

Parent Training and Information Centers: An Evolving National Network?



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At age 30, Parent Information and Training Centers (PTIs) have begun to glimpse the potential muscle of a nationwide network. Technology, harnessed by organization and cooperation, is helping the nationwide network of PTIs reach new heights.

Supported by U.S. Department of Education funding, PTIs exist in every state and Puerto Rico, American Samoa & US Virgin Islands – founded by parents to provide access to information, training and education to families of children with disabilities.

The first five PTIs, then called Parent Information Centers, were established in 1976 as a federally funded experiment in the wake of the landmark Education for All Handicapped Children Act (the forerunner of IDEA), which flung open the doors of the American public school system to those whom it had traditionally barred or segregated: children with disabilities. Those pioneer PTIs were organized and operated by parents of children with disabilities, a marked break from the traditional approach to parent training, which had been administered by university-based experts who told parents what to do.

In the ensuing years, other parent centers were established and were included in the first IDEA reauthorization, which provided

funding for a nationwide system of parent centers, as well as a technical assistance program. Based on the success of the PTIs, Congress appropriated additional funding for Community Parent Resource Centers (CPRCs) to work with specific populations or within certain geographic regions.

Today, three decades after their founding, PTIs face a choice: continue to exist as a loose confederation or begin to pool their capabilities in order to provide services and influence policy on a truly nationwide scale by fully utilizing the power of the Internet and telecommunications technology. This issue examines the current state of PTIs and the resources currently available from them.



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Roger Holt Speaks

For Roger Holt, education has been a lifelong quest for learning for its own sake that has taken him from the cutting edge of the computer era's earliest days to Billings, MT, where, since 1990, he has been technology program director of Montana's PTI, Parents, Let's Unite for Kids (PLUK). He has attended multiple colleges but has never earned a degree. For Roger Holt, however, the absence of a degree has never mattered. "I attended college to learn, not to earn a degree," he declares. He adds, "Every year I'm invited to teach a college course and every year I inform the college I have no degree. The college always says the same thing, 'So what?'"

Mr. Holt's quest began at Montana State University/Bozeman. "I was interested in science, computing, physics and chemistry and the school had excellent classes. They also had excellent advanced placement classes, but the following year closed them down. I left."

He entered the University of Montana but found that experience unsatisfying as well. Canada, where his family owned a ranch and where he was a legal resident, was the next stop.

He attended the University of Alberta in Edmonton during the oil boom in the 1980s. "The school had plenty of money, the best equipment, great professors. There was no comparison with Montana. I took every course I could in the physical sciences – and French." He took advanced math courses, chemistry and nuclear physics in French.

Next was a French immersion program in Quebec, in eastern Canada. "I fell in love with old Quebec City. I vowed to return there to live, which I did a couple of years later."

When he returned to Quebec, he was not a student. "I wasn't officially in school but went to the university every day to read and study on my own." He enjoyed the lush street life of Quebec and living in the walled city. Months later, a fateful knock on his door – he had no phone – changed his life forever.

The visitor referred Mr. Holt to a group of individuals who had been awarded a contract to set up a betting system for the racetrack in Quebec City. They were from Montana, knew my family, heard that I was in the city and knew that I was bilingual." His bilingualism was a key factor in his unanticipated desirability. French-speaking Quebec had enacted laws mandating exclusive use of the French language in commerce throughout the city and province.

"I thought the job was interesting because the group had a great Hewlett Packard 1000 mini system at a time just before PCs

surfaced," Mr. Holt remembers. "The group members were giving me the opportunity to run a million-dollar computer system."



Roger Holt

Working with another young man with an electrical engineering background, they merged their skills.

"My software and programming background was a good match for his hardware and engineering skills. We were like two kids in a candy store with this state-of-the-art equipment."

Carrying the job title "systems manager/technician for online data processing", he and his partner, still in their early 20s, combined to lay the foundation for the racetrack's betting system. "We created and ran every aspect of the technology, including the ticket-selling terminals, the main duplex computers that ran in parallel processing the incoming data and outputting all of the indoor video displays, which displayed the odds, plus the big infield board that showed all the information outside."

According to Mr. Holt, the installation was hugely complex." But its very complexity was the challenge. "I had to learn the entire system, in French. Everything in the system was in French." For 3 ½ years he operated the system in real time and maintained the equipment. During his off hours he took computing courses at Université Laval, also in French. "One of my professors had worked for the Department of Defense and was one of the developers of the APL system for IBM. He was developing an APL system on a mini computer. He was the best instructor I'd ever encountered. I took every class he taught just to acquire his experience."

Then Mr. Holt got an opportunity to return to the U.S. to work on his organization's "biggest and toughest contracts" here. "I was invited to start the organization's corporate training program that was held in Billings, which I did by bringing in computer equipment and the technical and marketing staff from all over the country." Then the company landed its biggest contract ever, to build a network system in California.

The contract called for 15 cities to be networked. It was the late 1980s. "I had now spent years on the cutting edge of the computer explosion. The group I was attached to in California had devised statewide lottery systems. It was a fantastic learning experience, especially since the contract required us to build this

network in just 45 days, from scratch, beginning, literally, in an empty room without even a phone.” He had to use a payphone outside to start the process in those pre-cell phone days, he remembers.

Seven days before opening, the system failed to work. “I called the president of the company and advised him to sell his stock. We pulled in programmers from California. They arrived the next day – and we did it. We made the system functional in the nick of time.”

Europe, where there was another big contract that needed to be serviced, was next on his itinerary. “I was over there and back many times. Finally, a woman here in Billings whom I had met made it clear that she wanted me back here to stay.” He spied a classified ad for a bookkeeper in the Billings newspaper. The advertiser was PLUK.

“I’d helped set up several non-profits and was familiar with their structure and reporting.” The director, PLUK founder Kathy Kelker, said to him, “You’re not a bookkeeper.” Mr. Holt admits, “I had to acknowledge the truth in that observation.” She responded, “I’ve got something else you might be interested in.” The job was to fix an unusable management system that had been designed by a consultant. “She then introduced me to PLUK’s [assistive technology] (AT) component, which I have remained fastened onto ever since.”

His fascination and facility with AT continue to help PLUK in unexpected ways. In early June PLUK executive director Dennis Moore fell from his roof, suffering a severe spinal cord injury and concussion. Mr. Moore’s spinal cord was not severed but swollen from the trauma. Says Mr. Holt, “He damaged C1, 2, 3, and 4. Usually, no one survives that type of injury.”

Mr. Moore did wake up, but the hospital in Billings did not the tools to cope with his level of need. “They have nothing for communication,” Mr. Holt said. “I checked all the resources in the community, beginning two days after the accident when Dennis was starting to try to communicate. Mr. Holt’s search goal was to assemble the components for an assistive technology device to help Mr. Moore communicate.

“The AT I assembled for Dennis was basically an eye-gaze communications system. I went to Home Depot, Lowe’s and Office Depot to get a clear, Plexiglas sheet, some sticky pads and pens to make a clock dial with letters that can be seen from both sides. Someone holds it in front of Dennis’ face allowing him to spell out words by looking at the letters. The person holding the plexiglass sheet can see what letters he looks at. Pretty simple really”

The family used the homemade AT device immediately. “The first word he communicated was ‘thirsty.’ The second word was ‘scratch.’”

Mr. Holt’s device was so effective, “the hospital used it until they completed the tracheotomy and got the tubes out of Dennis’s mouth so he could actually talk.”

Today, Mr. Moore is continually improving. Some feeling has returned to his shoulders, and he is starting to breathe on his own. Comments Mr. Holt, “Actually, everything looks quite good now that he is beginning the rehab process.”

Added Mr. Holt, “It showed that a simple device can make a big difference in someone’s life, which is a concept I strongly believe in.” He concluded, “The best AT devices for our families are not the high tech gizmos, but the equipment made from components that anyone can find at a local store.” The AT future for PTIs, he notes, “won’t be found in Silicon Valley, but on the shelves of Wal-Mart and Home Depot.”

Supporting our interview with Mr. Holt are resources to help families better utilize the capabilities of PTIs. We also feature members of our *Knowledge Network*. The members spotlighted this month reflect our focus on PTIs. We invite you to contact these members for further information.

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



Family Center
on Technology
and Disability

www.fctd.info

Cracked Windshields: A PTI Plies Big Sky Back Roads

**An Interview with Roger Holt, Technology Program Director,
Montana's Parents Let's Unite for Kids (PLUK)**

Begun in the 1980s under founder Kathy Kelker, PLUK, Montana's Parent Training and Information Center (PTI), covers one of America's largest but most thinly populated states. Today, with about 25 staffers, including 10-12 in the field, the organization uses technology to maximize its statewide capabilities while minimizing travel time, says Roger Holt, PLUK's technology program director since 1990. Still, however, PLUK staffers are famous for the arduous travel conditions their job entails in this vast Big Sky state.

A few years ago, Mr. Holt recalls, a visitor from the Massachusetts parent center noticed something that all PLUK field staff had in common: All their cars had cracked windshields. "Even though we try to minimize travel time here, our minimum far exceeds the maximum in any other state," Mr. Holt claimed. "Those cracked windshields are caused by spewed gravel on our back roads. We never travel 100% paved roads. Consequently, virgin windshields don't last long around here."

Parent Centers Are Critical – and Unique

Mr. Holt believes that PLUK and other parent training and information centers nationwide are critical factors in providing a continuous supply of information to parents of children with disabilities. "The information PTIs offer is not easily understood, although parents are required in IEP meetings to get a basic flyer detailing their rights in the IEP process." Explaining parental rights and responsibilities to families of children with disabilities involves the conveying of complex information, "but that's why parent centers exist -- to train parents on how special education works."

Every parent center in each state is unique, Mr. Holt asserts. "They do business differently because every state is different due to population disparities and available resources." Some centers, he notes, conduct more one-on-one training, providing individual assistance. Others conduct more group training because there simply aren't enough resources to serve their large populations. In some states, he adds, services may be rationed and individuals may need to pay for educational advocates.

In Montana, though, "we've always done the one-on-one assistance. We have representatives in all regions of the state. Most PTIs in most states are structured that way."



PLUK is Montana's lone PTI, although high population states like California and Texas have multiple centers.

Collaboration, Not Competition

Many states also have community parent resource centers (CPRCs), which target underserved communities that PTIs have not been able to reach, like inner city neighborhoods and isolated geographic areas.

Once somewhat competitive, PTIs and CPRCs now often collaborate, Mr. Holt explains. In fact, some PTIs have assisted in the development of community parent resource centers by, for instance, helping them write their grants. The community resource centers are a benefit for the larger PTIs, he adds, because working in tandem helps serve hard-to-reach populations in the state.

From Humble Beginnings

PLUK began as a parent support group in Billings. The group wrote the first PTI grant and was funded in 1984.

From humble beginnings in a tiny office staffed by two part-timers at Montana State University-Billings, the organization now spans the state, with its 10-12 field staffers working directly with families and individuals in their respective areas.



"In a single city or a large geographic area, our field people work one-on-one," Mr. Holt declares. Each field staffer has a toll-free number so that families with children with disabilities can talk to a PLUK staffer directly. School is the usual subject of conversation, he explains, but the conversation might also center on medical, behavioral or family issues. "We're not like a government agency, where eligibility and documentation of disability are required," he says. "These are not issues for us." PLUK staffers also coordinate and conduct training in their respective territories.

While most PTIs are created equal, PLUK is more equal, in one respect, than many others, according to Mr. Holt. "We have a unique program developed by our director, Dennis Moore, that does not exist in any other state: We have associate boards. In fact, we have 17 such boards in Montana now." These boards, he explains, are groups in communities around the state that provide a voice to the organization on community needs and also serve as a development arm so that fundraising activities, as well as additional activities for children or parent-centered activities and training, can be conducted.

"The associate boards give us a voice from the communities when we need support letters for a new grant. They're also a training ground for new governing board members where they can learn

about PLUK.” Associate board members are not always parents, he explains, but can also be community leaders, educators and professionals. “We try to assemble a diverse group of individuals,” Mr. Holt says.

“We’ve just started youth associate boards for the kids themselves. Our pilot is here in Billings. We’ll use that board format elsewhere in the state.”

The Evolution of PTIs: What Needs to Be Done

PTIs, says Mr. Holt, have reached a crossroads in their evolution, and changes must be made in their operation and in fundraising strategy.

“First, as with all non-profits, PTIs need to be run like businesses – with diverse sources of funding – in order to survive.” Secondly, he continues, “their main business is information and training, and they need to leverage technology in the most efficient way possible.” Third, he advises, “the national PTI network has the potential to be very powerful in providing services and influencing policy.”

Run PTIs Like Businesses

In the beginning, he notes, parent centers were small “mom and pop operations” funded by a single grant that provided for one kind of service for families. Some of the centers, he adds, have grown enormously, like the Pacer Center in Minneapolis, which is one of largest parent centers nationwide in terms of budget, scope and reach. “Large centers like this are probably involved in hundreds of different grants, but share the same mission as every PTI,” he declares.

“Centers like ours, which are small-to-medium-sized, too often still have limited funding sources. When one source disappears, it’s very traumatic and could lead to the death of the organization. That is not a sustainable design for the organization. There still exist parent centers that are on that model. They will struggle and may eventually fail. Yes, they will survive for a while, but change is overtaking them rather rapidly.”

Fortunately, Mr. Holt continues, many PTI organizations have seen the light and the need to diversify funding sources, reducing the percentage of government funding by including funding from corporate and private sources. They achieve this, he explains, “by conducting fundraising locally and statewide, or via any creative way available in order to raise the money.”

The goal, of course, he adds, is to make sure that if one source dries up that other sources can plug the gap without negatively impacting the organization.

“We view ourselves at PLUK as a crisis-counseling, information providing organization. Ideally, we should be available to our constituents 24/7, 365 days a year. That’s what we are working toward, as are other parent centers across the country. Technology gives us a good opportunity to meet those aspirations.”

Every non-profit is experiencing the same need, the same challenges, he notes. “They all have to do this or die.”

Fundraising Diversification: Start Now

At PLUK, Mr. Holt explains, “Dennis [Executive Director Dennis Moore] is extremely good in the development aspect. That’s why he was hired. He came to us from Mississippi and was one of the founders of a Mississippi non-profit and was its director for 25 years.”



Dennis Moore

In Mr. Moore’s final year as director for the Mississippi non-profit, Mr. Holt claims, the organization raised more than one million dollars – from diversified sources.

“That’s what we needed at PLUK. He had worked with youth at risk, which gave him a basic knowledge of our field – but his real strength was in development. He has done an unbelievable job here of developing our organization and has provided a model for other parent centers. Many are taking the development plan we’ve implemented successfully and are molding it for their own purposes and situations.”

But diversification, Mr. Holt concedes, cannot be accomplished from a standing start. “It takes years.”

Organizations that have wisely spent their time and resources on diversification efforts have spent years planning for and implementing the transition, he points out. “It’s hard work. Getting money from corporate and private non-governmental sources requires a different approach from pursuing government sources. My advice to parent centers that are considering diversification is, start now.”

Leverage the Network

In addition to achieving fundraising diversity, PTIs nationwide, Mr. Holt says, need to discover ways to efficiently leverage their national network.



The parent center network has the potential to be powerful, he declares. “The problem, however,

is that it's not being used." He offers an example. "I once made this suggestion: What if there was training provided for all parent centers nationwide on various topics? Why can't we do that? Why can't we provide that training for PTIs in every state to offer to their constituents rather than what exists now, where each parent center is trying to develop that capability on its own?" He adds, "If we could do this strategically on a national level – not everything, but some things – that is an effort we all need to join together to undertake."

Such an initiative, he explains, would also include a combined effort to work on strategic planning for providing information and research for policy studies. "This seems to be a natural, but there has never been anything done as far as I can see."

It's a not a mystery to Mr. Holt as why this has not yet occurred. "Change is hard. Sometimes someone has to die or retire. What I do know is that there is enormous untapped potential that is not being used. Part of it can be attributed to territoriality. However, territoriality is beginning to disappear as a factor among the more progressive centers, but the tipping point hasn't quite been reached wherein the change I'm suggesting can occur. Hopefully, it will."

Update the Field Staff

Mr. Holt insists that he would implement his vision by updating the PLUK field staff on disability related topics and developments, especially regarding school issues and state and federal legislation.

"It's a real need is for our field staff, the people in our organization working most directly with families, to be constantly updated. If a national system existed where we could tap into experts and speakers from around the nation whose ideas could be broadcast over the web in real time, costing little or no money for staff development, that would be the starting point." Maybe, he suggests, a more formal system could be developed that would certify the professionals providing one-on-one assistance to families.

"Dennis [Moore] and I have talked about this," Mr. Holt says. "We agree that this approach would be ideal and could be implemented even for parents, providing certification showing that they have gone through training in specific special needs areas." On an individual parent center basis, he notes, "we don't have the resources to do all of this. But if parent centers nationwide could pool some resources, we would all benefit greatly."

Be Creative: Use Existing Tools

"I don't know of a model that works like what I am suggesting -- yet," Mr. Holt says. Parent centers, he advises, "must be creative and make the most of the new technology tools as those tools come online." One approach, he adds, is to use the tools that

already exist.

"Universities do some of what I'm suggesting. I know of several that would love to participate, or facilitate, a nationwide parent center real-time information-sharing system. I know enough individual instructors and professors who see the need for this and would leap on it and do it as part of what they are already doing."

This strategy, he states, "fits in exactly with what regional resource centers do. Some specialize in different areas and could be tapped into. The technology cost is minimal."

PLUK's Evolution: Statewide Presence Will Increase

PLUK will evolve by continuing its steady growth and by increasing its presence in more communities around the state. In addition, says Mr. Holt, the organization will expand its constituency to include all families with any kind of need.

"Our evolution depends on what families need. That's why the organization was founded. All the services we provide, including assistive technology (AT), exist because parents, families and individuals have asked for them. If we get numerous questions on a specific topic we begin to think about maybe starting a publication, doing additional research dedicated to that topic, or find some money to fund a service. That's how we evolved and how we will continue to evolve."

One way for PLUK to enhance its presence statewide, he adds, is to create additional offices. "We do have a satellite office right now but I see more offices opening statewide in the communities we serve." Those offices, he predicts, "will be located in storefronts and have computer access and would have our family support professionals there to provide materials and answer questions, or do one-on-ones, or maybe have a small computer lab where kids can get training."

Basically, he continues, "these satellites would be micro versions of the main office where we'd be able to connect up using telecommunications, to conduct statewide meetings or trainings, among other activities."

Addressing the Needs of Montana Families

Unfortunately, declares Mr. Holt, the needs of Montana's families are great and there are few resources with which to meet them. A major problem, he explains, is the lack of AT as part of the curriculum in pre-service, which inhibits training of professionals and educators in its use. Another need is for more professional development opportunities. "PLUK fills the gap as best we can," he adds, with no funding to provide the service.

"There's very little AT knowledge among too many of our families,

which can be attributed to the rural nature of this huge state and the physical isolation of many families. Very little AT training is provided to the educators, professionals, and counselors, who possess cursory information but not much more than that." The system that produced that training deficiency is changing, he says, but slowly.

Fortunately, he says, "The Tech Act project in Montana is excellent. We work together very well. It has a loan program that we utilize that costs nothing, although they do charge for their evaluation services." PLUK provides free information and consulting.

Basically, however, "the knowledge base out there is small and our attempts to build it up are stopgap. What exists does not begin to solve the problem, which is huge. There's no solution in sight that I can get a glimpse of. So many things need to change in order to make it part of the system. Unless a parent or individual specifically asks for information about AT, nothing is done. Unfortunately, that's the way it is."

Montana's Uniqueness: The State Is 100% Rural

With a large geographic area and small population, Montana is one of the few states in the nation that is 100% rural. The advantageous result of that uniqueness, Mr. Holt asserts, is a well-developed telecommunications system, including videoconference studios, in nearly all the state's communities, medical centers and reservations. For years, he says, PLUK has utilized this advantage to accommodate trainings and meetings statewide.



This close relationship with the communities it serves has also resulted in a similarly close relationship with educators at the state level. "The state conducts trainings for us. We have a constant exchange of views on issues. Our state special education head, Bob Runkel, says, 'The best thing about Montana is that we all talk. We work things out.'"

There are very few formal complaints registered through the school system because problems are talked through before they reach the state level, Mr. Holt claims. "That's a part of the culture here in Montana that may not exist in other states which seem to be mired in due process issues and the mutual aggravation and frustration they generate. "

Do those issues surface in Montana? "Sure, we have a few bad apples that we have to deal with annually. There are some admin-

istrators who believe that they have their own fiefdom, and then it takes a while to get things fixed. But they get fixed by everyone working together."

Despite the state's uniqueness, the needs of families of children with disabilities are not so different from other states, he notes. "Families everywhere in the U.S. want the same things. They want to see their children succeed." Montana's rural setting, however, adds additional challenges, like having to travel long distances to access needed services.

"Families want appropriate services. They want the basics. Nobody wants the moon. They don't want to have to slog through the same issues day after day. In Montana, once we get involved in a case, things are usually resolved quickly. Sometimes just our presence makes a difference and we don't really have to get involved."

Rural Families and No Child Left Behind

Some of the imperatives of No Child Left Behind do not connect with the needs of rural families, Mr. Holt notes. "There aren't any other schools for children to change to if their current school fails to make the grade. The nearest school might be 100 miles away. Some of those provisions can't possibly be applied in a state like Montana."

Secondly, he adds, proximity to school and services is an issue. "A child with significant special needs might be living on a ranch 30 miles from his/her school and a hundred miles from medical services. Think of how issues like transition, employment or transportation might affect family and child? That family and child have no access, no connection, to any organizations that can assist them with any of the above. In that kind of situation, when you're dealing with that level of remoteness, creativity is a must."

An organization like PLUK, he declares, "must look realistically at what it wants to do, and what the individual or family want to do because things must be done completely differently than in a less remote environment."

Saved By the Internet

One of the saving graces for that family, and for PLUK, he points out, is the Internet. "The web has made a huge difference for families that live in these isolated areas. Information-wise, the web presents them with a world of information. Also, it provides them with access to virtual support groups, giving them other families to chat with. And it enables them to access our website or to contact us



directly via email. We do an enormous amount of work via email, a volume that increases annually.”

Being able to connect families statewide, making productive parent-to-parent matches between families that have succeeded and are willing to share their strategies with other families that have been struggling is another excellent benefit of the web, Mr. Holt states.

Wish List: Statewide AT Training

If his organization possessed additional resources, Mr. Holt says he would institute ongoing hands-on regional and statewide training and consultation in assistive technology topics.

Next, he would alter the curriculum in the state universities at the pre-service level by adding an additional component or degree program curriculum in special education, rehabilitation and counseling. “There also should be a stand-alone AT curriculum, especially for physical and occupational therapists, speech therapists, the professionals who really should be up to date on AT.” AT courses should be part of the system and required, he emphasized.

Third, information about AT evaluations must be integrated into the state government bureaucracy, “but there’s no one to do that. Nobody knows how. The state will designate individuals as responsible for AT in their departments, but they have little knowledge about it.”

The Future: Mainstream Technology

As the future unfolds, Roger Holt is excited about the improved accessibility of mainstream technology. “I’m excited about the technology itself. I look for the technology right off the shelf that can be used right away. It’s a huge advantage for families to know that they can get what they need at Office Depot or Home Depot and then create their own communication device, like I did to help Dennis.”

For his injured executive director, Mr. Holt concocted a small wireless mouse control “which can be run with a light touch, like a micro joy stick, with your cheek or tongue by using a presenter remote and then adding a joy stick to it with a small mount.”

That homemade device cost \$50. “That’s a lot cheaper than an \$1,800 equivalent, and it’s wireless! That kind of information I find to be the most powerful because it’s simple to try and to implement by using off-the-shelf components.”

He is also excited by built-in accessibility, “like in Windows and the Mac that most people won’t know about and which offers basic accessibility for everyone on every computer. That’s the first

thing I always train people on. Unless they’ve been to one of my trainings, they’ve usually never seen it.”

Everybody uses a computer now, he says. “And computers can be made accessible where they stand. With a little adaptation, anybody with any needs can use it.”

A technology program director who takes pride in his field staff’s cracked windshields does not become overly excited about high tech developments “because they work with such a small number of the families and individuals.”

High-tech, he concedes, “is great stuff, for sure, but it doesn’t make much difference for the vast majority of the people I work with.” The recent brain/computer interface that garnered such intense media attention failed to impress him. “That effort has been underway ever since I’ve been involved with PLUK. But if they’re not selling it at Wal-Mart yet it isn’t much use to the families we try to help.”



Things to Do To Prepare Your Student with Disabilities for the Upcoming School Year

Jackie Hess, FCTD Director

- Maintain “learning momentum” throughout the summer.
 - o Read with him/her, both fiction for fun and non-fiction (history, current events, science) for reinforcement of lessons learned.
 - o Buy one or more math workbooks or download free curriculum materials from the Internet. If possible, set aside a designated time each day for your student to work on math.
 - o Make summer studying fun by working with your student (generally they far prefer this to working alone) and going for ice cream (or another treat) afterward.
 - o If your family eats dinner together, use the conversation for concept reinforcement and encouragement.
 - o Enlist older siblings (in some cases, younger siblings) in summer learning activities.
- Visit the school during the summer, particularly if your child is making a transition to another school. Schools like for you to make an appointment prior to coming. Trace the routes that your child will take from class to class and to the library, cafeteria, gym, and other common areas. Make an appointment to meet the school personnel who will be dealing with your student – guidance counselor(s), teachers, nurse, coach(es). During these meetings, make sure each one has your phone number and e-mail address and encourage them to contact you before

potential problems arise.

- If your child will be taking the bus to and from school, drive the entire route several times during the summer, pointing out interesting landmarks (a well-tended garden, a restaurant, a park). During your school visits, be sure to identify the place at which your student will board the bus at the end of the day.
- If your child is sensitive to clothing fabrics, dyes, and tags, shop for new clothes early. This will give you plenty of time to pre-wash items (perhaps several times), cut out tags and have your child get used to the new clothes.
- Order name and address labels (they take several weeks to arrive). You'll probably want to put labels on all school supplies, jackets, and other items. If you already have labels, check the remaining supply to make sure you have enough.
- It's never too early to begin to teach your child about life after school. Whether you're at a museum, a hotel, a shopping mall or food store, take the opportunity to identify and discuss the variety of jobs being performed. Talk about the skills and educational requirements needed for each job. Get a sense of your child's interests and follow-up with age-appropriate books and pictures that build on those interests.

son's disabilities. The newsletter, which is produced in English and Spanish, also highlights legislative updates.

http://www.familiestogetherinc.org/newsletters/June_06_news.pdf

The Navigator

Pilot Parents of Southern Arizona

Produced quarterly by Pilot Parents of Southern Arizona, the state's second PTI, and written from parents' perspectives, The Navigator provides reviews of lending library books and videos as well as information about upcoming training sessions, disability-related articles and updates on state and local issues. Issues can be downloaded from the Pilot Parents of Arizona website or mailed in print version to home or office. For further information contact:

Pilot Parents of Southern Arizona
2600 North Wyatt Drive
Tucson, AZ 85712
Phone: (520) 324-3150
Fax: (520) 324-3152

<http://www.pilotparents.org/navigator.htm>

<http://www.pilotparents.org/main.htm>

The Voice

Parents Educating Parents and Professionals (PEPP)
April 2006

This quarterly newsletter on disability issues is produced by PEPPAC, the Georgia-based PTI affiliate of PEPP, which provides updated resources on disability-related community and educational events throughout Georgia and the nation.

<http://www.peppinc.org/Portals/0/April%202006%20newsletter.pdf>

Information Resource Centers

North Dakota PASS (NDPASS)

Affiliated with Pathfinder, North Dakota's PTI, NDPASS is the state's parent information resource center (PIRC). NDPASS offers families of children with disabilities access to a book and video lending library, workshops, online literature plus links to the state's K-12 schools.

<http://www.pathfinder.minot.com/index2.html>

Disability Brochures

Wyoming Parent Information Center (WPIC)

WPIC provides access to numerous disability-related brochures. Topics include: Asperger's Syndrome, attention disorders, attachment disorder, autism, Down Syndrome, dyslexia, learning disabilities, Section 504 and solving problems at

RESOURCES

Information Links

Parent Educational Advocacy Training Center (PEATC)

PEATC's website features an extensive collection of assistive technology links which include:

- Virginia's Training and Technical Assistance system (TTAC)
<http://www.peatc.org/ttac.htm>
- Virginia Assistive Technology System (VATS)
<http://www.vats.org/>
- Assistive Technology Loan Fund Authority (ATLFA)
<http://www.atlfa.org/>

http://www.peatc.org/info_links.htm#ASSISTIVETECHNOLOGY

Newsletters

Families Together, Inc.

Summer 2006 issue

Families Together is the Kansas PTI's quarterly newsletter. The organization's summer 2006 newsletter spotlights the state's transition summit, linking IEPs to state standards and a "family story," a brief but poignant account of a mother's attempt to focus on her two sons as children rather than on her younger

school. Also available is a brochure entitled, Why Call the PIC? which explains the role of Parent Information Centers in helping parents of children with disabilities. All brochures are available online from the WPIC website. Download is free. A lending library is also available. Long distance users of the libraries, books and videos are responsible only for return postage. For more information on WPIC, contact:

Wyoming Parent Information Center (WPIC)
55 North Lobban
Buffalo, WY 82834
Phone: (307) 684-2277; (800) 660-9742 (toll free)
Fax: (307) 684-5314
Contact: Terri Dawson, Director
tdawson@wpic.org
<http://wpic.org/default.htm>
<http://wpic.org/brochures.htm>

Guides

A Parent's Guide: The Educational Rights of Students with Disabilities

By Ronald J. Gidwitz, Dr. Glenn W. McGee
Illinois State Board of Education - 2001

This booklet is available free from Family Matters Parent Training and Information Center, the Illinois PTI. The booklet addresses the following questions:

- What kinds of services are appropriate in meeting my child's need?
- Is my child too old or too young to receive special services?
- Are these services going to cost a lot of money?
- What are my rights?
- What can I do to help?

The guide is available from:

Family Matters, Inc. Parent Training and Information Center
2502 South Veterans Drive
Effingham, IL 62401
Toll Free: (866) 436-7842 ; (217) 347-5428 (Voice/TTY)
Fax: (217) 347-5119
<http://www.fmptic.org/publications.html>

With Open Arms: A Financial Resource Book for Parents of Children with Disabilities

Easter Seals and the National Endowment for Financial Education (NEFE) - 2005

This 72-page guide includes information on estate planning, finding the right attorney or financial planner, wills, special needs trusts, government benefits and savings options insurance plans. The booklet can be obtained from:

Family Matters, Inc. Parent Training and Information Center
2502 South Veterans Drive
Effingham, IL 62401
Phone: (866) 436-7842

Toll free; (217) 347-5428 (V/TTY)

Fax: (217) 347-5119

<http://www.fmptic.org/publications.html>

Why Parent Centers? Why the Alliance?

The Technical Assistance Alliance for Parent Centers (TAAPC)
The PACER Center - 2002

PACER produces many guides and brochures aimed at assisting PTIs and community parent resource centers. This brochure explains how parent centers serve families and how the TAAPC serves the nation's community parent resource centers and PTIs. Data on parent center effectiveness is included along with contact information. Cost: \$3, or 10 copies at \$2 each. For more information on PACER TAAPC publications, contact:

The PACER Center
8161 Normandale Blvd
Minneapolis, MN 55437-1044
Phone: (952) 838-9000 (Voice); (952) 838-0190(TTY / 711 Relay); (888) 248-0822 (toll free)
Fax: (952) 838-0199
Contact: Gretchen Godfrey (Alliance Project @ PACER)
<http://www.pacer.org/publications/technical.htm>
www.taalliance.org

Information Packets

Support and Training for Exceptional Parents (STEP)

This Tennessee-based PTI offers an AT information packet. Limited to Tennessee residents, these packets may be obtained by phone or email. There is a nominal charge for packets mailed out of state. For additional information on STEP's information packets, contact:

Support and Training for Exceptional Parents (STEP)
712 Professional Plaza
Greeneville, TN 37745
Email information@tnstep.org
Phone: (800) 280-STEP
<http://www.tnstep.org/information-packets.php>

Q&A

Specialized Training of Military Parents (STOMP)

STOMP is the Parent Training and Information Center for military families whose children have specialized education or health needs. The STOMP website's Q&A includes information on such topics as: child and youth services, childcare, discipline, dispute resolution, Exceptional Family Member Program (EFMP), evaluation, Medicaid, Section 504, Tricare and Social Security.

<http://www.stompproject.org/qa.asp>

KNOWLEDGE NETWORK MEMBERS

Specialized Training of Military Parents (STOMP)

The Specialized Training of Military Parents (STOMP) Project is a federally funded Parent Training and Information (PTI) Center. It was established for the purpose of assisting military families who have children with special education or health needs. STOMP Project staff are parents of children who have disabilities and have experience in raising their children in military communities and traveling with their spouses to different locations.



The staff works together to provide four main services to the families they serve.

- (1) They provide information and training about laws, regulations and resources for military families of children with disabilities.
- (2) They work to connect families with other families to enhance their support network.
- (3) They assist parents and professionals in developing their own community parent education and support groups.
- (4) They advocate on behalf of a variety of issues faced by military families of children with disabilities.

One of the ways that STOMP provides information and training to military families is through workshops and presentations. These training opportunities cover a variety of subjects and have been given all over the world. Each workshop is planned and tailored to meet the needs and concerns of the families at that specific location. Common themes of the workshops provided by STOMP include educational intervention, accessing resources, making informed decisions, and working effectively with military systems.

According to Director Heather Hebdon, "STOMP has been doing a great deal to help families become more aware of technology and the role it can play in services and support." STOMP has worked with the Computer/Electronics Accommodations Program (CAP) to ensure military families and professionals are aware of the availability of resources through this program. They work to make sure their parent/professional network is aware of the resources that are out there to help them and the families they work with. They have also acquired the National Assistive Technology Research Institute's Assistive Technology Planner and have shared the information contained within it to assist families.

For more information on STOMP, please contact:
STOMP Project c/o Washington PAVE
6316 South 12th Street
Tacoma, WA 98465
<http://www.stompproject.org>

Phone (V/TTY) : (253) 565-2266 / 1-(800) 571-7368

Fax: (253) 566-8052

Contact: Heather Hebdon, Founder/Director

Email: hhebdon@washingtonpave.com

Parent Educational Advocacy Training Center (PEATC)

The Parent Educational Advocacy Training Center (PEATC) is the parent information and training center that serves families and professionals of children with disabilities in the state of Virginia. They are committed to building better futures for children with disabilities. They work toward this goal by acting collaboratively with families, schools and professionals in order to improve their opportunities for excellence in education and success in school and community life. PEATC offers research-based disability information, education, advocacy, training and support.



According to Executive Director Cherie Takemoto, "PEATC is committed to reaching all families, including traditionally underserved, rural and low-income populations and those families that do not know how their effective involvement can make a difference." Their outreach efforts include program support for African American and Latino populations across the Commonwealth. To reduce the impact of language barriers on certain people accessing information, PEATC offers some information in Spanish.

PEATC understands the importance of and the impact technology has on our society today. They partnered with George Mason University's Kellar Institute for Human Disabilities and developed LiteracyAccess Online. This is an Internet-based, hands-on, interactive instructional tool that was designed to teach parents, teachers, volunteers, teaching assistants and others literacy skills necessary to teach children having reading difficulties in grades 4 through 8. The program guides parents, teachers, volunteers and paraprofessionals through creative strategies, training and student-involved exercises to reach and teach students who experience frustration in learning to read. Areas of literacy training currently include: language arts, science, social studies, math and the general curriculum.

For more information on PEATC, please contact:
6320 Augusta Drive, Suite 1200 Springfield, VA 22150

<http://www.peatc.org>

Phone: (703) 923-0010 Toll-Free: 1-(800) 869-6782

Fax: 1-(800) 693-3514

Contact: Cherie Takemoto, Executive Director

Email: partners@peatc.org

Support and Training for Exceptional Parents, Inc. (STEP)

The Support and Training for Exceptional Parents, Inc. (STEP) is a statewide family-to-family program in Tennessee. The purpose of STEP



is to support families by providing free information, advocacy training, and support services to parents of children eligible to receive special education services under IDEA who reside in Tennessee.

STEP services are available to parent or family members of a special education student or a student who may need special help in school (birth through age 22). There is no charge for services to parents. Professionals in the education field are welcome to attend free workshops as well. The workshops that STEP offers may include information about the IEP, the special education system, transitioning into adult life and independent living.

In addition to workshops, STEP also offers many information packets, addressing such topics as: ADHD, Assistive Technology, Early Childhood, Evaluations, IDEA 2005, Functional Behavioral Assessment, Section 504, and more.

For more information on STEP, please contact:

712 Professional Plaza
Greenville, TN 37745

<http://www.tnstep.org>

Phone: (423) 639-0125

Toll-free: 1-(800) 280-7837

TTY/Text: (423) 639-8802

Contact: Jenness Roth, Executive Director

Email: information@tnstep.org

Fiesta Educativa, Inc.

Fiesta Educativa was founded for the purpose of informing and assisting Latino families in obtaining services and in caring for their children with special needs. It was formed by family members and professionals who recognized the need to provide assistance and advocacy to Spanish-speaking families.



The organization is dedicated to empowering the Latino families of persons with disabilities through education, training, referral, and information. This is accomplished through various projects such as their annual conference, which is held each summer at the University of Southern California in Los Angeles. The conference offers an opportunity for parents and professionals from California and throughout the United

States to meet and exchange ideas and information.

The organization is committed to the philosophy that individuals with special needs are entitled to the benefits of full integration into their community. In order to accomplish this goal, Fiesta Educativa collaborates with a wide range of public and private organizations in assisting families to obtain services.

The services that Fiesta Educativa provides are: parent training, community outreach, educational and training workshops, referral service, research, parent support groups, advocacy for individuals with special needs, public awareness, and speakers/conferences.

For more information on Fiesta Educativa, Inc., please contact:

163 South Avenue 24, Suite 201
Los Angeles, CA 90031

<http://www.fiestaeducativa.org/accessible/index.html>

Phone: (323) 221-6696

Fax: (323) 221-6699

Email: info@fiestaeducativa.org

Wyoming Parent Information Center

The Wyoming Parent Information Center (WPIC) works to inform and educate parents about special education law and the rights and responsibilities they and their children have under the IDEA legislation.



Their main goal is to help families better understand education issues as they relate to their child's disability, and to provide support and encouragement to parents as they face their child's journey through life.

The services available through WPIC are available to parents of children, age birth to 21, with any type of disability or chronic health need. The staff at WPIC works to stay as well informed as possible about the law, education, medicine, human services, rehabilitation and technology so that the parents and professionals to whom they provide information, referral and support have access to the best information available.

WPIC sponsors workshops, PICs-N-Pieces, Keys Handbook, brochures, Parent-to-Parent Connection, and a lending library. The workshops are offered throughout the state and focus on IDEA, the IEP process, and other disability-specific issues. PICs-N-Pieces is a bi-monthly newsletter that is mailed to nearly 3,600 Wyoming households, schools, and professionals. It provides up-to-date information about various disability issues. The Keys Handbook is a free handbook published to help parents become confident and

effective participants in the special education process.

Parent-to-Parent Connection is a support network for parents. WPIC maintains a database of parents who have volunteered to provide support to other parents. This list can be accessed to connect families in a community who may be dealing with similar disability issues.

For more information on the Wyoming Parent Information Center, please contact:

5 N. Lobban
Buffalo, WY 82834
<http://wpic.org>
Phone: (307) 684-5314
Toll-free: 1-(800) 660-9742
Fax: (307) 684-5314
Contact: Terri Dawson, Director
Email: tdawson@wpic.org

Family Matters Training and Information Center (FMPTIC)

Founded in 1989, Family Matters was awarded a grant in 2002 from the U.S. Department of Education to serve as a PTI from the entire state of Illinois outside Chicago. Family Matters provides information, referral, linkages and training to parents, students with disabilities, and special education professionals.



Through a toll-free help line individuals can get assistance with special education problems or concerns, obtain information, and request training opportunities. Regional coordinators throughout the state offer free workshops on special education rights and responsibilities and related topics.

The organization aids families in learning about early intervention services for children from birth to three years of age, provides information about special education services for school aged children, helps with transition issues for students leaving the educational system and offers access to resources, best practices, specific disabilities, parent to parent connections and training opportunities and conferences.

For more information on Family Matters, please contact:

2502 South Veterans Drive
Effingham, IL 62401
<http://www.fmptic.org>
Phone: (217) 347-5428 / 1-(866) 436-7842 (V/TTY)
Fax: (217) 347-5119
Contact: Debbie Einhorn, Project Director
Email: info@fmptic.org

Parents Educating Parents and Professionals for All Children (PEPPAC)



PEPPAC is Georgia's PTI. The organization assists children with disabilities ages 3-21

throughout the state of Georgia by providing informative and educational trainings to parents and professionals along with aid and resources. PEPPAC support includes printed information on disability topics, updated information on IDEA, instruction in methods and skills needed to establish working relationships with professionals in a child's life, a workshop training program, a resource center library, knowledgeable staff and referrals and personal assistance.

For further information on Urban PEPPAC please contact:

3680 Kings Highway
Douglasville, GA 30135
<http://www.peppinc.org>
Phone: (770) 577-7771
Toll-free: 1-(800) 322-7065 (GA only)
Fax: (770) 577-7774
Contact: Linda Shepard, CEO
Email: peppinc@peppinc.org

Partners Network Resource, Inc. (PRN)



Founded in 1986, PRN operates three regional PTIs in Texas, that provide statewide coverage to parents of children with disabilities. The projects are funded by the U.S. Department of Education, Office of Special Education Programs (OSEP). Services include training, education, information, referral, emotional support and technical assistance. Parents are assisted in understanding their child's disability as well as their rights and responsibilities under IDEA. In addition, parents are aided in obtaining and evaluating resources and services and participate as team members with professionals in planning and decision-making. Professionals are also assisted on a limited basis with information on working with parents and building effective parent-professional partnerships. Regional PRN services are free to parents.

PRN sponsors an annual Parent Leadership Institute aimed at enhancing parents' leadership capacity as advocates for their children.

Recently, PRN bought 26 acres of property in Jasper, TX on which the organization plans to develop a year-round camp/retreat for children and adults with disabilities and their

families. Camp programs will include summer camp, respite weekends, family retreat weekends, fishing, horseback riding and family festival days. Off-site events such as All-Sports Days are planned as well to take place at parks and recreation areas in East Texas. The target date for opening of the camp is 2007.

PRN also offers two Internet courses developed by Partners in Policymaking, Minnesota Governor's Council on Developmental Disabilities: Making Your Case teaches advocacy skills; Partners in Education instructs parents in how best to maximize their leverage in the public education system.

The organization's website features PartnersTX, an interactive discussion group in which parents communicate with each other and with PRN regional coordinators and information specialists.

PRN publishes a bi-monthly newsletter that spotlights disability-related issues.

For additional information on PRN, contact:
1001 Main Street, Suite 804
Lubbock, TX 79401

<http://www.PartnersTX.org>

Phone: (806) 762-1434

Toll-free: 1-(877) 762-1435 (TX only)

Español: 1-(877) 762-1435

Fax: (806) 762-1628

Contact: Janice S. Meyer, M.Ed. Executive Director

Email: partnerspen@earthlink.net

Advocates for Children of New York, Inc. (AFC)



For over 35 years AFC has worked to secure quality and equal public education services for New York City's most impoverished and vulnerable families. AFC focuses on children from infancy to age 21 who are at greatest risk for school-based discrimination and/or academic failure. These include children with disabilities, ethnic minorities, immigrants, homeless children, foster care children, limited English proficient children and those living in poverty. AFC provides free individual case advocacy, technical assistance and training for parents, students and professionals about children's educational entitlements and due process rights in New York City.

AFC combines legal services, from advice to administrative and court representation, impact litigation, individual case representation, public education, training, organizing and

in-depth research and policy analysis.

AFC's work on institutional reform engages key public policy making entities in strategies to modify existing educational legal structures, procedures and regulations. AFC engages in ongoing policy analysis of the institutionalization of inclusionary, effective and equitable school practices.

For more information on AFC, please contact:

151 West 30th Street, 5th Floor

New York, NY 10001

<http://www.advocatesforchildren.org>

Phone: (212) 947-9779

Fax: (212) 947-9790

Email: info@advocatesforchildren.org

Parent Advocacy Center for Individual Rights Center (PACER)

Founded in 1977, PACER is staffed primarily by parents of children with disabilities and works in coalition with 18 disability organizations.



PACER houses the Simon Technology Center, which aims to make technology more accessible to children and adults with disabilities. The center provides and operates Project KITE (Kids Included through Technology are Enriched), which trains parents and early childhood educators to use software and other technology that helps children with disabilities interact with their peers. The center also provides and offers in-services, workshops, a library, used assistive technology and AT and education technology to schools.

PACER helps identify resources and services ranging from toddlers' special needs to helping prepare teenagers with disabilities to enter the workforce. PACER programs include: a support group for new parents of children with disabilities; parents-helping-parents workshops; early childhood intervention; surrogate parent services; children's mental health services; multicultural services; the American Indian Project for families of children with emotional/behavioral disorders; and information and support services for grandparents of children with disabilities.

Programs for students, schools and professionals include: puppet shows for pre-school and elementary-aged children aimed at fostering acceptance of children with disabilities; and the Perkins Initiative, which prepares children with disabilities for the rigor of post-secondary education.

PACER produces numerous publications. Its Catalog of

Publications, free to parents and social service professionals, provides information on educational materials. PACER is a partner organization in the Family Center on Technology and Disability.

For more information on PACER Center, please contact:

Alliance Project at PACER
8161 Normandale Blvd.
Minneapolis, MN 55437

<http://www.pacer.org>

Phone: (952) 838-9000 TTY: (952) 838-0190

Toll-free: 1-(800)537-2237 (MN only)

Contact: Gretchen Godfrey,

Email: pacer@pacer.org

**You can add your organization to the
Family Center on Technology & Disability
Network at**

<http://www.fctd.info/members/join.php>

**You can add a colleague to the FCTD listserv at
<http://www.fctd.info/members/signupIndividual.php>**

**Have you checked out the
Family Center on Technology and Disability
website lately?**

**We're always adding new resources!
Take a few minutes to browse:**

www.fctd.info



**Family Center
on Technology
and Disability**

www.fctd.info

Project Director: Jacqueline Hess
Newsletter Editor: Thomas H. Allen
Design and Distribution: Ana-Maria Gutierrez
Project Support: Annie Czapp

Family Center on Technology and Disability

1825 Connecticut Avenue, NW

Washington, DC 20009

Phone 202-884-8068

Fax (202) 884-8441

fctd@aed.org

www.fctd.info