



Parent Support Groups: Start Where You Are

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IN THIS ISSUE...

When asked when and where to begin the long, hard road to progress, early civil rights leader Booker T. Washington replied, "Cast down your bucket where you are and start there." The same principle holds true for the formation of groups made up of parents of children with disabilities whose aim is to gain access to services and to assistive technology. There is no prescribed starting point for the formation of these groups. It requires the energy and imagination – and yes, the desperation -- of individuals acting in ones or twos who have had enough and want to move ahead on their children's behalf.

Venting can take a parent only so far. It can act as the ignition for meetings with school district officials and an IEP committee. It can spur angry letter writing campaigns to the local newspaper or to local, state or national governments officials. But venting is a catalyst, nothing more. Too much of it turns off those who might help. With luck, however, public venting can attract others with similar issues regarding their children that urgently require addressing. Soon, the beginnings of a support group take shape. Then the hard work of organizing – and funding – starts and never stops. Fueled by urgency and sustained by information and hope, a parent support group can act as a powerful aid for those who have no power: children with disabilities.

This issue examines parent support groups and the resources available to facilitate their formation and to provide them with information about access to vital services, including AT.

Bridgette Reeves Speaks

When the venting phase peaked, when her level of frustration boiled over in a flurry of angry phone calls and letters, Bridgette Reeves was an employee of the Department of Motor Vehicles in South Carolina. She had recognized as early as kindergarten that her son, Brandon, now 13, was having severe learning difficulties. Like many parents in similar situations she approached school district officials and requested an evaluation for learning disabilities. The evaluation, school district officials informed her, came up clean. There would be no significant accommodations provided, no IEP, no AT. She had Brandon evaluated by an outside psychologist who came back with a diagnosis of ADHD, and auditory processing and sensory perception disorders with severe learning disabilities. Still, the school district offered no services.

By age eight, Brandon was unable to recite the days of the week or to remember his home address. He was kept back in third grade and failed fourth grade but was granted promotion. Desperate now, Ms. Reeves enrolled Brandon in a private school 69 miles away, a commute that forced her to leave her DMV job. Her mother and in-laws helped with the steep tuition. Brandon thrived in his new environment. His grades rose dramatically. Thanks to a chance conversation with a former DMV colleague, Ms. Reeves was able to enroll her son in the TEFRA-Medicaid program, which helps cover the cost of therapies and is based upon the child's income, not the parent's. Eventually, however, commuting and financial factors forced Ms. Reeves to make a pivotal decision: She would home-school Brandon. He was 12 years old. During those years, Bridgette Reeves had developed no familiarity with AT.



She wrote a letter to her local paper detailing Brandon's saga and her frustration. The next week, two readers responded with letters of their own. Each shared a similar story. Ms. Reeves phoned the paper and asked for the readers' contact information, which, due to privacy constraints, the paper was unable to provide. Instead, she was asked to write a second letter requesting any parents sharing similar concerns to contact her at home, and provided her home phone number and mailing address. She was shocked at the response volume. Called People Offering Parents Support (POPS), her parent support group now consists of about 25 parents who regularly attend monthly meetings in her church's fellowship hall with another 50 parents on the group's mailing list.

Meeting every month but August, POPS garners guest speakers from disability organizations to help members cope with school system issues, IEPs, 504 plans, IDEA – and access to AT. Along with contacting guest speakers, Ms. Reeves has acquainted herself, and her group, with AT and its benefits, securing numerous demos for use by POPS members.

She declares, "I'd heard AT mentioned in passing when he was in public school, but only in passing because he didn't qualify." And now? "Once I became acquainted with AT I became fascinated with its potential." That fascination, she adds, has spread to members of the support group who mount their own Internet searches to gather information they can share. "Much of our time at meetings is spent sharing that AT information. Good gracious there's a ton of AT out there! Our task now is to gain access to it for our children."

Supporting our interview with Ms. Reeves are resources to assist parents and others in forming and utilizing parent support groups. We also feature members of our Knowledge Network. The members spotlighted this month focus on various aspects of parent support groups that wish to learn more about assistive technology. 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.



You've Got Mail: A Letter to the Editor Draws a Response – and a Parent Support Group Is Born

*An Interview with
Bridgette Reeves, Parent Support Group Co-Founder*

Finally, fury and frustration yielded a last attempt to connect with someone, anyone, who could help Bridgette Reeves gain some recognition for her son Brandon's multiple disabilities and some help in coping with issues associated with them, including access to assistive technology (AT).

Recalls Ms. Reeves, "My husband and I dropped our attorney, who cost a lot and didn't accomplish anything. I started venting on the Internet. I wrote letters by email to local, state and federal government officials. I wrote to Oprah, to Dr. Phil, to every newspaper I could find, and I even wrote to the President of the United States. I received numerous letters in return from them, but no one could help with my son's situation."

Then she wrote to her local newspaper in Lancaster, SC. "I actually wrote three letters. In the first letter I vented about Brandon's former elementary school." She wrote the second letter after Brandon began attending a private school in Columbia, SC. "I wrote this letter to inform everyone in Lancaster, how great Brandon was doing at his new school. After the first letter was published, almost everyone in our county knew my situation from reading it in the newspaper. I wrote, 'With the right teachers and the right teaching methods, children like Brandon can succeed with academics.'"

After that letter, she says, "My husband told me to just stop. He said, 'Give it up, please, and relax.' He was right. I had become stressed out."

Something Wonderful Happened: Calls from 22 Parents

A week passed "before something wonderful happened." In response to her letters, two parents wrote anonymous letters to her local newspaper concerning the relationship between their children and the local school system. "After reading those letters, I picked up the phone

and called the newspaper editor. I asked the editor if she could give me the names and numbers of those two parents so I could call them. I thought maybe the three of us could help each other."



The editor told Ms. Reeves that privacy issues prevented the release of the letter writers' names and contact information. "She told me if I really wanted to talk to those parents, I would have to write another letter to the paper and include my contact information so that those parents could use it to contact me if they chose."

She then wrote her third and final letter to her local paper. "That letter was published on a Wednesday and by the following Sunday, 22 parents had contacted me by phone. My phone was literally ringing off the hook that whole weekend. My husband was in shock, but I was extremely excited. I just couldn't believe so many parents, especially in our little town, would be calling me."

After writing down all the parents' names and their numbers, she recalls, "I told my husband I have got to do something for all these parents. I realized that parents need to stick together if we want to change how our children are educated. I just couldn't sit back and do nothing. Here I was thinking all this time that I was alone in dealing with issues concerning my son. It turned out I was happily mistaken in that thought."

That same week, "I got on my computer and started ordering everything I could possibly order concerning every disability I could think of. I put my name on the mailing list of every disability organization and vendor." In the ensuing two months, she received more than 50 boxes filled with information. "My living room became my central point for storing all of these materials, catalogs, fact sheets and brochures. It felt like the mail was only coming to my house and no one else's."

The Group Takes Shape: POPS

"I gathered up all my new items and stacked them up neatly against my living room wall. I then started making phone calls to all the parents to confirm a date to finally meet each other face to face. We finally agreed on a time, but we needed a place.

"I decided to go before my church elders and I talked to them about my idea of starting a support group in our area. They loved the idea and asked me to have the meetings at our church. I called up all the parents again and informed them of our exciting news.

"I then had to come up with a catchy name for our group. My son has ADHD and he was being his usual self, running around the living room. My daughter said, 'Mom, please make Brandon stop popping around the room, he pops around way too much.' I

stopped for a minute and thought, wow, what a wonderful name! I started typing up words that fit the POPS acronym. It took me about an hour before I came up with Parents Offering Parents Support: POPS. I called up all the parents and they all loved it."

Seventy-seven Parents

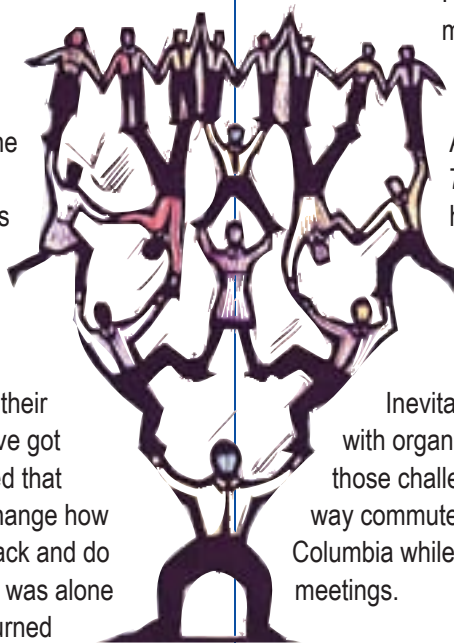
For two years, the POPS support group has met monthly in the fellowship hall of Ms. Reeves' church.

A group that began with 22 parents now claims 77 members on its mailing list, although "I haven't figured out how to bring all 77 parents together under one roof yet, but I am working on it." Most meetings, she says, attract 20-30 parents.

Inevitably, the group's inaugural year was fraught with organizational challenges. Ms. Reeves dealt with those challenges and continued her daily 69-mile-each-way commute to and from Brandon's private school in Columbia while organizing and shaping the monthly POPS meetings.

Some of the POPS parents, she says, wanted her to cancel summer-month meetings, but she disagreed. Retaining the monthly meeting schedule, she says, enabled her to meet another parent, Vickie, whose 16-year-old bipolar son had recently committed suicide and whose daughter had also been diagnosed as bipolar. "Vickie needed to talk to someone. I was so thankful that I didn't cancel those summer meetings because if I had, I would have never been there for her that day. We sat there for three hours and talked and supported each other."

Several months into get-acquainted meetings, she began campaigning to garner guest speakers for the group. "I called organizations like ProParents, Family Connections, Federation of Families, and many more. I gathered many guest speakers that first year to help teach us how to cope with our children, how to



handle issues dealing with the school system, and about topics such as IEPs, 504 plans, IDEA -- and AT.

Vickie convinced her to get a guest speaker from NAMI, the National Alliance for the Mentally Ill. "She told me that it would help her greatly if I could do that. After making that phone call that week to NAMI, I met two more wonderful parents, Dan and Betsy. Dan soon conducted a very effective workshop for us that provided an overview of mental illness."

A Merger Looms

NAMI approached Ms. Reeves with an invitation to help build YouthNet, a NAMI affiliate. YouthNet is a regional program aimed at preventing children with serious mental illnesses from being placed out side of the home.

"I then called up all the parents and asked their opinion about merging our group with NAMI. They all agreed it would be a wonderful opportunity." The affiliation was cemented and the group's name is now POPS-YouthNet.

The new affiliation, she explains, has enabled her to continue the support group while also continuing to home-school Brandon. As a bonus, NAMI has signed on Ms. Reeves as a part-time employee to help build YouthNet in her area. The NAMI affiliation, she notes, helps POPS pay for mailings, ink, paper, envelopes, and snack supplies for her meetings, "which is important to me since I stay at home now."

The next step for POPS, she says, is to make the organization even more well-known in the community. Ms. Reeves created POPS business cards and flyers on her computer that she places in grocery stores, restaurants, doctors' offices, supermarkets and superstores, like Wal-Mart.

"We also produce a newsletter to keep everyone informed about our meetings. My daughter, Brittany, helped me design our newsletters and we have been mailing those out to everyone we come in contact with who has an interest in disabilities." The newsletter, she adds, informs POPS members about upcoming meetings and updates those who may have missed a meeting on what transpired there in their absence.

"We have all begun a relationship of supporting, helping and learning so much from each other. I have met so many friends and talked to so many people because of my wonderful journey. It has really been a blessing.

AT: An Epiphany

"Together, we have found so many new strategies in helping educate our children," she notes. The use of AT is one of the group's recently discovered strategies and has helped Brandon improve

academically at home, Ms. Reeves explains. "We found that AT is for the very mildest to the most severe learning disabilities, and it is a huge help."

She credits POPS co-founder Rhonda Ebersole, a parent of a child with autism, for researching AT and presenting that information to the group. "Together, Rhonda and I have found out so much information about AT and we are spreading the news. Our goal one day is to build an AT learning center in our area. We realize that it would take many years of planning, but it's a goal worth planning and working toward."

AT, she states, "has really helped Brandon. We recently used the Kurzweil 3000. It's a scan and read product that, in my opinion, has helped a great deal with his reading comprehension. We have the device only for the length of a 30-day demo, but it really has helped him improve a great deal with his auditory processing challenges."

"Using the scanner, I scan in his reading pages and/or his academic tests on my computer. The Kurzweil software places his reading pages and/or his tests on the computer screen and reads each word of it out loud to him, with each word highlighted for him to follow. He then answers all of his text or test questions on the computer screen using the keyboard."

For pleasure reading, she adds, Brandon also uses the Kurzweil 3000 to scan and read Star Wars chapter books. "He scans without any help from me. Once the pages are entered into the computer and placed on the computer screen, he puts on his headphones and listens and follows along while the computer reads each page to him highlighting each word to follow." Thanks to this device, she says, Brandon's reading experience is far more enjoyable and productive.

"WE ARE INFORMING ALL PARENTS THAT AT IS ANOTHER VALUABLE TOOL TO HELP OUR CHILDREN ACADEMICALLY. IT'S NO DIFFERENT THAN HAVING TO WEAR EYEGLASSES OR EVEN USE A PENCIL GRIPPER FOR OUR PENCILS. I HAD A PARENT TELL ME ONCE THAT HER CHILD DIDN'T NEED AT BECAUSE HER SON WASN'T IN A WHEELCHAIR. AFTER EXPLAINING TO HER WHAT AT REALLY WAS, SHE ASKED ME TO GIVE HER MORE INFORMATION AND TO PROVIDE DEMOS TO HELP HER CHILD."

"We are informing all parents that AT is another valuable tool to help our children academically. It's no different than having to wear eyeglasses or even use a pencil gripper for our pencils. I had a parent tell me once that her child didn't need AT because her son wasn't in a wheelchair. After explaining to her what AT really was, she asked me to give her more information and to provide demos to help her child."

Ms. Reeves has encountered "a great number of parents who misunderstand what AT really is. That's why we want to spread the word and inform parents who are members of support groups like ours. It could open up a whole new world for their children in ways parents just can't imagine."

Such an outreach approach, she feels, may bridge the current information gap about AT among parents of children with disabilities in the state's public schools. "We are doing our best to spread the word and I hope our efforts will help all children in our state."

Recently, Ms. Reeves and POPS co-founder Rhonda Ebersole were interviewed on a local TV news program about the benefits of Play Attention, a helmeted virtual reality system attached to a personal computing system to improve a student's ability to pay attention. Play Attention, she remarks, is another tool that could help all children with their attention and focusing challenges. "We are currently using it twice a month to help Brandon with his attention and focusing challenges." The device, she asserts, ought to be made available in the state's public schools.

Making Changes One Day at a Time

Since starting POPS, "I've learned so much about my own child's disabilities as well as others. The parents in the group have taught me to take one day at a time and to cherish the little things in life. The members of our group all face similar issues concerning AT, IEPs, 504 plans, IDEA laws and dealing with doctors, therapists and insurers, but we come together and learn how best to handle those issues."



She continues, "I had a parent tell me once that I should be proud of my accomplishments. She said I took a situation that made me resentful and turned it around to help others. Now I can look back and smile and say to myself, 'Wow, was that me!'"

In the beginning, she conceded, "I used my anger to keep the support group going. I just wanted to make sure that other parents did not make the same mistakes I made in my rocky relationship with the school system and with my own child."

In the end, however, "I helped form a group of parents who supported each other. I never imagined in my wildest dreams that I would ever have the ability to accomplish what I've accomplished – and what the group has accomplished for the benefit of all of us. It's been so satisfying and beneficial not just to the parents but ultimately to our children."

She concludes, "I know in my heart that if parents would join forces and speak out about their children's educational issues, that there would be changes made. They may seem like small changes, but those changes will come, one day at a time."



To make convergence work, he says, "many individuals and groups must be brought together that represent numerous relevant stakeholder groups in school systems and within the business world." Whether it's universal design or using an AT product for a broader purpose, "it's all acceptable if we're reaching a greater population that might be made more successful and productive in our society. This is our contribution. Our industry cannot compare to the computer industry, for example, in scale, in number and size of companies, but our importance to those who need us is, and will continue to be, immeasurable."

The Family Information Guide to Assistive Technology is now available in Spanish!



Available on the FCTD website in both html and PDF versions.

Spanish

Guía Informativa Familiar sobre la Tecnología Asistencial

<http://www.fctd.info/resources/fig/spanish/>

English

Family Information Guide to Assistive Technology

<http://www.fctd.info/resources/fig/>

RESOURCES

Articles

Disability and the Family

Abilitymagazine.com
1997

If overwhelmed, seek help. That's the advice offered by the author to families seeking support in addressing issues common to all families of children with disabilities. The article deals with medical and legal issues relating to a child's medical care and insurance coverage, offering information on a child's right to treatment and a parent's right to medical records. The author offers advice to parents about the most effective ways to cope with physicians and insurance companies and emphasizes the advantage of hiring an attorney to help cope with the knottier issues many families face. "Aside from answering legal questions and doing the necessary legal work, the attorney may be able to provide options and offer suggestions, such as how to obtain help paying medical expenses, that the family was not aware of." The one step every parent should have already taken, the author notes, "is to have read all of their health insurance policy—even the fine print. Know your deductible, maximum benefits and any coverage exclusions. It is important to address any coverage deficiencies before you find that you need them. Realizing your insurance will not cover a major health problem can be nerve racking and well...just plain unhealthy. If you are going to pay large premiums for your family's security, it's good to know what that security encompasses."

http://www.abilitymagazine.com/diana_family.html

Become Your Child's Advocate

Illinois Technology Project
1998

A seven-page report that encourages parents to participate fully in the formulation of their child's education plan, *Become Your Child's Advocate* provides advice on record-keeping, planning, IEP meetings and on disagreement resolution. The article also references other resources focusing on the specifics of individual and parental rights. To obtain the report in hard copy at no cost contact:

Illinois Assistive Technology Project
1 West Old State Capitol, Ste. 100
Springfield, IL 62701
Phone: (217) 522-7985

http://www.iltech.org/parents_act.asp

Books

A Parents Guide: The Educational Rights of Students with Disabilities

Illinois State Board of Education

The book provides an overview of the educational rights of children with disabilities, outlines their parents' role in formulating a child's education and sets down the timelines school districts must follow to be in compliance. The author also provides sample letters for filing a complaint and requesting a due process hearing and an evaluation. Single copies are free. To obtain a copy of this book, contact:

Illinois State Board of Education
100 N. First St.
Springfield, IL 62777-0001
Phone: 217-782-4321

Road Map for Funding Sources

RESNA Press

This book focuses on technology funding sources available to parents of children with disabilities and contains sections on special education programming, special education laws and rules. The book, at a cost of \$25 plus \$3.50 for handling, is available from:

RESNA Press
Department 4813
Washington, DC 20061-4831
Phone: (202) 857-1199

Technology and the Individualized Education Program

RESNA Press

This publication covers mandates for educational technology in special education legislation, technology terminology definitions, the uses of devices and services, the determination of technology needs, educational technology and the IEP, funding responsibility, the responsibility for delivering technology services to children, taking the technology home and the supports needed for a technology program in school. Cost: \$10. To obtain this book, contact:

RESNA Technical Assistance Project
1101 Connecticut Avenue, NW, Ste. 700
Washington, DC 20036
Phone: (202) 857-1140

How to Get Services

Family Resource Center on Disabilities

This book examines assertive and non-assertive behaviors and aids parents in developing effective assertive techniques in accessing services for their children with disabilities. Cost: \$10 plus \$2 postage. To obtain the book, contact:

Family Resource Center on Disabilities
220 S. State St.
Chicago, IL 60604
Phone: (312) 939-3513 (TTY)

Guides

Baby Power: A Guide for Families Using Assistive Technology for Infants and Toddlers

By Patsy Pierce, Debby Reinhartsen, Jane Steelman, Susan Attermeier, Rebecca Edmondson

The Center for Literacy and Disabilities Studies, University of North Carolina at Chapel Hill -1998

The authors concentrate on the following topics: how infants with disabilities learn; how learning opportunities for small children with disabilities can be enhanced; and sample goals for the Individual Family Service Plan (IFSP) and IEP. Patsy Pierce defines AT and provides a rationale for considering its use with infants and toddlers. She also provides a brief overview of the guide. Rebecca Edmondson discusses the key ingredients in successful collaborative relationships between parents and professionals and the parents' role in screening and assessment and developing individualized plans that include technology. Susan Attermeier, a physical therapist, discusses strategies and AT devices for maximizing positioning and mobility of infants and toddlers. Sample goals for individualized plans are provided. Debbie Reinhartsen and Patsy Pierce address the role communication plays in everyday learning and stress the importance of AT to aid in the development of communication skills. Jane Steelman, an instructional technology specialist, discusses how the computer can serve as an equalizer for children with developmental disabilities who otherwise may not be able to participate in physical learning situations. A resource list of books and computer software is included.

<http://www2.edc.org/NCIP/library/ec/Power.htm>

First Steps: A Parent Information Handbook

By K.A. Keller

Parents Let's Unite for Kids (PLUK)

1997

The authors aim to assist parents and families to understand and negotiate early childhood education IFSPs and IEPs. To obtain this book, please contact:

Parents Let's Unite for Kids (PLUK)

516 N. 32nd Street

Billings, MN 59101

Phone: (406) 255-0540

<http://www.pluk.org/FS1.html>

Parent Training and Information Centers

By Theresa Reborn

National Dissemination Center for Children with Disabilities (NICHCY)

The author defines and explains the purpose and utility of regional Parent Information Centers (PTIs) and PTIs' close relatives, Community Parent Resources Centers (CPRCs). The author writes, "Parent Centers know about the needs of children and families. They understand school policies and practices. Through their experience with the education of chil-

dren with disabilities, the needs of families and schools, Parent Centers make valuable contributions on a local and statewide basis in support of schools to improve services and outcomes for students with disabilities."

<http://www.nichcy.org/pubs/basicpar/bp3txt.htm>

Finding Help for Young Children with Disabilities (Birth-5)

National Dissemination Center for Children with Disabilities (NICHCY)

1994, updated March 2005

The publication outlines the impact of the arrival of a baby with disabilities on families and provides information on the emotional, health and developmental support available for the child at the infant, toddler and preschooler stages. Links to parent support groups are provided.

<http://www.nichcy.org/pubs/parent/pa2txt.htm>

Websites

Mothers United for Moral Support MUMS

MUMS is a national organization for parents or care providers of a child with any disability, disorder, chromosomal abnormality or health condition. The organization provides parents with a networking system, matching them with other parents whose children have the same or similar condition. Through a database of over 16,000 families from 49 countries covering over 2,800 disorders, even very rare syndromes or conditions can usually be matched.

<http://www.netnet.net/mums/>

Federation for Children with Special Needs

The Federation brings parents of children with disabilities together with parent organizations. Organized in 1975 as a coalition of parent groups representing children with a variety of disabilities, the Federation operates a Parent Center in Massachusetts that offers a variety of services to parents, parent groups and professionals.

<http://www.fcsn.org/>

Parent Pals.com

Targeting multiple aspects of special education, this website offers numerous resources in areas that are disability-specific, as well as on broader topics such as AT and special education. The site offers recommendations for books, a dictionary of commonly used special ed terms and publishes a newsletter.

<http://parentpals.com/gossamer/pages/>

Parents Helping Parents

For parents of children with disabilities, this website is a source of comprehensive information on early intervention, identification, appropriate education and parenting support. The site benefits parents and professionals.

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

KNOWLEDGE NETWORK MEMBERS

Parent Leadership Project

The Parent Leadership Project was created to sup-



port parents in Massachusetts whose children receive early intervention services. The Project's main goal is to promote lifetime advocacy, leadership skills and the development of an informed parent constituency, which will encourage early intervention services to be increasingly family centered. The project maintains a robust website with a wide range of information of use to Massachusetts families.

For more information about the Parent Leadership Project, please contact:

Phone: (877) 353-4757

Darla Gundler, Statewide Director

Email: Darla.Gundler@state.ma.us

<http://eiplp.org/>

Beginnings for Parents of Children who are Deaf or Hard of Hearing

The mission of BEGINNINGS is to help parents be



informed, empowered and supported as they make decisions about their child. In addition, BEGINNINGS is committed to providing technical assistance to professionals who work with these families to help the children achieve full participation in society.

BEGINNINGS offers emotional support and technical support to families with deaf or hard of hearing children and deaf parents with hearing children and professionals serving those families. BEGINNINGS is a place to start when you have questions about the hearing of your child ages birth to 21. The organization maintains offices in North Carolina, but provides information to people nationwide through a free V/TTY number.

For more information on BEGINNINGS, please contact:

P.O. Box 17646

Raleigh, NC 27619

Toll-free: (800) 541-4327

Phone: (919) 850-2746 / Fax: (919) 850-2804

Dr. Joni Y. Alberg, Executive Director

Email: raleigh@beginningssvcs.com

<http://www.beginningssvcs.com>

Connecticut Parent Advocacy Center, Inc.

The CT Parent Advocacy Center, Inc. (CPAC) is a statewide nonprofit organization that offers information and support



to families of children with any disability or chronic illness, age birth through 21. The Center is committed to the idea that parents can be the most effective advocates for their children, given the confidence that knowledge and understanding of special education law and its procedures can bring. It is CPAC's mission to support families in their efforts on behalf of their children with disabilities.

The staff at CPAC consists of parents of children with disabilities. These parents have training in, and personal experience with, the law and disability issues.

For more information about the Connecticut Parent Advocacy Center, Inc., please contact:

338 Main Street

Niantic, CT 06357

Phone: (860) 739-3089

Voice/TDD: 1-(800) 445-2722

Fax: (860) 739-7460

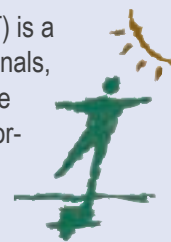
Contact: Nancy Prescott

Email: cpac@cpacinc.org

<http://www.cpacinc.org>

Families for Early Autism Treatment

Families for Early Autism Treatment, Inc. (FEAT) is a non-profit organization of parents and professionals, designed to help families with children who have received the diagnosis of Autism Spectrum Disorder, including Autism, Pervasive Developmental Disorder, or Asperger's Syndrome. FEAT offers a network of support to the Northern California Autism Community where families can meet each other and discuss issues surrounding autism and treatment options.



FEAT provides a free Lending Library where families can obtain information about Autism and check out teaching materials for their therapy programs. They also publish a quarterly newsletter of current news and events that can be accessed at no cost through their website.

Parent Resource Meetings, which are held on the third Wednesday of each month, are designed to provide information to families whose children have been diagnosed with Autism and to provide access to a network of families who can be supportive. On the website you can find a listing of parent

support meetings and workshops in northern California as well as locate other FEAT offices across the country.

For more information on the Families for Early Autism Treatment, please contact:

P. O. Box 255722
Sacramento, CA 95865-5722
Phone: (916) 463-5323
Fax: (916) 381-5029
<http://www.feat.org/>
Email: feat@feat.org

Families Helping Families Network

Families Helping Families has nine Family Directed Resource Centers across the State of Louisiana. According to Sharon Dousay, the FHF Coordinator, "The Nine Regional Centers in Louisiana work together to assist and strengthen individuals and families with special needs



through a coordinated network of resource, support and services." Families Helping Families provides information and referrals, education and training and peer support for all persons with disabilities and their families. They also serve as a resource for professionals.

Combined, these nine Resource Centers provide a variety of programs. Their Project PROMPT provides information about educational laws and rights through their advocacy workshops and trainings. Their Inclusive Education Family Project provides direct assistance and training to help achieve fully inclusive options in schools and community for people with special needs. Their Parent to Parent Support System matches parents with trained parents for one on one support. Finally, their Sibshops program sponsors workshop activities for siblings of children with disabilities ages 8-13.

For more information on the Families Helping Families Network, please contact:

323 Rosemont Drive
Thibodaux, LA 70301
Phone: (985) 446-3445
Cell: (985) 688-8101
Fax: (985) 446-6891
Contact: Sharon Dousay, FHF Coordinator
Email: fhfcoord@charter.net
<http://www.fhfla.org>

Family Connection of South Carolina, Inc.



Family Connection of South Carolina, Inc. is a support network for families who have children with special needs. They

strive to help thousands of children in South Carolina reach their potential by providing parent-to-parent connections, linking families to community resources, and sponsoring a number of educational and support programs.

Their programs and services are centered around parent-to-parent networking, a program based in the principal that families with shared experiences are uniquely qualified to help each other. Family Connection matches parents of children with disabilities with Support Parents who have children with similar conditions and have faced similar challenges and celebrations.

Family Connection of South Carolina is also part of a worldwide network of parent-to-parent support programs and is financed through grants, donations and contracts with many private and governmental organizations. Today, there are Family Connection offices in Columbia, Greenville, Rock Hill, Anderson, Spartanburg, Aiken, Charleston, and Florence, with Support Parents in all counties of South Carolina.

For more information on the Family Connection of South Carolina, Inc., please contact:

2712 Middleburg Drive; Suite 103-B
Columbia, SC 29204
Phone: (803) 252-0914
Toll-free (In-state): (800) 578-8750
Fax: (803)799-8017
Contact: Connie Ginsberg, Executive Director
Email: info@familyconnectionsc.org
<http://www.familyconnectionsc.org/>

Parent to Parent of Georgia, Inc.



Parent to Parent of Georgia

Providing support and information to parents of children with disabilities

Parent to Parent of Georgia is a non-profit organization providing support and information to parents of children with disabilities in Georgia. Their services are based on the philosophy that one of the most meaningful sources of support are other parents who have experienced parenting a child with a disability. The services that Parent to Parent of Georgia offers are free and include the following: One-to-

One Parent Match, Parent to Parent Support Groups, and a Parent Message Board.

One-to-One Parent Match connects parents living in Georgia with a volunteer supporting parent. Parents are matched with a Support Parent based on the child's disability, health care needs, or special concerns. Support is usually provided over the telephone, but some parents do eventually meet face-to-face.

If you feel like it would be more helpful to talk to more than one parent, you can join one of their Parent Support Groups, which are found throughout the state. The four main groups are the Augusta Group, Marietta Group, Middle Georgia Online Support Group, and the South Atlanta Group. Others exist and can be found by searching the Parent to Parent of Georgia's Special Needs Database. Hispanic Support Groups are also available.

Parent to Parent of Georgia not only supports parents, but also provides a lot of information to the community about helping people with disabilities.

For more information on Parent to Parent of Georgia, please contact:

3805 Presidential Parkway, Suite 207

Atlanta, GA 30340

Phone: (770) 451-5484

Toll-free: (800) 229-2038

Fax: (770) 458-4091

Contact: Debra S. Tucker, Director at

info@parenttoparentofga.org

<http://www.parenttoparentofga.org>

PARENTS, Inc.

PARENTS, Inc. is a

partnership of Alaska families

of children with disabilities, which provides support, training, resources, and advocacy statewide. PARENTS, Inc. believes that strong capable families are the best resources for children with special needs. They also believe that parents of these children can provide support and information to each other.

This statewide program offers information, training, referrals, support, and advocacy services to both parents and professionals. Through the Parent-to-Parent matching program parents can connect with other parents who have similar needs and experiences. The Parents Anonymous program hosts regional support meetings for parents of children of all



ages as well as meetings for youth participants.

For more information on PARENTS, Inc., please contact:

4743 E Northern Lights Blvd

Anchorage, AK 99508

Phone: (907) 337-7678 (907) 337-7629 (TTY)

Fax: (907) 337-7671

parents@parentsinc.org

<http://www.parentsinc.org>

Exceptional Family Resource Center



The Exceptional Family Resource Center (EFRC) is a community-based collaborative agency serving the San Diego area. The agency is staffed by parents and professionals and is designed to serve families of individuals with special needs by providing a broad continuum of information, education, and support.

Their family services include Parent-to-Parent Support, support groups, information and referral, a resources and lending library, and other parent training and education programs. Services and supports are offered in English and Spanish

Services to professionals include information and referral, technical assistance on family-related issues, presentations, training and education, disability information, books and videos, curriculum planning resources, and support.

For more information on the Exceptional Family Resource Center, please contact:

9245 Sky Park Court, Suite 130

San Diego, CA 92123

Phone: (619) 594-7416 1-(800) 281-8252

Fax: (858) 268-4275

Contact: Joyce Clark, efrc@projects.sdsu.edu

<http://www.efrconline.org/>

Support for Families of Children with Disabilities



Support for Families of Children with Disabilities (SFCD) is a parent-run San Francisco-based non-profit organization that was founded in 1982. They support families of children with any kind of disability or special health care need as they face challenges. Their purpose is to ensure that families of children with special health care need have the knowledge and assistance they need to make informed choices that support their child's health, education and development. They

provide peer support to families, and information and education to families, professionals and the community at large.

The programs offered by SFCD reflect their desire to help families and in particular parents. Parents can obtain information from the organization by using their phone line, drop-in center, or resource libraries. Here, they can obtain individualized information, referrals, and help. If they are not looking for information, and just looking for support, parents can join a support group. These groups help families find solutions to challenges, learn advocacy skills, explore resources, and gain strength by sharing experiences with peers.

A great part of the support found in these groups comes from the volunteer parent mentors. These people are trained volunteers and are matched to families based on a shared culture, language or disability issue.

Finally, Support for Families of Children with Disabilities reaches out to the community in many ways. They offer educational workshops and clinics for informational purposes and publish a quarterly newsletter. They also sponsor social family gatherings throughout the year.

For more information on SFCD, please contact:

2601 Mission Street, #606
San Francisco, CA 94110-3111
Phone: (415) 282-7494
Fax: (415) 282-1226

Email: info@supportforfamilies.org
<http://www.supportforfamilies.org>



THE FCTD ONLINE DISCUSSION OF:

Effective Assistive Technology Mediation

CONTINUES UNTIL FEBRUARY 28TH

Some topics that have already been discussed include:

- Resources for training on effective communication and negotiation
- Who should be present in mediation?
- The role of advocates/attorneys in mediation
- Facilitated IEP's versus mediation

We are pleased to be having an open dialogue amongst a diverse group of people, including: FCTD expert moderators, special education professionals from schools and school districts, parents, mediators, and others from the AT field. The process of mediation involves team work in order to fulfill the ultimate goal of best helping the child. The conversations that we have seen so far throughout this discussion allow deeper exploration into the roles of all members involved.

Join Nissan Bar-Lev, Jeanne Bowman and Jan Serak, as they lead an information-rich discussion of Effective Mediation in Special Education. Share your stories and your questions with colleagues throughout the country.

There is no cost, no registration, no prior knowledge required. Simply log on to www.fctd.info and click on the link to the discussion to participate.

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