding/team-process.cfm>
 - vii. Words+ - http://www.words-plus.com/website/news_at_a_glance/news1.htm
 - viii. Dynavox - <http://www.dynavoxsys.com/Default.aspx?tabid=29>
 - x. Rifton - <http://www.rifton.com/resources/lettersofmedicalneed/index.html>

6. School Evaluations

- Minnesota Assistive Technology Manual: Assistive Technology Forms and Checklists http://education.state.mn.us/mde/Learning_Support/Special_Education/Evaluation_Program_Planning_Supports/Assistive_Technology/AT_Resources/index.html (page 76)
- Evaluation of the Effectiveness of Assistive Technology by Joy Zabala (15-minute video and Power Point Presentation) http://coefaculty.valdosta.edu/spe/ATRB/video_1/at56/at56_files/default.htm
- Responsiveness to Intervention (RTI) - <http://www.wested.org/nerrc/rti.htm>

7. Trying Assistive Technology Before you Buy It/ AT Loans/ AT Recycling

- Institute on Disabilities: University Center for Excellence in Developmental Disabilities <http://disabilities.temple.edu/programs/assistive/index.htm>
- Wisconsin Assistive Technology Initiative - www.wati.org
- Georgia Tools for Life - www.gatfl.org
- Lekotek - <http://www.lekotek.org/>
- Wheelchair Recycling Program - www.wrp.org/

8. General Assistive Technology Resources

- Assistive Technology Resource Bank: Video List http://coefaculty.valdosta.edu/spe/ATRB/Video_Tips.htm
- Georgia Project for Assistive Technology – Resources <http://www.gpat.org/Resources%20Main.htm>
- Protection and Advocacy for Assistive Technology Contacts <http://www.nls.org/paatstat.htm>
- New Hampshire Assistive Technology - <http://www.nhassistivetechology.org/>

9. Legal Information

- Building the Legacy: IDEA 2004 - <http://idea.ed.gov>
- ADA Best Practices Toolkit for State and Local Governments <http://www.usdoj.gov/crt/ada/pcatoolkit/abouttoolkit.htm>
- ADA Accessibility Guidelines Homepage - <http://www.access-board.gov/adaag/about/index.htm>
- DBTAC-Great Plains ADA Center - <http://www.adaproject.org/>

10. AT Companies providing access information and/or philanthropic efforts

- Microsoft - www.microsoft.com/enable
- Apple - <http://www.apple.com/accessibility/>
- Mitsubishi Electric America Foundation - <http://www.meaf.org/>

- Dell K-12 Solution Center - http://www.dell4k12.com/program_detail.php?pi=4
- Adobe – Corporate Affairs/Community Relations
<http://www.adobe.com/aboutadobe/philanthropy/commgivingprgrm.html>
- AT&T Foundation
http://www.att.com/gen/corporate-citizenship?pid=7736&DCMP=att_foundation
- Verizon Foundation - <http://foundation.verizon.com/>

11. Freeware/Shareware Software

- Click N Type virtual keyboard - <http://www.lakefolks.org/cnt/>
- Dasher – innovative text-entry interface for PC -
<http://www.inference.phy.cam.ac.uk/dasher/>
- Read Please – text to speech - <http://www.readplease.com/>
- Universally Accessible Chess - <http://www.ics.forth.gr/hci/ua-games/ua-chess/>
- One Stop for Free Assistive Technology -
<http://www.onlineconferencingsystems.com/at.htm#top>



Effective Statewide Advocacy

Introduction

We often tell families that they need to be advocates for their children. We tell small non-profits that they need to advocate for increased funding. We tell everyone that they need to advocate for disability-friendly legislation and regulation. But what does effective advocacy look like? What are the tools of advocacy? Where does one start?

The federal government funds several national networks of organizations to serve families of children with disabilities. There is the Parent Training and Information Center (PTI) network and the Assistive Technology Act Program network. In addition, there are groups and centers associated with the Alliance for Technology Access (ATA) and quite a few state and regional centers associated with universities. Each can be considered a stakeholder in the disabilities support infrastructure. How does one identify and engage these centers in effective advocacy? How can the lessons learned by one convey to the others?

Recently the Florida Alliance for Assistive Services and Technology (FAAST) led a successful statewide advocacy effort aimed at passing legislation to allow Florida students to request that their assistive technology follow them after they leave one school system for another or to transition to post-secondary education. It was a legislative coup accomplished with help from many organizations and individuals. During our Winter Institute Jane Johnson, Executive Director of FAAST will discuss the advocacy efforts that led to passage of the bill. She and Joan Breslin-Larsen, long-time statewide advocate in Minnesota, will share strategies that have been successful in their states and which can be successful in yours.

Learning Objectives

1. Identify the fundamental elements of statewide advocacy.
2. Identify the key stakeholders involved in statewide advocacy.
3. Identify the indicators of success in assistive technology advocacy.
4. Discuss successful advocacy strategies that have been used by AT advocates in specific states, such as Florida and Minnesota.
5. Identify and discuss the barriers to effective AT advocacy.
6. Identify resources that can be used by Institute participants to develop and pursue their own statewide advocacy plans.

Expert's Corner

Expert's Bios

Joan Breslin-Larson

Joan Breslin-Larson is the Assistive Technology Specialist for the Minnesota Department of Education. She has provided assistive technology services for more than twenty years. She currently focuses her work on developing and supporting collaborative practice in assistive technology for children and students receiving services under IDEA. She facilitates the Minnesota State Assistive Technology Leadership Team, an interagency group that supports the state Department of Education in developing and supporting assistive technology and universal design for learning practices. Joan is an active member of the Quality Indicators for Assistive Technology (QIAT) Consortium and speaks nationally on collaborative decision making in assistive technology.



Joan Breslin-Larson

Joan brings a unique perspective to the FCTD AT Winter Institute, coming from an advocacy background as well as representing a large education organization. Prior to working for the state education agency she founded and ran an independent AT consulting firm.

Jane E. Johnson

Jane E. Johnson is the Executive Director of the Florida Alliance for Assistive Services & Technology (FAAST), the federally designated Assistive Technology Program for the state of Florida, whose mission is to improve the quality of life for all Floridians with disabilities through advocacy and awareness activities that increase access to and acquisition of assistive services and technology.



Jane E. Johnson

Ms. Johnson has worked in the areas of public policy and systems change since 1995, and has been involved in all aspects of the long term care continuum, including skilled nursing, assisted living, home health care and affordable housing.

Ms. Johnson was appointed by Governor Bush in 2002 to serve on the Affordable Housing Study Commission and was re-appointed in 2005 for another two-year term. In this capacity, Ms. Johnson represents the interests of low-income elders and individuals with disabilities. Ms. Johnson was appointed by Governor Bush in 2005 to serve on the Accessible Electronic and Information Technology Task Force, whose charge is to review and assess the state's current web-based systems, identify accessibility barriers and recommend changes using existing and emerging technology.

In 2004, Ms. Johnson was named one of the Top Ten Outstanding Women in the Community by Tallahassee Community College for her volunteer and civic contributions. She is also an avid long-distance runner and triathlete.

Expert Perspectives

Joan Breslin Larson

I am the assistive technology and universal design for learning specialist for the Minnesota Department of Education. I have been in this position for a little over seven years. Previously, I was an assistive technology consultant, working for an advocacy organization. And, prior to that, and always, I have been a Mom, which included being a foster mom to several youngsters with disabilities. I have sat at the IEP table, both on the professional side, and on the Mom side. I learned that sometimes, it did not feel so good to sit on the Mom side. I have also had the very good fortune to have some educators who helped me know how great it was to be the Mom of great kids. A lot of what I think and feel as a state specialist, and what I strive to help educators in Minnesota do, is based on the potential I know exists from the use of assistive technology and what I have learned being a Mom in those meetings.

Let me tell you about an episode that changed how I think and felt in IEP meetings. My son Joe received speech therapy services for articulation. Joe did not talk much. This may have been due to his frustration at not being understood easily, or may just have been part of his personality. At his IEP meetings, his Dad and I regularly heard “Joe is shy and quiet. He never has anything to say.” One year, however, we had a speech therapist who took time to talk with Joe’s dad and I, to his teachers, and to observe him in informal situations. She got to know the boy- not just the case file. And, in a meeting, this speech therapist talked about what she learned. “Joe is reserved and introspective. He does not waste time in idle chatter. When he does talk, you better pay attention, because it will be worth listening to.” This wonderful woman took the time to look past a youngster who seemed pretty apathetic and indifferent, and found a really funny and insightful individual. That speech therapist taught me several things. She viewed Joe, and all the children to whom she provided service, as being students with value and worth. She shared that perspective, and opened the door for positive interaction. She became the model I have tried to emulate.

During this on-line class, we will be talking about collaboration and the role of all players in this task. I will put one caveat out there. We all know what it feels like to not have a positive experience in IEP meetings. Sadly enough, it just takes one angry or disinterested individual-whether an educator, administrator, advocate or parent to poison the atmosphere in the meeting. So- let’s talk about how to be collaborative partners, with wisdom and information about the students for whom we care. Let’s talk about what good practice looks like, and learn together how to be models for others. I look forward to our discussion.

Jane Johnson

The recent mid-term elections in the U.S. underscore the fact that America's political infrastructure truly allows for a government "of the people, by the people, and for the people." However, those very important phrases imply – and demand – a direct participation on the part of the individuals affected by the decisions of local, state and federal government.

Thanks to the efficiency of electronic communications, there has never been a better (or easier!) time for citizens to communicate with their government representatives and have an impact on the laws, regulations and policies that affect their daily lives. This is especially important for persons with disabilities, who have historically had great difficulty in getting their voices heard.

“All politics is local”

Effective statewide disability advocacy usually begins at the grassroots level when concerned citizens identify problems or barriers affecting individuals with disabilities in their local communities. Ideally, those concerns can be taken to the agencies and organizations that can address them, where resolution can be achieved through dialogue and negotiation. In some instances, however, the problems are statewide in scope, and legislative change is necessary.

Collaboration is essential

Disability advocacy groups in many states have grown increasingly influential in the past decade, by aligning disparate groups in support of shared policy goals and by bringing the faces and voices of individuals with disabilities to policymakers. Collaboration among diverse constituency groups, such as seniors, persons with developmental disabilities, persons with acquired disabilities, injured war veterans, and persons with physical and cognitive disabilities is vitally important to the achievement of meaningful public policy reform.

Find a Champion for Your Issue

Identifying the problem and devising a legislative or regulatory solution are the first steps in the process, but your chances of actually achieving your public policy goals are inextricably linked to the commitment you can secure from bill sponsors. Don't just ask a sponsor to offer a bill for you – take the time to educate him or her about the issue and make true believers out of them! If the bill sponsor appreciates the importance of an issue, he or she will be more likely to push to have it heard in committee and to secure additional sponsors.

Get Your Message Out

Securing the commitment and enthusiasm of a bill sponsor is a significant accomplishment, but you will still need the support (and votes) of a majority of the elected Legislature to get your bill passed. Successful advocates will develop and distribute concise, easy to understand issue briefs, hold press conferences, meet individually with members of key committees and

encourage constituents to set up appointments in the legislators' districts when they are at home. Don't be discouraged if you have to talk to staff, instead of the legislators themselves. Many legislators rely on their staff to educate them about issues they don't have time to research on their own. If you can win over a staff person, you have often won over a legislator's vote.

Know Your Enemies

Most changes in laws or regulations that benefit one constituency group will inspire opposition other constituency groups that would be adversely affected by the change. To the extent that you can identify who your opposition might be in advance, it can really help to meet with those groups early in the process and try to mitigate their concerns or strike mutually agreeable compromises. Political opposition often takes the form of passive aggression, with the result that bills get stalled in committees or in one chamber or another for "no apparent reason." In such instances, if you don't know who your potential enemies are, you won't be able to track the source of the logjam.

It's Not Over Until It's Over

Stay on top of your bill through the entire process. Very few bills move through the committee hearing process and onto the floor without significant outside pressure. You will likely have to request to have a bill put on committee agendas, and also to be put up for a floor vote. During the committee process, be on the lookout for possible amendments that may derail your legislation. If your bill isn't moving, consider amending your language onto another bill that is. When it looks like passage is certain, start talking to the staff in the Governor's office to find out if there is any chance of a veto.

Celebrate and Give Credit

If your issue is successful, be sure to thank the staff and legislators who were instrumental in person and in writing. If you have a website, magazine or newsletter, include a feature story about the bill's passage, highlighting the legislator's hard work and support and the consumers who will benefit. Include photos and testimonials.

Recommended Resources

1. **A Profile in Advocacy**

<http://www.schwablearning.org/articles.asp?r=850>

This article, published by SchwabLearning.org is presented in an interview format between the writer and an advocate. This advocate, Sandra Britt, is a mother of three children with learning disabilities, who started small and eventually was able to attend the White House as an LD advocate. She talks about the various steps of starting out as an advocate for a cause. She discusses the importance of starting small and working your way up. She gives information about how to go about contacting the state level officials in your state to tell them what you want them to do as your representative. It is a good example of an average citizen in a small town advocating for the rights of her children and making it all the way to the top.

2. **Advocacy in Action: A State Model for Change**

<http://www.asha.org/about/legislation-advocacy/state/advocacy-change.htm>

This link provides a link to a 61 page PDF file about how you can successfully advocate at the state level for change. This link provides a general introduction of the document, including a list of “The seven steps for success”. These seven steps are described in more detail in the PDF file. Also in the document, they give samples of the documents that you can use when presenting information to the state government. This document is full of very useful information and is was published by the American Speech-Language-Hearing Association.

3. **Public Policy/Advocacy: Florida Legislation Action Center**

<http://capwiz.com/faast/state/main/?state=FL>

This link is from the Florida Alliance for Assistance Services and Technology website. At the bottom, there is a chart with various aspects of advocating at the state level. Many of these are directed towards residents of Florida, but the idea can be taken and applied to any other state. Here, you can find elected officials, state agencies, local elected officials, issues and legislation, congressional delegation, and media guides.

4. **National Council of Nonprofit Associations: Lobbying and Advocacy**

<http://www.ncna.org/index.cfm?fuseaction=Page.viewPage&pageId=624>

Many organizations that work with people with disabilities are non-profit. This link is dedicated to those particular organizations and offers information about how they can advocate at the state level for the issues they believe in. They provide a brief overview of how to navigate through the laws and how to lobby for various issues. Under the section about Current Law, there is a link that leads to an excel spreadsheet of each state’s lobbying laws. It condenses the information into an accessible format, and also provides links to where further information can be obtained.

5. **Advocacy Tools: Family and Individual Advocacy**
http://www.ucp.org/ucp_generaldoc.cfm/1/8/6602/6602-6628/994
This brief article, produced by United Cerebral Palsy discusses three different types of advocacy for families and individuals with disabilities: state level, local level, and individual advocacy. Under each heading, they give the most important points to remember when advocating at that level. It is a good reference to get you started in advocacy efforts.
6. **University of Kentucky Assistive Technology (UKAT) Toolkit**
<http://edsrc.coe.uky.edu/www/ukatii/index.html>
The University of Kentucky Assistive Technology (UKAT) Toolkit is a product of six years of assistive technology (AT) research conducted at the University of Kentucky in collaboration with six school districts in Kentucky. It provides a systematic method of delivering AT services to students in schools.
7. **Advocating at the State Level**
<http://www.narmh.org/pages/resadvoc.html>
This article, written by Peter G. Beeson discusses various aspects of advocating successfully at the state level. He first discusses the importance of advocating. He makes the point of, “if you don’t, who will?” According to him, everyone has the ability to be a successful advocate. Beeson then discusses twenty do’s and don’ts of advocacy. This list is split up into the different aspects of advocacy, including the proposal, the importance of working together, and the advocating in general. It is a straight forward organized article that can serve as a guide for preparing an advocacy effort.
8. **State Action Plan: IDEA Final Regulation**
<http://capwiz.com/ndss/issues/alert/?alertid=8970956>
This link provides information about how states will be effected by the new IDEA Legislation that was recently passed. It gives tips on how to work with the state to make sure that the special education services provided can be the best possible. The source discusses the importance of working together as a coalition. There is a list of strategies for success. Finally, they discuss the key provisions in IDEA that will affect state regulations. This article provides a decent overview of the new law.
9. **AAMR F.Y.I. Talks to Cathy Ficker Terrill**
http://www.aamr.org/FYI/interview_CathyFickerTerrill.shtml
This is an interview that the American Association on Mental Retardation did with Cathy Ficker Terrill, who is the President and CEO of the Ray Graham Association for People with Disabilities and past president of the AAMR. Cathy has been a successful advocate in the field of disabilities and she answers many questions about how to successfully advocate, particularly at the state and federal level. She shares tips about what works and what doesn’t.

10. **Getting Started at the State House: A Resource Guide for Nonprofit Organizations on Influencing Vermont State Government**

<http://www.snellingcenter.org/article/view/13340/1/2016>

This article, written by Julie Davis at the Snelling Center for Government, discusses how to advocate at the state-level. It is directed toward Vermont, but much of the information can be used elsewhere. The article begins with a brief introduction and then moves into advocacy and how it is more than just lobbying. The next section looks at state advocacy and lobbying rules and regulations. Next, the federal lobbying rules and regulations are discussed. Davis talks about how to prepare for the legislature and the legislative process. The final section focuses on taking the first step towards advocacy.

11. **Technology in Schools. Suggestions, Tools and Guidelines for Assessing Technology in Elementary and Secondary Education**

<http://nces.ed.gov/pubsearch/pubsinfo.asp?pubid=2003313>

This guide was written by the National Forum on Education Statistics under NCES's Cooperative Education Statistics System. Directed toward state and local education agencies, it describes how to measure technology use by examining planning and policies; finance; equipment and infrastructure; technology applications; maintenance and support; professional development; and technology integration.

12. **Quality Indicators for Assistive Technology Services**

<http://sweb.uky.edu/~jszaba0/qiatqualityind.html>

This link under the Quality Indicators for Assistive Technology Services contains current and historical versions of Quality Indicators for Assistive Technology Services in School Settings. They give you all of the documents since 1999 and show each revision that has occurred since then to get the most recent document, Quality Indicators 2005.

13. **Assistive Technology Policy Checklist**

<http://natri.uky.edu/resources/reports/cheklst.html>

The Assistive Technology Checklist is a multi-faceted tool that can be used by those who are developing assistive technology (AT) policies, analyzing existing AT policies, or obtaining feedback from stakeholders about the appropriateness of AT policies. The purpose of this report is to describe the elements of the checklist and explain various ways that it can be applied.

14. **Top Ten Tips for Disability Policy Change Agents on How to Influence Policymakers and the Policymaking Process**

<http://www.nls.org/conf2006/top%20ten%20tips.htm>

This article, produced by the Center for the Study and Advancement of Disability Policy gives ten tips for individuals to use when advocating for policy changes. The authors discuss the importance of understanding historical and policy context. They also discuss how to articulate values, principles and goals of disability policy and talk about the importance of understanding the policy and the need for having strategic plans. It is a clear list of tips, and each tip has supporting information along with it.

15. **Guidelines for Meeting with a Policy Maker**

<http://www.nls.org/conf2006/meeting%20policy%20maker.htm>

This resource gives ten guidelines that should be followed when meeting with a policy maker. The authors give advice on what you should do in preparation for the meeting. They also discuss what should be mentioned at the meeting and how to present your information in an appropriate manner. They also offer follow-up activities.

15. **Enhancing System Change and Academic Success Through Assistive Technologies for K–12 Students With Special Needs**

<http://www.ncrel.org/sdrs/areas/issues/methods/technlgy/te700.htm>

This article discusses successful assistive technology initiatives in Wisconsin and Illinois, to frame a focus on key elements of effective systemic change to improve schools. The promising benefits of assistive technology, evidenced by projects currently in place in Maryland, Kansas, Texas, and Michigan are discussed.

16. **American Public Works Association: State Advocacy**

http://www.apwa.net/Advocacy/State_Advocacy/

This link shows all fifty states and allows you to click on your state to go to another link that contains the state advocacy information for that particular state. The information you can find here includes: information about the state government, state bills, state in general, legislature, agencies, and advocacy. There are many additional links that can lead you to the information you are looking for. It is a good place to start to obtain information about your particular state.

Transcript

- **What is success? by JoanBL on Dec. 03, 2006**

I would like to talk with you all on what skills, expectations and supports come into play to support successful advocacy for students, and to welcome the voice of the advocate. Perhaps later on, I would also like to direct the conversation towards helping students become successful self advocates. I look forward to the conversation.

- o **Re:What is success? by Linda Taylor on Dec. 04, 2006**

I agree with you. Being the mother of a special child in a school designated for special children in Memphis, I know that success on an individual basis is the first step. There is a lack of equipment for each child, however. The class relies on our personal insurance to purchase many of his technological equipment. We are blessed to have insurance that caters to all of Jesse's needs. I sometimes feel for those students who are not so blessed, however. Plus, the school system, overall, lacks much in the way of technological help for all of the students within the system. I will pass all that I learn on to the right person within the Memphis school system, and I will look forward to a fruitful upgrading of the system -- one day. Here's to hope and faith.

- **Re:What is success? by Joan BL on Dec. 04, 2006**

The provision of equipment is such a huge issue. I hope we will all get some tips from the funding conversation going on concurrently.

You raised the issue of technological help throughout your school system. Sometimes, we need to advocate inside our school district- to the school board, to the PTA, to the folks holding the fundraising dollars (things like the Campbell labels or the General Mills education funds) that technology- for all kids- is essential. I have seen far too many schools where the special ed classrooms get all the old computers when the rest of the school upgrades.

Sometimes we also need to advocate for technology support inside the school for the "tech guy" to support the assistive technologies. Schools in MN need to complete and submit school technology plans in order to qualify for funds to help pay for technology infrastructure. I know we are really lucky in MN- the state department staff person responsible for this area sees and values the inclusion of assistive and accessible technologies. But I will tell you that one reason she remembers this is advocacy- there are enough informed AT advocates (primarily educators) who make sure she has good information to include in developing the plan. So- we have a strong need, a "hero" who can move the agenda along, good information about why the need is so important and a concrete plan to propose.

- **Re:What is success? by Kelly C on Dec. 06, 2006**

Here in RI, the funding issue is huge---both in terms of assessment and acquisition and support of AT tools. Everything from “special” pencils to batteries to AAC devices is often debatable. Legislation here says we must consider AT, but provides no means for supporting it...very frustrating! However, individual schools (i.e. PTA/PTO’s) cannot really be held responsible...many of the districts here are already struggling to maintain programs with level funding, with individual schools resorting to supporting their own students for things such as field trips/busing, etc. Unfortunately, technology is not available in many schools for any students. Personally, I believe that the issue has to be addressed at a federal level, with funding being the priority! That will make things much easier on states, educational teams and families--- and ultimately the student who needs assistive technology to be successful!

- **Re:What is success? by Carlene Volbrecht on Dec. 06, 2006**

Here in Wisconsin, some parents who search for funding to assist their students accomplish ADL or school tasks use the WISLoan program. They can borrow many AT items from the loan closet to try out first to see if they are helpful. If the student and family find the borrowed item helped address some of the barriers faced by the student then they can apply for a low cost loan to purchase the item through the WISLoan program. We too are faced with dwindling financial supports from the state for our schools and many programs and services are being cut out of school budgets. As students transition out of the local school system, to pursue post secondary education, they can take the individualized education plan from high school to the students with disabilities office on campus to request accommodations. Often this becomes a give and take discussion between the student, parents, and the college and/or technical school to make sure the accommodations address the needs of the student. However, if post graduation the student decides to seek employment, then another set of barriers may be encountered with employers not understanding the ADA. Many employers lack experience or knowledge about how to modify work stations or how to provide accommodations that might include job sharing, job carving or flex time to allow for success in the employment arena for the student interested in employment. The disincentive of losing medical coverage due to income earnings also presents families with additional dilemmas as the student attempts to become independent. I don’t have any magic answers. I think stakeholders need to come together and discuss the issues facing individuals with disabilities and form coalitions to raise public awareness of these issues. If we can get local groups to agree on the importance of these issues we can then expand to the regional level and then to the state level. I see this process as a way to bring about changes through legislation. But laws without funding won’t help. Too many of our communities are struggling financially and I am not sure how we can change that piece of the puzzle.

- **Re:What is success? Transition concerns by Joan BL on Dec. 07, 2006**

I am probably going off my own topic, but something Carlene talked about is something I worry about a lot. When students leave their K-12 setting, most of their AT supports disappear. As much as we, as AT advocates know that things can be better in our school systems, it might be the best system in place right now. Research was conducted among young people who have exited K-12 settings, but had received AT services in the school. The majority of these young adults were not able to identify what AT they had used, why they needed it, or knew how to request it in their new setting. The bottom line- we have not taught these young men and women how to advocate for themselves in their use of AT. This skill is something that needs to be learned. We have drafted a few solutions here in MN that I can talk about, but I would love first to hear if anyone else has thoughts? I know WATI has a resource- perhaps someone can talk about that and I would love to hear about other options also available.

- **Re:What is success? Transition concerns by Jane Johnson on Dec. 07, 2006**

The Florida Dept. of Education funds the Assistive Technology Education Network (ATEN), whose mission is to assist in the enhancement of student outcomes through provision of information, training, and technical support in the area of assistive technology. ATEN's professional staff includes educators, speech-language pathologists and occupational therapists.

ATEN provides information and resources related to assistive technology via phone, fax, e-mail, and their website at www.aten.scps.k12.fl.us

ATEN also offers a variety of workshops throughout the state. The majority of workshops feature practical hands-on exploration of assistive devices and software and are free to Florida public school system employees, students, and their family members and caregivers. Continuing professional education credits are available for workshop participation.

We also have Local Assistive Technology Specialists (LATS), which are a network of professionals, appointed by their school districts, who serve as a front line of support for students with assistive technology needs. LATS also support school personnel, family members and caregivers. The LATS coordinate their district's evaluation and implementation efforts.

- **Re:What is success? Transition concerns by Dr. Brenda Scott on Dec. 10, 2006**

Joan, I do not have a solution to offer, however, I can really identify with this issue. I sit on IEP teams with parents and students and one of the issues I try to raise to include in the IEP is a section on teaching the student to advocate for their needs (AT and otherwise). I tell them about my experiences with post secondary education (I do some evaluations in that arena also) and why this is important. Sometimes I meet with resistance from parents who want their student to have an assistant to help them versus using (and learning advocacy for) a technology. In these cases, I do try to explain why it is better to make that student more independent and also an advocate for what they need. It is a slow process, however, I do feel we are doing better about changing perceptions.

- **Re:What is success? Transition concerns by jcruce on Dec. 11, 2006**

Here in SC our Vocational Rehabilitation department has a transitional program to help students with special needs transition from school to work. We get involved in the student's junior year, so we have access to the student's IEP team and can develop an understanding of the technology the student uses during the two years leading up to graduation. This access helps ensure a smooth transition from school to work (especially when the currently-used technology belongs to the school and will not be going with the student). One of our goals is to ensure that the IEP teams know about Vocational Rehabilitation and the services we provide, so they can refer students to us at the appropriate time.

Of course, our aid is limited to the technology required to enable the student to go to work, so there are still some individuals who slip through the cracks. As an organization, we hope those individuals know about the states' Tech Act programs, and we try to educate them when they come to us, but in my experience I find that the Tech Act programs are under utilized.

- **Re:What is success? Transition concerns by Joan BL on Dec. 11, 2006**

One of the biggest concerns I have in supporting students transitioning to post secondary settings is that they need to either be a self advocate, or have an advocate in place who understands and can support the use of assistive technology. For those students who can develop self advocacy skills, we have proposed a sequence of skills a student can practice over time to become more skilled and take on more responsibility for their AT. To find the form which assists a team in looking at the sequence of skills visit.... http://education.state.mn.us/mde/Learning_Support/Special_Education/Evaluation_Program_Planning_Supports/Assistive_Technology/AT_Resources/index.html

Please note this links to the ENTIRE Minn. AT manual. The forms are at the end of the document, so you should just scroll to the very end, and I think this form is 3 to 5 pages from the end.

- **Re:What is success? Transition concerns by Grace F. on Dec. 15, 2006**

Thank you for the link to this very helpful manual! I found the information on pages 92-94 exactly what I had been looking for in transition planning and self-advocacy. The website is now on my Favorites!

- **Re:What is success? Transition concerns by Joan BL on Dec. 18, 2006**

Thanks! We are proud of this resource and are happy to share.

- **Re:What is success? by cpichler on Dec. 12, 2006**

Employers are not the only ones who need to understand the ADA. People with disabilities, their families and advocates also need to understand some key points that are often overlooked. The harsh reality is that the ADA is not an affirmative action program, and voc rehab is not intended to be a lifelong support system. People with disabilities must be QUALIFIED to do the job. In other words, they need to have the skills, with or without AT. AT is great at leveling the playing field, but employers are frustrated with Ex Ed graduates who do not understand their own needs, do not know how to use their devices, and expect a level of support that an employer is simply not obligated to provide. They are also frustrated with regular ed graduates who do not have a good work ethic, but that is another story.

While education is a right, employment is a privilege, and students need to be prepared to assume the responsibilities of employment. We need to make sure that students in transition know what AT they need for accommodations, why they need it, and they need to know how to ask for accommodations. Unlike education, an employer is not obligated to identify and accommodate a disability unless asked. Employers have told me that they do not mind supplying accommodations, but they do not want to have them take time away from other job duties. For example, they do not mind supplying a timer for a worker who cannot tell time and needs to be cued to return from a break, but they do not want to have to set it. They want the worker to take that responsibility. We need to recognize the difference between the entitlement of education and the privilege of employment, and prepare our students to move into a world with fewer supports.

- **Re:What is success? by croberge on Dec. 13, 2006**

THANK YOU, THANK YOU! For stating this, now if only parents and advocates can begin to wrap themselves around this idea. We have a few students who have begun the transition process and the parents are still asking what is the school system going to do about obtaining AT needs. I think these ideas need to be discussed early so parents and advocates are not surprised during transition so that their children will be better prepared for the work world.

- **Re:What is success? by Jane Johnson on Dec. 13, 2006**

That is an excellent point. The IDEA is like a protective umbrella that provides students and parents with expectations that their needs will be met - and rightly so.

When a student leaves the K-12 system and enters employment - or even post-secondary education, they step out from under the umbrella of the IDEA and into the world of the ADA, which, as someone else noted is not affirmative action.

Part of the transition process should focus on the difference between IDEA and the ADA. Post-secondary students and employees will have to learn to identify their needs and request the appropriate accommodations. This is a big difference for many students and parents and can cause a lot of confusion and frustration if it isn't addressed up front.

- **Re:What is success? by Laurie DuBose on Dec. 18, 2006**

I agree that employment is a privilege and a responsibility. Too often students with disabilities (and many youth without disabilities for that matter) have been told who, how, what, when and where --all of their lives. Good intentions on the part of parents, caregivers and teachers do not prepare a student to manage the responsibility of being employed, live independently, or instruct others in his/her care. It also seldom promotes the confidence and motivation required to be successfully employed or to live independently. Employers are often willing to hire individuals with disabilities however they do not want to hire two people to do the job of one, or to assign self management tasks to other employees (such as setting the timer, assisting with meals, etc. They may rearrange job duties, consider job-sharing, allow caregivers to provide needed personal care, and so on however the expectation of a "day's work for a day's pay" is only fair.

- **Re:What is success? by speddie1 on Dec. 19, 2006**

I agree that families need to understand ADA as well. My sister is intellectually disabled and applied for a job. She had done the job at a different store before but

this store required a computer test to be hired. My mom asked if she could read it to her because she can't read and doesn't know how to use the computer and they said no. My mom just got mad and took my sister and left. I don't think that was right of the store and that they should have made accommodations. My mom didn't know my sister's rights therefore let it go. This could happen to someone else now. I agree that individuals need to know what assistance they need and make sure the employer helps them.

- **Re:What is success? by Laurie DuBose on Dec. 05, 2006**

Funding for AT is an ongoing issue --whether it be for replacement batteries to power a device (small or large) to upgrading software and so forth. As technology advances and "newer better" ways to accommodate individuals with disabilities are developed, (including more and more options) keeping up with these advances is a challenge for all concerned, financially and educationally.

- **Re:What is success? by Kim Moccia on Dec. 05, 2006**

Laurie, you bring up some good points, especially regarding how quickly technology changes. It is important to remember that funding sources aren't known for purchasing devices simply because they're newer and better. If a new device is better equipped to meet a consumer's needs documentation should be provided to support the request. Funding AT can be a never-ending cycle but, in my opinion, worth the effort!

- **Welcome by JoanBL on Dec. 03, 2006**

I join Jackie in welcoming you to this Winter Institute. I was so pleased to see the breadth and depth of knowledge among participants. Rather than "teaching" I expect that I will hopefully be learning from many of you.

To prepare for this institute, I have been thinking long and hard over the last few weeks about what I wanted to share about advocacy, particularly as it relates to assistive technology. The recent implementation of IDEA 2004 reminds us of how important effective advocacy is. One of the things that IDEA says to me is that the Team is perhaps more important than ever. I think all team members, including the student, need to be effective advocates. But, to be effective, it is essential to know about goals for the student, goals for the program, and what it means to use AT effectively. I hope some of you can help me analyze these components and, in our other subtopic, examine the factors for success. I am excited to work with all of you.

- o **Re:Welcome by Jane Johnson on Dec. 04, 2006**

I am very excited to be a part of this Winter Institute and to share information about advocacy. As Joan mentioned in her welcome, effective advocacy is vital to ensuring that children receive the education to which they are entitled. In addition to cultivating good parent and student advocates, however, it is also critical that we advocate for improved education delivery systems, so that educators, parents and stu-

dents who are new to disability issues in education don't have to continually re-educate school districts each time a student has a special need. Through this two-week Institute, I hope we can help you learn how to develop an "advocacy infrastructure" in your districts and your states.

- **Re:Welcome by Linda Taylor on Dec. 04, 2006**

Within that "advocacy infrastructure" should there be funding to teach parents and family members the intricate details of how the technology works -- and teachers, too? I am a parent with a cerebral palsy child (Jesse is nine years old). I feel frustrated when it comes to home carry-over using his "4-talker". More advanced technology would probably really floor me. I do know that he has the ability to learn more effectively from a technological base. Maybe money should be made available to teach teachers and parents about the use of various advancements.

- **Re:Welcome by Kim Moccia on Dec. 04, 2006**

The following is from an article on the Neighborhood Legal Services, Inc web site –

"To support implementation of AT goals, the definition of AT services includes training for the student with a disability, as well as the family, if appropriate.[292]

The regulations strengthen this concept by adding to the definition of "parent counseling and training." The definition now includes "[h]elping parents to acquire the necessary skills that will enable them to support implementation of their child's IEP." [293] The comments note that this change is consistent with "the more active role acknowledged for parents" by IDEA '97."

You'll find this article at <http://www.nls.org/specedat.htm>.

- **Re:Welcome by Joan BL on Dec. 04, 2006**

Linda- You raise an important issue. Parent and family training is essential. Here in MN, there are multiple family training grants issued by the Department of Education, including grants specifically to support families being aware of the range of assistive technology. I also work with both PACER Simon Technology Center and the Arc to provide family training. The federal government does support family training centers, which includes PACER (www.PACER.org) as the national center, and six regional centers. You can learn more about these centers at <http://www.taalliance.org/index.htm>

You may also find one of these centers is close to you geographically. Certainly this institute is one of those federally funded opportunities to share information.

One of the things I have learned in my years working in a state education department is that there is no mandate that says HOW to make sure parent training is important. I believe each state has a state special education advisory panel. This may be a group that could raise the importance of family training in AT.

I can discuss how we work in MN to support family training in greater detail, but the shortest

answer possible is that parents and advocates have been part of my personal “circle of friends” to help me remember how to keep parents in the information flow.

- **Re:Welcome by Laurie DuBose on Dec. 05, 2006**

Follow up with the students/clients, families, caregivers, educators etc. is a critical piece of the AT picture that is often skipped or skimmed over. All members of the “AT team” need to be invested in the evaluation, implementation, education, and use of the AT device to ensure success. The care, maintenance, programming, and instruction in the use of the device/ equipment falls to the parents and/or caregivers; frequently after only a cursory instruction/ demonstration period. Often in cases where the demands of everyday living are overwhelming, without the added responsibility of incorporating complicated AT into this routine, the technology may be viewed as a burden and abandoned as unsuccessful. Help and support for teachers, students and caregivers needs to be available until functional use of the technology is demonstrated by the intended user.

- **Welcome the FCTD Winter Institute on AT by Jackie Hess [SI Faculty] on Dec. 03, 2006**

We’re very pleased that you’ve chosen to participate in the Family Center on Technology and Disability’s first Winter Institute on Assistive Technology. Many of you have participated in our summer institutes and know how informative and rewarding they can be. We’re trying a few new things with this institute and are interested in your evaluation of their utility.

Quite a few people have, in the past, asked us for the option of being notified by e-mail when new posts appear. We’ve included that feature in this institute and will be anxious to see how well it works. Please remember that it’s only an option. You do not have to register for e-mail alerts if you prefer not to.

We’re also trying something new in structuring the discussion strands by “sub-topics.” Each of you have received the learning objectives established for each strand. We’d like to focus the discussion within each week to certain aspects of funding and advocacy building. However, please know that you can continue to pose questions and offer comments on ANY sub-topic at ANY time throughout the next two and a half weeks. As always, you can post questions and comments on additional topics as well. We have an excellent faculty and an extremely impressive group of participants and I’m certain that the collective knowledge base is both broad and deep.

So welcome! I hope you’ll check the discussions often and won’t feel a bit intimidated from posting. Remember, everyone is here to help kids with disabilities and their families and we’re all in this together!

Jackie Hess - FCTD Director

P.S. Please feel free to phone or e-mail Ana Maria Gutierrez or me at any time:

jhess@aed.org; (202) 884-8217; agutierr@aed.org; (202) 884-8068

- **Chicken or the egg? by Toni on Dec. 04, 2006**

When planning statewide advocacy efforts, is it better, do you think, to start with an expressed goal, say, “getting the state department of education to adopt a specific policy” or is it better to get stakeholders together who are generally interested in strengthening a state’s AT policies and then decide on specific goals? I would think that your criteria for “success” would be different, depending on which approach you take. Your timetable would also be different. Of course, in the end, I suppose you wind up in the same place (hopefully) -- getting specific policies adopted.

In the case of the Florida success described, how was it done?

- o **Re:Chicken or the egg? by Jane Johnson on Dec. 04, 2006**

In Florida, the specific policy goal was identified first. Parent advocates made us aware of issues that their children were having when they moved through the education system, but had to give up their AT each time they made a transition.

We identified a solution to the problem (a change in policy, which became our goal) and then pulled together a coalition of other disability groups, parent organizations and families to help us take our message to legislators.

I think you can say that we had success on two levels. We were able to change policy AND we created a very effective disability coalition that we have been able to mobilize for other issues.

If your goal is to develop a more cohesive and effective disability advocacy network, then getting stakeholders together should be your goal. However, sometimes groups like that can suffer from inertia if there isn’t a pressing issue to energize them and give them a focused purpose. They can become one of those groups that just meets to have meetings (which isn’t always a bad thing, because that is sometimes where the next big idea is born!)

- **Re:Chicken or the egg? by Joan BL on Dec. 04, 2006**

It sounds like you had a powerful and positive group. Can you talk a little about the length of time it took for this change to happen?

I also wonder if there were times that you hit barriers and strategies that were used to overcome them?

Who were your supporters? Did you go into this with champions at the government level? I am so intrigued with this, and am anxious to learn more!

- **Re:Chicken or the egg? by Carlene Volbrecht on Dec. 05, 2006**

This discussion is very meaningful to me as I recently began a new position here in Wisconsin. I am housed within a specific region of the state to identify stakeholders working toward overcoming employment barriers for individuals with disabilities. The concept of pulling together a

coalition to address this issue is both exciting and daunting. I am anxious to compare best practices and ideas with others who are also engaged in this process. I see AT as being a significant piece of the puzzle for long term employment success for individuals with disabilities.

- **Re:Chicken or the egg? by Jane Johnson on Dec. 05, 2006**

One thing that we have done in Florida is to circulate a flyer that lists our legislative or public policy priorities to the different disability organizations throughout the state. At the top of the flyer, we ask the group's representative to put a 'check mark' next to any of the priorities that his/her organization also supports.

When we get those forms back, we develop individual issue briefs for each issue. At the bottom of those sheets, we include a note to the effect that, "this issue is also supported by the Fla. Assn of CILs, the Advocacy Center, the DD Council, etc."

That helps the policymakers who are reading the issue brief get a sense for how broad public support for the issue is and whether it's a potentially divisive issue within the disability community.

- **Re:Chicken or the egg? by Jane Johnson on Dec. 05, 2006**

The effort took about two years from the time the problem was identified until the bill was passed and corresponding rules were promulgated.

We hit a few snags along the way because the state Dept. of Education originally opposed the legislation. We had to meet with their governmental affairs staff and explain what we were trying to accomplish and why it was important, then meet with staff in the Governor's office to get their support as well.

Our supporters included the state DD Council, other parent advocacy groups, and as the state AT Program, our entire board worked to support the issue. Starting in February, bills begin to make their way through committee hearing process, mass e-mails are sent to these different groups, asking them to contact committee members and ask them to vote in favor of the bills.

Our champions at the government level were the House and Senate members who agreed to file the bills for us, but when we brought our board members to Tallahassee for a legislative work day, they were able to get additional sponsors during their visits with legislators. It really helped when they could convey a personal story that explained why the bill was so important.

- **What states are doing what? by Joan BL on Dec. 04, 2006**

In the last year, some state specialists in AT from departments of education began meeting. We have identified that we all have multiple areas where we need to do better, and, we identified that we have skills and strengths we can share to save on recreating wheels. Not all states are participating, in fact, not all states even have a state specialist with AT responsibilities. But- I will check with those folks who are participating in SLATE (state leaders of AT in education) to find out who these leaders consider to be their “go to” people for parent training. I will share that information with FCTD as a resource.

- **What are the fundamentals of statewide advocacy? by Jane Johnson on Dec. 04, 2006**

First of all, what is meant by statewide advocacy? Statewide advocacy consists of influencing public policy decisions in a way that will impact the entire state, not just a local school district. This is different from advocacy for an individual student, because it results in programmatic changes that can touch the lives of all students within a state. An example of statewide advocacy would be working to convince a state Dept. of Education to offer its high stakes test in a web-based format so that certain students with disabilities can access it more readily.

What are the fundamentals of statewide advocacy?

1. Identification of the problem or issue.
2. Development of a strategy for addressing it.
3. Building a coalition of like-minded organizations and individuals who will support your advocacy efforts.
4. If the solution requires a change in law, find a legislator who will embrace your issue and file a bill to achieve your legislative goals.
5. If the solution is regulatory (state policy or rule), respectfully request a meeting with the state agency charged with oversight of the program or service where you want the change to occur.
6. Develop “issue briefs” that concisely explain the current problem and list the positive results that would be achieved if the law, policy or rule was changed.
7. Negotiate with decision makers.
8. If appropriate, ask grass roots supporters (members of your coalition) to contact legislators or policy-makers and ask for their support on the issue.
9. Contact local and statewide media - give them press releases with real life examples and quotes from affected individuals.
10. Don't be afraid to compromise in the short term - you can always come back the next year to get what you aren't able to get the first time. Something is better than nothing.

- o **Re:What are the fundamentals of statewide advocacy? by Joan BL on Dec. 04, 2006**

What great ideas! I really identify with step 2- to build a coalition of like minded individuals.

I belong to a large advocacy organization here in MN. They annually sponsor a Day at the Capitol. Dur-

ing that day, the organization sponsors breakfast, a brief training session on how to lobby effectively, provides the participants with talking points and handouts on relevant issues. They also have a list of legislators to help the participants (who come from the entire state) identify who they need to target. The most powerful tool is telling that personal story.

The advantage of working with those like minded individuals, particularly a statewide group, is that it helps identify the legislative champion who has a history of moving the type of issue ahead.

- **Re:What are the fundamentals of statewide advocacy? by Linda Taylor on Dec. 04, 2006**

This is all new to me. I have heard of great things happening in the field of assistive technology in Tennessee, also. I just have never had an urge to learn about the field. Now I have that urge. So far, I have not heard of an Advocacy Day at the Capitol for the sole purpose of assistive technology. That should get attention as in MN.

- **Re:What are the fundamentals of statewide advocacy? by Carlene Volbrecht on Dec. 05, 2006**

I plan to use the 10 points of discussion as a starting point as I work toward developing a coalition here in Wisconsin to address employment barriers for individuals with disabilities. Schools, county, state and private programs already in place focus on parts and pieces but at this time there isn't communication between all of the stakeholders. I am looking for ideas and best practices from others who have experience in coalition building. It will be interesting to see if an advocacy group develops from the coalition that will become politically active.

- **Identifying needs by Joan BL on Dec. 05, 2006**

Jane has told a powerful story of the steps FFAST took to move a necessary piece of legislation forward. I am moved by the work it took and the dedication of the partners.

I wonder what natural supports participants know about in their state and how they collaborate? I know here in MN, there is a collaborative of agencies that support services for persons with disabilities, including some strategies that will address AT needs. This collaborative does not include state agencies, so there is no opportunity for me, for example, to impact their discussion. I have made sure, however, that members of that group participate on my leadership team, so that the voice of advocates is heard. This has impacted how I try to do my job. Do other states have something like this?

- o **Re:Identifying needs by Carlene Volbrecht on Dec. 06, 2006**

Here in Wisconsin I have recently become involved with the Pathways to Independence Project. One of the tasks I am currently undertaking is to identify stakeholders in my region of state. I am to ask

them to talk about the employment barriers faced by individuals with disabilities within my region. The stakeholders might include but not be limited to individuals with disabilities, County Human Service providers, medical providers, families, school systems, Job Centers, employers, and state agencies. The goal is to develop a coalition to address employment barriers so that individuals with disabilities can have full inclusion in the community, including employment if desired. So we too are trying to include state agencies in this process.

- **Who do you turn to? by Joan BL on Dec. 06, 2006**

I wonder what resources participants have used to support their advocacy activities. As I mentioned earlier, I annually participate in an advocacy day at our state capitol. This day is supported by a coalition of state-wide advocacy groups, including Arc, UCP and PACER. (By the way- I do this on my own time- NOT as a state employee).

There is an association in MN called the Consortium for Citizens with Disabilities, which made up of representatives of advocacy groups. They have a legislative agenda that they send to the state legislature through legislators who are champions for disability issues. Do other states have similar groups? Are the challenges with this structure? Jane- is this similar to what you established to move your agenda forward?

- o **Re:Who do you turn to? by Jane Johnson on Dec. 07, 2006**

Florida does not have a formal disability consortium, but over the years, we have established strong relationships with other disability groups. That was no small feat in many instances, as many times, disability groups wind up competing against one another for funds, programs, credibility, etc.

We do try to “piggy back” on events that other organizations sponsor - as a gesture of support to the organization and also to convey a more united front from the disability community. That support is typically reciprocal, so we can usually count on getting help from those organizations when we sponsor events.

There is definitely strength in numbers, and this is particularly true when you are dealing with state legislatures. The more constituents (voters) you can demonstrate in support or opposition to an issue, the more likely you will be to get a policymaker’s attention.

Our state DD Council does sponsor a DD Awareness Day at the capitol each year, and we bring our board members in for that so they can visit their legislators and advocate for our issues.

If a state has several disability organizations that have boards or advisory councils, I would recommend holding a disability summit prior to the start of the legislative session. The summit would bring together representatives of each of those organizations’ boards so the groups can brainstorm about the legislative issues that they might want to partner on and develop strategies for working together to achieve the shared goals.

- **Re:Who do you turn to? by JH on Dec. 08, 2006**

Jane, I like the idea of a disability summit, but am wondering how resource-intensive it is. How you deal with the budget and personnel resource needs? Do multiple organizations contribute? Do you think it works best if one organization serves as the primary organizer? Given that many disability organizations are grouped by specific disability and that most probably aren't very sophisticated politically, how do you educate people across the board with respect to common legislative and regulatory goals? Thanks. John H.

- **Re:Who do you turn to? by Jane Johnson on Dec. 08, 2006**

Pre-event planning for a summit can be conducted via teleconference or by email. Once the location, date, and agenda are agreed upon, a budget can be developed.

Ideally, you will receive financial support from multiple organizations. This establishes a stronger "buy in" from those involved. Most states receive funds that can be used to promote advocacy and awareness for disability groups. Those monies can come in the form of sponsorships from state agencies or non profits such as the state DD Council or AT Program. The funds can be used to pay for the cost of the meeting room and meals for summit participants.

If you are bringing in representatives of various disability organizations, the costs of travel and attending the meeting should be covered by those organizations.

A key goal of the summit should be to educate the participants about the legislative process and explain how legislative advocacy works. This can be done through "Advocacy 101" presentations and reviewing issue briefs.

Many of the state chapters of national disability organizations such as ARC and Easter Seals have access to some very sophisticated advocacy tools that can be used to demonstrate how to communicate with policymakers effectively.

Once you explain how the process works, participants will have a framework for developing their public policy goals, which should help to guide the discussion. Without that framework established, discussion can easily erode into gripe sessions about what's wrong with the system, with no clear direction about how to go about fixing what's wrong. It's really important to develop clear strategic objectives for the achievement of the public policy goals so participants know what they need to do next.

- **Re:Who do you turn to? by Cpichler on Dec. 12, 2006**

Another great resource found in every state are the Independent Living Centers. These are federally funded, cross disability, community based organizations whose goal is to help people with disabilities live independently in the community. Because of their cross disability focus they can be great members of a legislative advocacy team. To find the CIL nearest you visit <http://www.ncil.org/directory.html>

- **Re:Who do you turn to? by Linda Taylor on Dec. 08, 2006**

This is just a question: Do you have a branch of the ARC in your states? I happened upon one of their meetings a month ago, and those are some very informed, advocative people involved in that aspect of the world of disability. Check it out, if you don't know what that organization entails.

- o **Re:Who do you turn to? by Dr. Brenda Scott on Dec. 10, 2006**

Joan, I would be curious as to how the Consortium for Citizens with Disabilities got started. Perhaps you could share with us if you know how this came about. I do think that in order to effect change, you have to be effective at the legislative level. NC has a group called Governor's Advocacy Council, however, I am not sure they are active at the legislative level.

- **Re:Who do you turn to? by Joan BL on Dec. 10, 2006**

You know- I don't know. But, I will check with several of my associates, and find out!

- **Re:Who do you turn to? by Kelsie Williamson on Dec. 12, 2006**

Hello, here is some of the history of the Minnesota Consortium for Citizens with Disabilities. I should quantify that I was not around during the founding of the organization, but picked up a fair amount of the history working for the organization for a little over two years.

In 1995 CCD was formally founded in Minnesota in reaction to state budget cuts proposed to personal care services for people with disabilities and threats to the TEFRA program. The proposed cuts were very significant and impacted the people served by many disability organizations here so it made sense to them to coordinate their efforts to fight the cuts. The organization was set up and continues to function as a coalition of organizations of persons with disabilities, providers and advocates that addresses public policy issues. From what I have gathered, in the Fall of 1993, a small group of staff from disability organizations began meeting informally. This group was instrumental in actually starting the formal CCD here.

How MN-CCD Runs:

Organizations are asked to become members of CCD, which means that their organization name is listed on the letterhead and also allows people from the organization to vote. Membership in the group is free, but organizations are asked to contribute funds to the work of the Consortium, as they are able. During the legislative session, the group meets every Friday for one or two hours. When the legislature is not in session, the full group meets once a month. Committees are formed to work on specific issues as needed. Weekly during the whole year, an update is emailed to the group. There are two Co-Chairs who serve two-year terms. The co-chairs come from different organizations and are elected by the group. They guide much of the work of the organization and the organization that they work for agrees to allow them to use time for coalition work. MN-CCD works because a strong core group of disability organizations are committed to it. Through the Consortium, disability organi-

zations here have been able to have much greater public policy success than they would be able to on their own.

Please let me know if you have any specific questions.

- **Re:Who do you turn to? by Jane Johnson on Dec. 13, 2006**

Is there a lead agency or organization who assumes responsibility for the administrative functions of the Consortium? (e.g., meeting agendas, providing meeting space, teleconference numbers, copying documents, taking minutes, etc.?)

- **Re:Who do you turn to? by Kelsie Williamson on Dec. 15, 2006**

Currently, the organization of one of the co-chairs does the agendas, teleconference numbers, minutes, listserv, and most of the copying. A space in the Capitol complex here is used for meeting most of the time, sub-committees often meet at member organization offices. The responsibility for administrative functions shifts based on needs and resources, but is always coordinated through the co-chairs.

- **Re:Who do you turn to? by Dr. Brenda Scott on Dec. 17, 2006**

Kelsie, thank you for the history. What a great way to get disability organizations working together for greater success!

- **Indicators of Success by Peter.Stack on Dec. 08, 2006**

Here in RI, when a student/ child and family seek AT with accompanying specialists' recommendation(s) of specific AT item(s) (including supportive justification), and approach the correct payor (funding source) and follow through with available appeals, this is initial success. It establishes credible need and validates the sincerity (so to speak) of the request, and it is constructive toward full success: the procurement of the item for the student/child.

Although we're such a small state, there are nevertheless different responses to such requests in the school setting, depending on the particular school system. Some have a more generous policy.

But regarding funding to the Medicaid-eligible individual for an item requested for use outside of school, the standard format and process for application and authorization here in RI is commonly known and practiced by individual-consumers/vendors/specialists, and it has been relatively favorable to these requests. I have heard rumblings of significant changes in Medicaid that may be forthcoming, particular to DME (durable medical equipment, where my experience has been), but even if true, perhaps (hopefully) the tidal shift following the last elections can buffer that to a milder or less-significant drop.

- o **Re:Indicators of Success by Linda Taylor on Dec. 08, 2006**

As is done in RI, it is done in Tennessee. There has to be justification for the various equipment that the specialists recommend -- which is as it should be. With those ducks lined up, usually, a child's needs are met through Medicaid -- in Tennessee.

- **Use those cell phones! by Joan BL on Dec. 11, 2006**

One of the nicest changes in technology is the ubiquitous cell phone. Particularly when there is a hot issue, I can call a legislator's office at limited cost for long distance. Last year, I managed to call several US congressmen on an issue close to me. At least one representative indicated that his vote changed due to the huge number of calls that came to his office providing information on the impact of a particular piece of legislation would have on real people.

It also helped that the advocacy groups with whom I associate had prepared several talking points that I could use in leaving my message.

- o **Re:Use those cell phones! by Andre Ryssemus on Dec. 15, 2006**

One thing to add Joan is the use of email as well. I found out that an email to a legislator with a basic paragraph of concern works. Plus, with a mass email list of the same paragraph concern, the numbers add up quick. Once a legislator reads the first few emails then notices the same header. Their office starts a tally on that particular header. Then the office can say that we received over 5,000 emails on a particular concern that merit a closer investigation.

- **Re:Use those cell phones! by Joan BL on Dec. 19, 2006**

Great suggestion! Some of the advocacy groups to which I belong have a service which allows me to identify my legislator, and will suggest the text for an e-mail which can be personalized. This is efficient and not very labor intensive. For those folks who feel they do not have the fluency to present their case adequately to a legislator, it becomes very simple. I have noticed, though, that I tend to get a more thoughtful response from a legislator if I have personalized the message somewhat and told a little of my personal concerns.

I know that national legislators have told Arc leadership that the massive number of e-mails, phone calls and visits they have received on some topics has changed their vote. Your voice is important!

- **keeping the message positive by Jane Johnson on Dec. 11, 2006**

Disability advocates usually become advocates as a result of their personal frustration with the "system." The issues we typically advocate for tend to focus on refining the existing system, creating more user-friendly rules and regulations, and expanding opportunities and access for people with disabilities.

As frustrating as your experience may have been, if you allow your anger to dominate your advocacy, it can really backfire and become a major barrier to success. Anger and frustration can serve as powerful catalysts, but they should be channeled into positive and productive strategies before you begin conveying your message.

If you initiate a dialogue with a policy maker or elected official about an issue and you come across angry or accusatory, you will likely put that person on the defensive and sabotage your success. Check your frustration at the door before the conversation begins, and focus on the positive results you are trying to achieve.

Help the other person see the benefits of the policy change you are proposing. Offer to work with them, provide background information - make it a team effort. Even if you see them as part of the problem, don't let them know that. They will be much more reluctant to return your phone calls or agree to meetings with you and your group if they know it will result in an adversarial dialogue.

Subtle diplomacy is a critical component of effective advocacy.

- o **Re:keeping the message positive by Joan BL on Dec. 11, 2006**

I cannot agree more! There is an old saying that “diplomacy is the art of telling someone to go to hell in a way that will make them look forward to taking the trip.” If you go in to work with potential champions with your guns blazing, you may end up shooting yourself in the foot.

- **Re:keeping the message positive by Joan BL on Dec. 12, 2006**

So- responding to myself... I spoke with a friend last night who is the executive director for a large advocacy group. One member of the organization (a volunteer) went to talk to the chair of a state senate subcommittee on health and human services. This volunteer did not practice diplomacy, and in fact, was rather nasty in what she said to the senator. This resulted in the senator calling the director of the organization and raising a little heck himself. So- remember that when you advocate, you often represent more than yourself.

- o **Re:keeping the message positive by Linda Taylor on Dec. 12, 2006**

I can appreciate sound wisdom. The lead person who advised us to “check” negativism at the door to successfully advocate helped me out a lot -- that is advice that can be used in other facets of life, too.

- **Barriers to advocacy by Joan BL on Dec. 11, 2006**

At the beginning of this institute, Jane presented her excellent 9 steps to successful advocacy on the system level. I wonder however, how this transfers to real life.

Most specifically, I wonder if, for each step there is a barrier. For example, a barrier might be the inability of a group of advocates to come to consensus on which of multiple concerns is the most pressing. If too many

issues are brought forward, will they diffuse the support of policy and decision makers?

How have any of you dealt with having too many pressing issues, and needed to choose what to prioritize?

o **Re:Barriers to advocacy by VA on Dec. 12, 2006**

I've seen this be a problem at parent support group meetings, where often the person with the loudest voice and least manners manages to dominate the discussion. When this is allowed to happen month after month, people start dropping out of the group. I think it takes skillful leadership and strong meeting management abilities to keep this from happening. One tool I've seen used effectively is to allow each person an allotted amount of time to speak about their particular issue, then be firm in enforcing the time. With respect to prioritizing issues, I see no way around voting (although this doesn't always produce a list that sophisticated advocates would agree with; it may just reflect what most gets everyone's goat emotionally). Because the number of people who attend any given support group meeting is only a fraction of the total on the books, I always try to conduct votes by email. That makes for a more inclusive process and also provides an easy written record of who voted for what. Of course, it's a problem if there's a significant number of people in your group who don't use email. We try to call those folks on the phone. Which brings up an advocacy tool I meant to suggest earlier - phone trees. We use them when we need to get out a message or action item quickly. They've worked well for us, as long as we don't go to the well too many times.

▪ **Re:Barriers to advocacy by Jane Johnson on Dec. 12, 2006**

You make some excellent points and I think it's very important to ensure that one or two outspoken people aren't able to hijack meetings or discussions. That type of behavior - along with letting your anger and emotions get out of hand - are sort of the elephants in the corner in many disability meetings. Everyone knows who the angry and outspoken members are, but no one wants to confront them.

I think it is helpful to talk about anger and frustration and the rules of "advocacy etiquette" right at the outset of a meeting and put all of that on the table. Sometimes a person just wants to be assured that their grievance is legitimate. Validate the anger many parents and advocates feel, but help them to see the value in controlling those emotions.

Describe what is appropriate and inappropriate behavior. Do some role-playing to demonstrate communication styles that are effective and those that alienate. Simply tolerating bad behavior won't make it go away, and will likely erode the effectiveness of the group.

As far as voting on a list of issues, I think that's a great idea, because the list will be reflective of what everyone is struggling with. Not every problem rises to the level of a legislative priority, but it's important to find out what the issues are. Some issues can be solved simply because they were put on the list, and someone else has already tackled the same problem and has a solution.

- **Re:Barriers to advocacy by Joan BL on Dec. 12, 2006**

Wow- great points from both of you. One book I keep on hand to refresh my skills in working with challenging groups is Getting to Yes. It has nothing to do with education or technology, but the message and techniques are helpful.

- **Re:Barriers to advocacy by Carlene Volbrecht on Dec. 12, 2006**

We recently received a 3 day training on facilitation. Boy was that insightful since that is one of the roles I will be undertaking in my Regional Coordinator position with Pathways to Independence here in North West Wisconsin. I like the idea of setting the ground rules at the beginning of the meeting by asking the following questions... 1. What can I do as the facilitator to insure that we do not accomplish our goals today? (Yes I worded that question correctly) 2. What can you (participant) do to insure that we do not accomplish our goals today? The responses are written down and posted at the front of the room and reminded everyone what ground rules were agreed upon for the meeting. Also a section of the room can be set aside so that anytime during the discussion a participant can post a comment on a sticky wall to be visited later without interrupting the facilitator or the group process. This area on the sticky wall is called a parking lot. The facilitator then must remember to read the cards and address the issues or questions on the cards to validate the participants who were willing to write down items on the cards. We also practiced the other tools including ORID, Appreciative Inquiry, Brainwriting and Coming to Consensus. Some of the other resources identified for us to explore were books by Thomas Kayser, Mining group gold: How to cash in on the collaborative brain power of a group. Sharon Lippincot, Meetings: Do's, don'ts and donuts. Peter Scholtes, The team handbook. It was a very intense 3 days that provided me with many ideas and resources that I hope to put into practice.

- **the power of a listserve in maintaining momentum by Jane Johnson on Dec. 11, 2006**

Keeping the momentum going after a major advocacy effort can be a challenge, because it's hard to stay energized without a specific cause to keep you going. But in the disability community, there are ALWAYS causes to focus on, so it's important to maintain some level of involvement and interest so you don't have to start from scratch when a new issue comes up.

Email listserves are a great tool for keeping the interest and energy alive. They are virtually free, very low maintenance and allow members of your constituency to keep the rest of the group updated on what is going on out in the local communities.

Listerves are interactive and allow members to communicate with one another and individually. They do require that someone assume responsibility for monitoring the content of the emails, so while they are free to those on the list, there is a human/staff cost associated with keeping the information flowing. A lead organization would have to offer to provide that service.

Beyond listserves, monthly advocacy updates are another great tool for keeping a coalition engaged. Again, someone has to be designated to write and distribute the newsletter, but it can be a short (1-2 page) document that is sent electronically and/or available as a download from a website.

o **Re:the power of a listserve in maintaining momentum by Joan BL on Dec. 11, 2006**

Listerves are very valuable! I would agree that this is a highly useful tool. It also helps to have guidelines regarding what is appropriate content for a list- for example, guidelines about protecting confidentiality issues.

I receive weekly e-mail updates from Arc of MN with information on what is happening regarding advocacy, and a Capitol Insider which focuses on disability issues at the federal level. This is helpful information to help keep me informed. A very helpful strategy they have used from Arc is an e-mail link to my federal and state officials, through which I can send an e-mail with thoughts or concerns. This allows me to communicate in a timely fashion. It is obvious that some elected officials are more tuned into mail than others, based on the responses I have gotten!

▪ **Re:the power of a listserve in maintaining momentum by Carlene Volbrecht on Dec. 12, 2006**

I agree that Listerves can be valuable tools. There isn't time enough in the day to keep current on all of the disability related issues that require my time and attention. A well managed Listserve can distill a large amount of information into more manageable pieces that I can then use as talking points when speaking with other stakeholders.

▪ **Re:the power of a listserve in maintaining momentum by Joan BL on Dec. 12, 2006**

Carlene is right. The right listserve provides you with the right information. Does anyone have ideas on what lists are good for national advocacy issues regarding disabilities?

▪ **Re:the power of a listserve in maintaining momentum by LMF on Dec. 12, 2006**

COPAA - <http://copaa.org/> The Council of Parent Attorneys and Advocates is an excellent place to problem solve and get broad national input. Very helpful!

▪ **Re:the power of a listserve in maintaining momentum by Joan BL on Dec. 13, 2006**

That's a new one for me. I will look forward to checking it out. Thanks!

▪ **Re:the power of a listserve in maintaining momentum by Tasha on Dec. 13, 2006**

My favorite listserve is the QIAT (quality indicators in assistive technology). Although it does not deal with advocacy issues, it does help me in knowing what good AT services should look like in a school, then when I go to the IEP meeting, I have better

information on what I should expect both in setting goals, and in talking about progress. Their website is www.qiat.org. You have to go to the listserv archives to sign up, although there is a link on the front page to join. That link does not work!

o **Re:the power of a listserv in maintaining momentum by Andre Ryssemus on Dec. 15, 2006**

KUDOS. One great example is FCTD!!!

▪ **Re:the power of a listserv in maintaining momentum by Joan BL on Dec. 16, 2006**

Andre- you are so right! I don't know of many other resources where you can get so much information for free. I have participated in several of the on-line conversations and several of the institutes sponsored by FCTD. I believe this is one of the better national conversations on AT, and always appreciate the opportunity to be involved.

• **Reaching non-English speakers by Nicole B on Dec. 12, 2006**

In my area we have a problem reaching parents who aren't fluent in English. I agree with earlier posts that talked about legislators and other decision makers needing to hear from families who are affected by their decisions. So we try to get information to our families and get them motivated to be part of the advocacy process. But language is a major barrier. Most of our organizers and AT professionals aren't fluent enough in Spanish, much less Asian languages. So talking to people on the phone is difficult, getting written materials translated is difficult, and following up and getting people to meetings is almost impossible. Does anyone have any suggestions about reaching the non-English speaking population? Thanks!

o **Re:Reaching non-English speakers by Joan BL on Dec. 12, 2006**

The Arc Greater Twin Cities (Minneapolis/ St. Paul) has had a project to provide outreach to Hispanic families. The program is, I believe, staffed by Latinos. I know there is someone on this discussion from that organization- I hope they jump in and give us more information.

Several years ago, I worked in a community project where we had huge numbers of Asian refugees. In particular when we had concerns about literacy, we made audio tapes and video tapes of information in the needed native languages. We did, of course, have to pay for translation services (and I learned it was a good thing to have 2 translations, since some terms can be construed in different ways). While my referrals did not skyrocket from the refugee community, I know that the information was widely disseminated and that our program received a great deal of respect for having tried.

▪ **Re:Reaching non-English speakers by carlene volbrecht on Dec. 12, 2006**

Here in the Eau Claire area we have an increasing Hmong population and recently a growing Hispanic population. I am not sure what is officially being done on a county or community level beyond

having signage in Spanish and English in many local business and public buildings. As far as for the Hmong population, we have a Hmong Mutual Assistance Program that offers translators to go to school IEP meetings, doctor appointments and so forth. They also offer written interpretation services to help fill out job applications and so on. We also have several individuals of Hmong ancestry in higher education and as social workers in the county and they have been valuable in providing interpretive services to families who experience difficulty with accessing services and programs in the community. Unfortunately as with all programs their grant funding has been cut and now many Hmong residents rely on volunteers within the community to assist them with interpretive needs.

▪ **Re:Reaching non-English speakers by Joan BL on Dec. 13, 2006**

I worked with a peer last winter to develop training for cultural competencies for county social workers regarding disability issues among refugees. I learned a lot, and was surprised A LOT also.

Particularly if you work with Hmong, the book *The Spirit Catches You and You Fall Down* was eye opening.

Being aware of cultural norms with the roles of women v. men, who holds power, who makes decisions, how confusion may be communicated are significant issues when working with groups not in your normal circle of comfort. I also worked with a Mutual Assistance Program to obtain translations of the documents used in my AT program. It helped some, but the personal connection they provided was invaluable. By having someone from their culture who trusted me made my services more trustworthy. And that went a long way!

▪ **Re:Reaching non-English speakers by Karen Petit on Dec. 14, 2006**

Joan BL: Who is the author of the book “*The Spirit Catches You and You Fall Down*”? What were some of the things you learned? The collaborative piece with people from the culture you are serving sounded as though it was very important to success.

Just yesterday, I had a meeting with a parent who asked for help in learning how to communicate with Americans so that she could access services for her child. She is also struggling with sorting through what are the cultural norms for her child and within the American culture to determine what is the best way for her to proceed regarding the root cause of her son’s global delays or even to consider them delays. The striking thing about this was the parent had the need for cultural advocacy clear in her mind. Karen SFT

▪ **Re:Reaching non-English speakers by Joan BL on Dec. 14, 2006**

I just re-read the powerpoint from the presentation I did on cultural competency with my associate from Gillette here in St Paul. Here are some highlights:

Dominant culture’s view:

- Disability is a physical phenomenon

- Disability is an individual phenomenon
- Disability is a chronic illness/condition
- Disability requires remediation/fixing

Another view:

- Disability is a spiritual phenomenon
- Disability is a group phenomenon (e.g. the family or society are causal factors)
- Disability is a time limited phenomenon
- Disability must be accepted, which affects whether the family seeks intervention.

Common assumptions for immigrant groups:

- Generally a sense of shame regarding the person with a disability.
- Will attempt to hide or cope at home with the issues with disability rather than ask for support.
- People from visible minority groups have more limited access to services than does the general population.

Impacting factors on how a family views disability and access to services:

- Impact of length of time in the country
- Regional differences
- Impact of education, income, employment, etc.
- Religious belief

The entire powerpoint can be found at http://www.fctd.info/resources/newsletters/upload/Tech1_JBL.ppt

▪ **Re:Reaching non-English speakers by JH on Dec. 14, 2006**

The author of the book is Anne Fadiman. You can learn alot about it and read and hear an excerpt at <http://www.spiritcatchesyou.com/bookexcerpt.htm>.

▪ **Re:Reaching non-English speakers by cpichler on Dec. 14, 2006**

Thank you for sharing that link. The book is fascinating!

▪ **Re:Reaching non-English speakers by Jane Johnson on Dec. 14, 2006**

That is a wonderful book and it really does provide great insight into the Hmong lifestyle and culture, but the lessons it teaches can be applied to any situation where a person from dominant culture is trying to make sense of the needs of a person from a very different culture through their cultural filter. You really have to forget your preconceived notions and expectations sometimes in order to fully understand another person.

- **Geography as a barrier by MKL on Dec. 14, 2006**

A major barrier to statewide advocacy in some states is geographic distance. It may be hard for some of you, in the east especially, to relate to is how hard it is for those of us in large, rural states to meet and carry out advocacy plans. Many of us hardly ever get to the capital, which can seem as far away as another planet sometimes.

Lately I've seen more and more groups using technology to overcome the barrier of distance. They've used online meeting tools to get a meeting organized and telephone conferencing services to get us all together. I've been impressed by how well it works, but don't know much about these services. Could anyone tell me how much they cost and how easy (or not) it is to deal with them as the organizer? I'm thinking of trying them out, but don't really know where to start. Thanks.

- o **Re:Geography as a barrier by Jane Johnson on Dec. 14, 2006**

We have problems with geography here in Florida. Our most populous city (Miami) is 8 hours from the capitol and the other large cities are 4 hours away. We conduct all of our meetings by teleconference. All of the meeting materials (agenda, minutes, etc.) are sent out electronically in advance of the meeting.

We are able to access the state's telecom system, so our rates are pretty reasonable for teleconference, but callers have to absorb the cost of the call on their end, because we don't use a toll-free line.

We have also used a commercial phone service for a toll-free conference line for our all-day board meetings, and that costs between \$150-\$200. The costs for a one-hour call would obviously be much lower, but it would depend on the provider.

- o **Re:Geography as a barrier by Kim Moccia on Dec. 15, 2006**

Great question! Here are a few online tools I've seen used successfully. Some of the resources below are free and some offer free trials. (Please consider this a sharing of resources and not an endorsement. Let the buyer/user beware!)

Online meetings:

<http://www.onlineconferencingsystems.com/index.htm>

www.gotomeeting.com

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

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

Online meeting scheduler: <http://www.meetingwizard.com/mwiz/home/default.cfm>

VoIP calls and conferencing (I've never used this but know folks who have and love it.)

<http://www.skype.com/share/>

Blog-create/share your own: <http://www.livejournal.com/> and <http://www.blogger.com>

Podcast-create/share your own:

<http://www.podcastingnews.com/articles/How-to-Podcast.html>

(And, if you're looking for a way to capture online audio programs to listen to at your own chosen time, try Juice <http://juicereceiver.sourceforge.net/#download>)

Online Community: <http://www.myevents.com/login.aspx>

Favorites sharing: <http://www.blinklist.com/>

Google: www.google.com (Did I really need to type Google's address?!) I've placed Google last simply because it offers so many free tools. From the Search page click on the "more" link and then select the "even more" link. This will bring you to the "more Google products" page. Some of the Google tools you could use to keep in touch with advocates include document sharing, calendar sharing, and groups.

Sorry that I let the "geek" in me take over and gave way more information than needed/ requested! Go slow to avoid information overload. There are tons of services available and more on the way. Decide what you really need to do (such as share a calendar) and start from there.

o **Re:Geography as a barrier by Grace F. on Dec. 15, 2006**

We are also in a remote area (the UP of MI) and very far from the legislative areas downstate. (We're actually much closer to Wisconsin, and do some sharing of ideas/training with them.) But regarding advocacy, we are very fortunate to have a state AT association whose director has included our region in all decision making. In fact, he and his staff have traveled up here numerous times to meet with all of the AT specialists in the UP, and he has scheduled training events here as well. Through email and listserves, we keep in contact, and he represents us at the statewide level. If it weren't for their support, we wouldn't have a strong voice from this distance (as has been the case in other legislative matters).

o **Re:Geography as a barrier by Joan BL on Dec. 16, 2006**

This really is an issue for many of us. I used to live in a more remote section of MN, and travelling to "the cities" was a huge adventure. Now, as a state employee with statewide responsibilities, I have tried to remember how that feels for folks for whom travel is an issue. In particular, I see some of my friends who have a disability or family members with disabilities. The challenge of finding accessible travel, accessible hotel rooms, and travelling through a usually old state capitol building for advocacy activities is a real challenge.

I know several of our larger advocacy groups conduct business via conference call, and I have supported satellite broadcast training and newer DVD training resources. We need to be more proactive in supporting folks who live in more remote areas.

This forum is an excellent example of how distance can be overcome through effective use of technol-

ogy.

- **Re:Geography as a barrier by Carlene Volbrecht on Dec. 19, 2006**

As I am in the process of beginning a new employment venture here in West Central Wisconsin where I try to listen to “all” the stakeholders engaged in removing employment barriers for individuals with disabilities, this thread perked my interest. As much as we think each state has unique needs, reading the comments on this site have demonstrated that we really are more alike than different. As are the various regions within each of our states... I have heard many comments around my region that those folks in Madison (our capital) don’t understand what is going on here in north west Wisconsin! I have heard the concerns that the Madison folks express in regard to a lack of rural transportation, diminished medical care, access to post-secondary education, and wait lists for transition services. Low and behold, these are the same issues being discussed locally here in north west Wisconsin. I think we must exchange ideas amongst all stakeholders and that all of us must remain open to engage in the process of advocating. This endeavor will allow all of us to work together to reach the same goal....full inclusion for all citizens, regardless of where they live within each of our states. Thanks to all of the participants for posting ideas, websites, books, and other materials for resources. I have printed off many of the threads so I can follow up with the information.

- **Regular updates by Joan BL on Dec. 15, 2006**

I am a member of Arc of Minnesota. One of their staff provides a weekly update on activities and information on advocacy opportunities. You can see this at their website at <http://arcminnesota.com/>. Go to the bottom of the page and click on SnapShots. It is a nice demonstration of what one group does that highlights the work of a coalition of advocates.

- **Self-Advocacy by Jeanne S. on Dec. 15, 2006**

I think one of the basic building blocks to “state advocacy” is first learning “self-advocacy”. All of us started advocating for ourselves, then progressed to advocating for our child, or our student, then we move on to advocating for students in general - and now we are talking about advocacy at the state level. My daughter has a disability and the single most important goal we had on her IEP was “self-advocacy”. At first there was concern about making it an “IEP” goal since it did not seem to fit in with any curriculum standards - but once everyone bought into to, it worked. By the time my daughter was a senior in high school, she was solely responsible for making sure all parts of the IEP team were providing her with what was agreed upon. She knew who to contact when computer software failed, when books on tape did not arrive in a timely manner, etc. At first it seemed like too big of a responsibility to put on her shoulders, after all we had people in the school district paid to coordinate this stuff - but it was well worth it. She is now a sophomore living on campus at Kent State University and easily handles (relatively speaking) the challenges of getting her needs met. She is not intimidated by professors (well most professors!) deals with scheduling repairs for her power wheelchair, and works with Student Accessibility Services to make sure all technology is in place

for the next semester. Knowing her needs are met - frees me up to advocate for others! I frequently work with parents who say “that’s the schools’ job” or “my child can’t do that”. Right now one of my “advocacy” projects is getting some type of a program for students on IEPs to address their self-advocacy needs. Wish me luck!

o **Re:Self-Advocacy by Grace F. on Dec. 15, 2006**

That is excellent! I’ve worked with students who are so dependent on others taking care of things that when they graduate they end up floundering out in the “real world.” We had this happen a couple years ago in a local school district. Now there are other students coming up through middle school and beginning high school, and the staff is much more firm in having them learn how to self-advocate. Are there some helpful tips you could give, or maybe even a list of what specifics (and how) to advocate for themselves?

▪ **Re:Self-Advocacy by Jackie Hess [SI Faculty] on Dec. 15, 2006**

There are a number of interesting online advocacy resources for youth with disabilities. www.ld-pride.net is specifically for students with learning disabilities. They’ve posted a self-advocacy guide written by Dr. Scott Crouse. Here’s an excerpt.

Ten steps to becoming an effective self-advocate:

- **Step 1: Accept your disability:**
Before you can advocate for yourself, you have to admit to yourself that you really do have a learning disability. You aren’t dumb. You aren’t lazy. You have probably worked very hard to hide your learning problems (even from yourself). Now is the time to admit to yourself that you have some difficulties and may need some special help in order to be successful.
- **Step 2: Admit your disability to others:**
You cannot be a successful self-advocate if you continue to hide your difficulties from others. Naturally, you can’t expect teachers to provide appropriate accommodations if they don’t know about your disability. But it is just as important to be able to admit your difficulties to your friends. When you can really be honest about your learning disability, you will find that you no longer feel so ashamed and embarrassed about your learning difficulties. You will be able to relax a bit more in school and spend more energy learning than hiding.
- **Step 3: Understand your learning style:**
Hopefully, you now have a pretty good understanding of how your brain works and how your processing difficulty interferes with your education. School psychologists and teachers can offer you some ideas that they have about your learning disability, but only you can decide what makes the most sense to you. If the ideas offered in this course don’t make sense, ask for help in understanding better. Or ask for other ideas about information processing that might “fit” you better. If you don’t understand how you learn, you can’t ask for accommodations that you really need.

- **Step 4: Realize how “other issues” might interfere with your self-advocacy:**
You have learned about the common effects of a learning disability including low self-esteem, communication difficulties, and attention problems. Think about how these issues might interfere with your ability to advocate for yourself. Are you too shy and withdrawn to ask for help? Do you get angry and aggressive when embarrassed or frustrated? Are you able to communicate your needs or do you need to ask someone (teacher, parent, friend) to help you ask for accommodations? Are you impulsive and tend to say or do things that you later regret? As with your learning disability, you need to be open and honest about any of these related problems before you can be an effective self-advocate.
- **Step 5: Know what you need:**
Do the accommodations listed in this course meet all of your possible needs? Which ones do you think will be the most useful for you? Can you think of other accommodations that may be better? It is not possible to anticipate all of the needs which your learning disability will cause for you. You will need to constantly rethink the accommodations and possibly come up with some ideas of your own.
- **Step 6: Anticipate your needs in each class:**
Don’t wait until the final exam to start thinking about accommodations. Right from the start of each class you should be thinking about how you might be able to learn the material better. Maybe the teacher has a style that confuses you. Maybe there are too many distractions in the room. Maybe assignments aren’t presented clearly. Begin talking with your teachers about accommodations as early as possible.
- **Step 7: Know your rights and responsibilities:**
You have learned about your legal rights to an appropriate education and appropriate accommodations to meet your needs. But are you really prepared to argue your rights with a teacher that may be “reluctant” to provide appropriate accommodations? Do you know where to turn for support when your needs are not being met? And remember, accommodations are intended to counteract the negative effects of your learning disability, not just make school easy for you. Don’t take advantage of your right to accommodations by requesting things you don’t really “need”.
- **Step 8: Be willing to compromise:**
Some teachers will bend over backwards to “accommodate” for your special learning needs. Others will be less “flexible”. Be ready to compromise in order to get at least some accommodation. You may also need to “prove” to some teachers that you really need help and are not just being “lazy”. Maybe make a “deal” or “contract” with a teacher. If you do this, be sure to follow-through with everything you have agreed to do. This helps to build trust.
- **Step 9: Know where to go for support:**
Sometimes even an effective self-advocate needs support. Maybe to help with a “difficult” teacher. Maybe to provide advice when you get “stuck”. Or maybe just so you don’t feel isolated and alone. Find someone who understands your learning disability and can provide support (or can

even advocate for you) when needed.

- **Step 10: Plan for the future:**

Many LD students just try to survive one day at a time and don't think too much about long-term goals. But to really advocate for yourself you need to think about where you want to be in one, two, five, or ten years. What kind of work do you want to do after your education? Do you want to go to college? When you have a very clear plan for the future, you will be better able to see the reason for your education today.

- **Re:Self-Advocacy by Jackie Hess [SI Faculty] on Dec. 15, 2006**

The Family Center on Technology and Disability will be coming out with a guide to advocacy and assistive technology in late 2007.

You can find a list of self-advocacy resources, with active links, at http://thechp.syr.edu/disres.htm#self_advocacy. It's provided by the Center on Human Policy.

- **Re:Self-Advocacy by Jeanne S. on Dec. 15, 2006**

One thing we started early on with my daughter is having her attend EVERY IEP (yep - she was sitting there in kindergarten - thought it was a party just for her!) I am hoping that I modeled some form of "effective advocacy" each and every time we met. Usually problem issues were discussed and resolved long before we sat down at the table (although not always) - so what she saw was people collaboratively working together for her. I think this helped make her feel comfortable and not worry that every request was going to be met with a "fight". As she got older (in middle and high school) I would often involve her in some aspect of an issue that had become "heated" and explain when I would use a letter, versus a phone call, versus a personal visit - and how to decide that something simply "was not worth fighting about." She is a quiet kid and likes to avoid conflict - and I used to worry about her (still do!) - but she continues to impress me. So bottom line - start early with self-advocacy, build in some successes, have high expectations, and grit your teeth and let them do it even when your instinct is to jump in and fight for them. - (isn't this how we teach a student most things?)

- **Re:Self-Advocacy by cpichler on Dec. 18, 2006**

I work in a cross disability agency, primarily with working age adults, and have seen over and over again that the people who are most successful in life are the ones whose parents "pushed" them the way you have. There is an old saying that I use when working with parents- "Prepare the child for the road, not the road for the child." We need to have a long term perspective. Where do we hope to see this child at age 25?? If the answer is living on their own and working competitively, we better start arming them early with the skills they will need to succeed in LIFE, not just in school. Your daughter is lucky to have had parents and educators who understood how to help her grow into a self-sufficient person.

- **Re:Self-Advocacy by Joan BL on Dec. 18, 2006**

Jeanne- I like your model in supporting your daughter in becoming an effective self advocate. Did you develop this on your own, or did you receive guidance in helping you out? I would love to see something like a “cheat sheet” of tips on how to help other parents learn to help their child become an effective self advocate. Thanks for your important post.

- **Re:Self-Advocacy by Jeanne S. on Dec. 19, 2006**

I think that parents need to have a firm vision of what they want for their child. I had a vision of her attending college and living independently from me. It is hard to do because when she was in kindergarten it was really hard to visualize where she would be at 10-15 years later. (In fact some days it was hard to imagine what tomorrow would look like!) So actually I had several visions or tracks for her until we were well into the education system and fully understood her physical and mental capabilities and needs. Once I had a reasonable vision for her I backtracked to figure out how we got to the vision from where we currently were. Self-advocacy quickly emerged as a need. It emerged as both a need for the future - but also a critical need for the present. Everyday she needed to have lots of needs met and I was not going to be there to oversee every aspect of her life. I think parents need to understand that self-advocacy starts small (“I want the chocolate chip cookie - not the sugar cookie” or “I need the mouse moved to the left side of the computer not the right side.”) It starts when they are young with easy things like cookies - and eventually builds to the bigger things - “Yes, I am entitled to funding from this state agency.” It is so important that I took it on as MY responsibility to make sure she received experience in it - and although it showed up in various formats on her IEPs - it wasn’t something I entirely left to the school district to teach her.

- **Re:Self-Advocacy by Jackie Hess [SI Faculty] on Dec. 15, 2006**

Here’s another excerpt from an article on self-advocacy by C. Amber Havens, posted on the National Center on Accessibility website, <http://www.ncaonline.org/monographs/14self-advocacy.shtml>. The focus of the article is on recreational settings, but the advice is universal.

“Now that you know your rights as a person who has a disability, here are some ideas to help you achieve your goal of becoming your own advocate and taking charge of your recreational pursuits.

Assert Yourself: This is the hardest part!

- a. Practice what you will say.
- b. Speak clearly
- c. Maintain eye contact
- d. Take your time when talking
- e. Ask for time to think if you need it

- f. Rephrase what you hear to be sure you understand
- g. Be respectful
- h. Be careful of your body language (do you look angry)
- i. Use I statements (i.e. “I feel that” not “You have to”)
- j. Be flexible (you might have to compromise)

Ask For Change: What have you got to lose?

- a. Start at the top. Always talk to someone in charge. This will keep you from having to explain your situation over and over again.
- b. Make clear, specific requests with rationale for the requests
- c. Don't make personal insults, accusations, or get into arguments - Remember you want to make positive change.
- d. Put it in writing (always document your request - you never know when you might need documentation)
- e. Encourage others to join your efforts

Follow-up: Make change happen.

- a. Always follow-up
- b. If action was taken send a Thank-you note
- c. If nothing has changed - contact the appropriate authorities (U.S. Department of Justice) - Remember there are laws in place to protect you!
- d. Make sure and document all contact with the agency or program you are trying to access.
- e. Keep trying!”

- **Re:Self-Advocacy by Dr. Brenda Scott on Dec. 17, 2006**

Jackie and Jeanne,

These are excellent points and resources, especially to impart to students. I am a firm believer in having advocacy as one of the goals, especially for middle and high school students. I am employed by the public school system and I believe we sometimes do students a disservice by making everything so available, taking care of needs, and furnishing assistants who do things for disabled students. Yet it is hard to break away from being so nurturing and sometimes hard to convince parents and teachers why its not a good idea for a student to have an assistant at school. I have also evaluated students with disabilities who are in college and found out how they are expected to do for themselves, some things we provide (for example, scanning a text to turn into a voice file).

- **Re:Self-Advocacy by cpichler on Dec. 18, 2006**

There are three accommodations that are routinely offered in public schools that are not available in a competitive work setting in the format our kids have grown used to. I emphasize the word competitive because sheltered settings will offer them. Those accommodations are extended time, human assistance, and modified curriculum.

In a work setting you can have extended probation to learn a job, but if you are doing piece rate work or being paid by the hour you do not get extended time to perform your job. In other words, you do not get paid the same to work slower. Folks who need longer to complete job tasks should consider salaried or commission work because production rate is not tied to reimbursement. Things to be aware of: Some employers will not allow staff to stay at work after hours -especially if they are paid by the hour. As odd as it may sound, sometimes employers will not allow work to be taken home-especially at entry level clerical positions and those paid by the hour.

Human assistance is not provided at the entry level, and no employer ever has to provide personal care-such as toileting and feeding. They have to permit an assistant to help DURING BREAKS, but they do not have to hire one. Because of OSHA regulations, many employers require the personal assistant to leave the premises during work times. Depending on who is paying the assistant, they may only be allowed to perform medical type tasks and actually not allowed to assist with clerical and other job related tasks.

The last accommodation I mentioned, modified curriculum is the worst. At school it is usually defined as lighter homework load. There very simply is no way a competitive employer will pay someone the same pay rate as other staff and allow them produce less.

AT is the way to level the playing field, especially if it can have a positive effect on timeliness and quantity of work. The more independent a student is with AT the more likely they are to be competitively employed.

- **Re:Self-Advocacy by jcruce on Dec. 18, 2006**

It's really important to talk to the employer before dismissing these types of modifications. Especially with the boom in smaller businesses, many employers are happy to make these modifications, especially if it means not having to purchase additional assistive technology.

Some employers **will** allow salaried employees to stay late to complete their tasks, although this can place a burden on the employee; 10-hour workdays are not fun for anyone. If such terms are requested by the employee, make sure that both employee and employer are very clear (in writing) what tasks must be completed before the day is considered "complete."

Additionally, there is a way to modify the “curriculum” at work to accommodate an employee with a disability. The word to keep in mind is “equality.” In schools, a lighter homework load may be indicated, but the load is not reduced to the point where the student doesn’t do enough homework to learn the material as well as the other students (or *shouldn’t* be reduced to that point, I should say). Sometimes the same approach will work in an employment setting. We can often find ways to swap job tasks with other employees so that our clients still have a full work load, but may be completing a different set of tasks than the employer originally intended. As long as the swap doesn’t put an undue burden on the employees we’re swapping with, all parties are usually satisfied.

For example, an employee that is great at using a computer but is unable to talk on the telephone because of speech issues may have customer service emails from a number of other employees forwarded to her, while those employees take on the task of fielding phone calls that would have gone to her. She is able to answer the emails that would have burdened the other employees, so everyone wins.

This type of accommodation is actually the second modification I look for, after modifying the work flow for a client. It’s free, so employers are usually eager to try it.

- **Re:Self-Advocacy by cpichler on Dec. 20, 2006**

Job sharing is a good way to modify the “curriculum” at work, and I will remember to include that option when I talk about accommodations. I really liked you email story, it is a great example of creativity and is what the ADA was designed to encourage.

My point about work flow needs to be restated. The ability to modify work flow is tied to the type of reimbursement. Salary and commission pay are the most amenable to working extra hours because the employer really doesn’t care how much time you put in. Coming in early, staying late, working weekends, etc is all fine because rate and pay are not connected. Students often feel they are deserving of more pay if they work more hours, but that is another discussion. Your point about small employers being more flexible is true. The issue comes up with hourly workers. I had a lady with a learning disability who was a FABULOUS counselor. She liked working with hard core youth offenders and people in crisis, and was very good at it. Unfortunately, much paperwork and documentation are required for those types of jobs, and that was her weakness. She first worked in a salaried position, and 55-60 hour weeks were routine and ok with the employer, who provided other accommodations willingly. She moved to an hourly position with an Employee Assistance Program and could not keep up with the paperwork. They would not allow her to work after hours because of a legal regulation about having to pay hourly staff for work time even if they are trying to volunteer. The AT would not interface with their dedicated reporting

software, and they were able to make a good argument about the cost of upgrading being unreasonable, and eventually she was let go. Happily she is now employed in another salaried position and doing well. She will ALWAYS need extra time for paperwork, and needs to work in an environment where that time can be granted somehow. She has decided that she will only work in salaried positions from now on and counsels the kids she works with about understanding employer reimbursement issues. Employers do have rights under the ADA, and they are beginning to exercise them more and more. Advocates are facing a lot of defeat when things get to the legal system because judges are routinely ruling on the side of the employer. We need to understand that so we can give our students accurate information about “the real world” and truly prepare them to succeed.

- o **Re:Self-Advocacy by Jane Johnson on Dec. 15, 2006**

What a great point - and what a wonderful success story.

You are absolutely right about the importance of learning self-advocacy. I have found over the years that most of the issues we work on at the state level come from issue that people have encountered at the grass roots level. When a self-advocate bumps up against a barrier that can't be solved at the local level, the role of an effective disability coalition should be to examine that issue and develop strategies to overcome it and take it to policymakers at the state level.

Ineffective (and sometimes damaging) policies are usually the result of people making policy decisions at the 30,000 ft level, without the input from the people on the ground to tell them how those policies will actually play out in real life. When self-advocates can demonstrate an ability to constructively communicate and collaborate with policymakers, they are more likely to be asked to come to the table when policy decisions are being made, which should result in better decision making.

- **Re:Self-Advocacy by Thao on Dec. 19, 2006**

WOW! I've read through all of the messages posted about self-advocacy, and it has re-opened my eyes to why we do what we do in the first place, why we chose our professions! I work for E.I., and sometimes I get stuck in my own little world of cute babies that I forget we are just a drop in the bucket for some these families. I do wonder what the future holds for my kiddos, and you all have answered it so nicely: for them to learn to advocate for themselves and to continue to remove barriers from disability.

- **Using Documentaries by Kim Moccia on Dec. 16, 2006**

A few months ago I received an invitation from a local organization to attend a dinner. The purpose of the event was to raise money and awareness. During the dinner they showed a documentary that they felt supported their cause.

Documentaries can be a powerful tool to educate folks and keep them motivated.

When my son was younger I provided those involved in his education with a copy of Rick Lavoie's FAT City video. (<http://www.ricklavoie.com/>) This video was my voice and helped me to communicate my son's needs. Today there are some excellent documentaries available including Freedom Machines (www.freedommachines.com).

Does anyone use documentaries/videos to educate and support their advocacy activities? If so, which ones?

o **Re:Using Documentaries by Jane Johnson on Dec. 18, 2006**

We have not used documentaries in our advocacy efforts yet, but your comments made me think about the role of a video camera in overcoming transportation barriers for people who live far from the capitol.

Especially if you are advocating for increased funding or availability of AT and AT services, a video showing the results of that funding in action can be a really great advocacy tool. A short video showing a person actually using a device to perform work, school or everyday tasks would send a powerful message. An audio message can be taped to go with the video and it can be sent via email as a video file attachment, or as a link to a video website.

Many policymakers who are unfamiliar with AT might have a hard time fully appreciating its importance. A video can make the point much more effectively than a spoken or written message.

Great suggestion!

• **Final comments and questions by Jackie Hess [SI Faculty] on Dec. 18, 2006**

Welcome to the final three days of the Family Center's Winter Institute on AT. I hope that the hundreds of you who have been following the discussion silently have found the information useful. We greatly appreciate the kind comments of those who have said so via post or email.

In these final days, we invite you to post comments and questions on any aspect of assistive technology policy or practice that may be of interest to you. We'll do our best to address them.

On the administrivia front: Each of you will be receiving the Family Center on Technology & Disability's 2007 "Assistive Technology Resources" CD-ROM and an Institute Certificate of Participation. Ana Maria will be coordinating the paperwork for those of you who want to receive CEU's for the Institute. (You're eligible for 3.2 CEU's.)

As always, it's been a pleasure working with all of you. - Jackie Hess

o **Re:Final comments and questions by Joan BL on Dec. 19, 2006**

Thanks to all of you for your great suggestions on advocacy, thoughtful questions, and success stories.

The most important message I would like to leave you with is that your voice is the one that can make a difference. Whether you are a professional or a self advocate or an advocate for someone you care about, the importance of advocacy is essential. No one can tell your story better than you. No one knows your issues better than you.

Join a group that has similar issues. Organize (look at the wonderful tips posted by Jane at the beginning of the institute) and work with like minded people to create change. Find you logical allies. Do not be afraid to contact state level folks. I know it makes a difference- I have changed what we do in MN schools because people have convinced me that something different had to be done.

Be reasonable in your expectations, but never settle for second best.

I will look forward to seeing you all again on-line!

• **winter institute by sandy nc on Dec. 18, 2006**

I would like to say how much I appreciate being a part of this institute. I have learned so much from others. Being an AT Coordinator in a school system and a person with a disability I see both sides. We all have to take responsibility for ourselves. As I mentioned earlier I recently did a presentation on emergency preparedness for those who use assistive technology devices. Make sure you or your loved one is ready for an emergency. Don't wait until disaster strikes. So many people were left behind during Hurricane Katrina and other situations. Be Ready!

RE: Work and self advocacy

At the North Carolina Assistive Technology EXPO Lynn Deese, who works for the North Carolina Assistive Technology program, presented a workshop called The Reality of Workplace Assistive Technology:

It's All About the Task. If you are interested in seeing the powerpoint you can find it at the NCATP website. http://www.ncatp.org/Resources/reality_of_workplace_assistive_t.htm

Molly Shannon of the North Carolina Assistive Technology program also did a great workshop on AT/ Work Setting for Persons with Physical Disabilities. She did a great job.

In a recent workshop at the North Carolina Assistive Technology EXPO there was a workshop on Accommodations in the Workplace: The "how to" guide to implementation. If you are interested in resources they used in reference to those who use assistive technology go to: <http://www.ncatp.org/Resources/RESOURCES.pdf>

It was presented by Shelley Kaplan, Director, Southeast Disability & Business Technical Assistance Center, Karen Milchus, Co-Director, Rehabilitation Engineering Research Center on Workplace Accommodations, and Lynne Deese, AT Consultant, NC Assistive Technology Program

There were many other good workshops available as well. These were just a few and I am sure other states offer more of the same.

Here is another website with lots of valuable information: <http://www.jan.wvu.edu/>

Here is one more good article on the United Cerebral Palsy website called Transferring Assistive Technology from School To Work - http://www.ucp.org/ucp_channel.doc.cfm/1/17/107/107-107/736

Thanks again.

o **Re:winter institute by Joan BL on Dec. 18, 2006**

Thanks for these wonderful resources. They really are eye opening, and I appreciate all you have shared. We will be examining what we need to do here in MN for an emergency.

• **Universally Designed Instruction/Assistive Technology by LMF on Dec. 19, 2006**

I have a final suggestion. There needs to be developed a “best practices” chart/grid for each of the disability classifications, including cognitive. And implementation practices for an “organized” process of Assistive Technology, including but not limited to AAC, Synthesized speech, Scanning, Intelli Tools.....

I realize this seems impossible; and stress that in some fashion, it needs to happen. Not necessarily as a final list but as a starting point.

It is true that education by today’s standard is going to change significantly for all students! See “Higher Education article - <http://insidehighered.com/news/2006/12/15/skills>

How will these systematic changes play out in the education of people with disabilities?

If we (as advocates, and professionals with talent) do not hold OSEP and state agencies by the hand and show them how to include people with disabilities in this process we will see more segregation, more special places, and less access to post secondary education options, employment and community participation.

Take a look at Frances Shapiro’s efforts in Texas - <http://www.chron.com/disp/story.mpl/front/4409033.html>

On the surface this looks like one thing, and over time will be just the tip of the iceberg. With the current movement to change education in the nation, without trained staff in validated methods and in educating students with disabilities it will become increasingly more difficult to support the public education system as the sole funded mechanism for kids with disabilities. And easier by the minute to support “special school”, “special places”.....

It does not have to be this way! Assistive Technology and Universal Design Instruction is the most effective leap for the future inclusion of people with disabilities in our communities. And the collective talent of this list/discussion can lead the way.

Build the bridges!!!! GO FORWARD. I so appreciate this opportunity. And look forward to the future!

Merry Christmas to all! - Louise Fulk - Coppell, Texas

- **Don't underestimate the power of personal advocacy by Jane Johnson on Dec. 19, 2006**

I have always loved Margaret Mead's quote that goes something like, "Never doubt that a small group of concerned citizens can change the world. Indeed, it's the only thing that ever has."

Just before I posted this comment, I received an email alert that President Bush today signed the Combating Autism Act of 2006 into law. What better proof to all of us that committed parents, advocates, individuals and teachers can start at the grass roots level to tackle and issue and wind up with federal legislation. This particular bill authorizes nearly \$1 billion over the next five years to combat autism through research, screening, early detection and early intervention.

I don't know all of the history behind the bill, but I will put money on the fact that it all started with parents and advocates.

This institute has been a true inspiration to me and I have learned a great deal from all of the participants. It is a privilege to work among such a committed and talented group of people.

- o **Re:Don't underestimate the power of personal advocacy by Peter.Stack on Dec. 20, 2006**

J. Johnson's points are well stated as they reference much of what has been contributed by many throughout this dynamic on-line Institute.

It is important to realize, despite our desire as social beings for acknowledgement by a response, that the use of cell-phones, even if only ending in a voice-mailbox, and the use of e-mail, even if no reply is obtained, and the use of snail mail of letters and petitions (with as many different senders and signatures whenever possible), all accumulate credibility and "weight" to one's issue(s). They reach and make contact. Such volume (bulk) gains volume (strength) in our advocating for appropriate change. And the Margaret Meade quote, along with "it takes a village...", and blended with Thomas Jefferson's "I hold it that a little rebellion, now and then, is a good thing" as well as many more quotes, are all part of the foundation to what this sixteen day discussion has included.

I share this from my recent experience here in RI, successfully obtaining legislation for a reversal of municipal residency requirement for employment. The municipality could not even find qualified applicants and could not properly serve the public school staffing needs.

Certainly our world has seen cataclysmic events that have brought sudden, dramatic change. But overwhelmingly, the majority of changes in our civilization(s) have been brought about incrementally, by the constant, dedicated, unrelenting energies of individuals, sometimes like the constant water wearing down rock, because it was just natural and right for it to eventually happen, like the Autism Bill.

I have appreciated this stimulating and informative discussion and plan to share many of the references with colleagues. Thank-you all.

- **Re:Don't underestimate the power of personal advocacy by Jackie Hess [SI Faculty] on Dec. 20, 2006**

Thanks, Peter. I don't think I've ever seen that thought better expressed. I've copied your post and sent it to colleagues throughout the Academy for Educational Development.

I spent most of the 1970's working in the U.S. House of Representatives and I could give you a hundred examples of the power of grassroots advocacy, examples that, in most cases, began with one or two individuals deciding that something needed to be done.

This discussion has been about identifying and using appropriate and powerful tools to develop and manage successful AT advocacy. But, just as the very best hammer doesn't build a house by itself, the tools of advocacy lie dormant without the committed action of parents, educators, therapists, researchers, and every type of community member.

Thanks again, Peter. Rhode Island's lucky to have you.

- **A final thank you by Jackie Hess [SI Faculty] on Dec. 20, 2006**

To all of you who have participated in our 2006 Winter Institute on Assistive Technology.

What seems to resound most strongly for participants in each of our institutes and online discussions are the voices of those of you who post comments and questions, sharing experiences and resources. Whether one is expressing optimism or frustration, delight or outrage, the fact that there are so many others out there having similar experiences, working toward similar goals, is very heartening to most of us. So while we've been happy to have each and every one of you with us for the past two and a half weeks, we're particularly grateful to those who shared their voices with us.

Of course, I'd like to thank our four expert discussion moderators: Joan Breslin-Larson, Milissa Gofourth, Jane Johnson, and Kim Moccia. You've done an admirable job.

Ana Maria Gutierrez, Anne Czapp and Justin Kennedy provide support for all of our online fora. Thanks to them as well.

I hope you'll join us in July for our Summer Institute on Assistive Technology and for the month-long online discussions that we host throughout the year.

I know that completing evaluations is no one's favorite task (it's not mine), but if you can take a couple of minutes to complete the evaluation that you'll be receiving from Ana Maria, it would be helpful to us.

So, in the not-so-immortal (but ever-syndicated) words of the Beverly Hillbillies announcer, "Y'all come back now, hear."

Additional Resource Links

1. What is Success? Transition Concerns

- Assistive Technology Education Network (ATEN) - <http://www.aten.scps.k12.fl.us/>
- Minnesota Assistive Technology Manual: Assistive Technology Transition Planning Checklist page 92-93
http://education.state.mn.us/mdeprod/idcplg?IdcService=GET_FILE&dDocName=001089&RevisionSelectionMethod=latest&Rendition=primary

2. Parent and Family Training

- The Public School's Special Education System as an Assistive Technology Funding Source: The Cutting Edge - <http://www.nls.org/specedat.htm>
- Technical Assistance Alliance for Parent Centers - <http://www.taalliance.org/index.htm>

3. Using Listservs to keep Momentum Going

- Council of Parent Attorneys and Advocates - <http://copaa.org/>

4. Reaching Non-English Speakers

- Multiple Views on Technology and Disability
http://www.fctd.info/resources/newsletters/upload/Tech1_JBL.ppt
- The Spirit Catches you and you Fall Down (book excerpt)
<http://www.spiritcatchesyoud.com/bookexcerpt.htm>

5. Geography as a Barrier

- Online Meetings:
 - i. Online Conferencing Systems - <http://www.onlineconferencingsystems.com/index.htm>
 - ii. GoToMeeting: Online Meetings Made Easy - <https://www.gotomeeting.com/>
 - iii. WebEx - <http://www.webex.com/>
 - iv. WebConference.com - <http://www.webconference.com/>
- Online Meeting Scheduler
 - i. Meeting Wizard - <http://www.meetingwizard.com/mwiz/home/default.cfm>
- VoIP Calls and Conferencing
 - i. Skype - <http://www.skype.com/share/>
- Blog-create/share your own
 - i. LiveJournal - <http://www.livejournal.com/>
 - ii. Blogger - <http://www.blogger.com/start>

- Podcast-create/share your own
 - i. Podcasting News - <http://www.podcastingnews.com/articles/How-to-Podcast.html>
 - Online Community
 - i. MyEvents - <http://www.myevents.com/login.aspx>
 - Favorites Sharing
 - i. BlinkList - <http://www.blinklist.com/>
 - ii. PortaPortal - <http://portaportal.com/>
6. Advocacy Updates
- Arc of Minnesota - <http://arcminnesota.com/>
7. Self-Advocacy
- Center on Human Policy – Self-Advocacy Resources
http://thechp.syr.edu/disres.htm#self_advocacy
 - You're Here...Now What? Making Self-Advocacy Work for You in Recreation Settings
<http://www.ncaonline.org/monographs/14self-advocacy.shtml>
8. Using Documentaries to Aid Self-Advocacy
- Rick Lavoie - <http://www.ricklavoie.com/>
 - Freedom Machines - <http://www.freedommachines.com/>
9. AT in the Workplace
- The Reality of Workplace Assistive Technology: It's All About the Task
http://www.ncatp.org/Resources/reality_of_workplace_assistive_t.htm
 - Accommodations in the Workplace: The “How To” Guide for Implementation
<http://www.ncatp.org/Resources/RESOURCES.pdf>
 - Job Accommodation Network Website
<http://www.jan.wvu.edu/>
 - Transferring Assistive Technology from School to Work
http://www.ucp.org/ucp_channel.doc.cfm/1/17/107/107-107/736
10. Universally Designed Instruction/Assistive Technology
- Jobs, News and Views for All of Higher Education
<http://insidehighered.com/news/2006/12/15/skills>
 - Autism Fuels Call for School Vouchers
<http://www.chron.com/disp/story.mpl/front/4409033.html>