On May 1, 2009, the Federation for Children with Special Needs celebrated their 35th Anniversary with a Spring Gala at the Seaport Hotel Boston. It was an unforgettable evening of celebration.

Angela Peri, our outstanding master of ceremonies, entertained us with her wit and loving stories about her son Rocco. Academy Award winning actor Chris Cooper and actress and screenwriter Marianne Leone Cooper graciously accepted the Federation’s Martha H. Ziegler Founders Award for their dedication to underserved families in need of advocacy support and services for their children. Marianne spoke of their son, Jesse Lanier Cooper, who was an inspirational young man. In 2005, the Coopers established the Jesse Advocacy Fund at the Federation in his memory. This fund has helped to improve the quality of life for countless families across Massachusetts. The Federation is grateful to Chris and Marianne for their continued generosity and support of families of children with special needs.

Trish Orlovsky received this year’s Patricia Blake Advocacy Award in recognition of advocacy she has done on behalf of hundreds of Massachusetts families.

Bill Henderson received the Federation’s President’s Award. Dr. Henderson recently retired as principal at the Patrick O’Hearn School, which has been renamed the William W. Henderson Elementary Inclusion School, in his honor.

The evening included a reception and silent auction, as well as entertainment. The silent auction featured items from the Bruins, Red Sox, and Celtics, gift certificates for hotels and restaurants, museum passes, works of art from local artists, cruises and much more. The smooth jazz of the Tough Love Trio provided a lovely ambiance for the silent auction and reception.

The Haggerty Chimes Ensemble of the Daniel A. Haggerty School, a model inclusion school in Cambridge, played three beautiful songs. This Ensemble, directed by Lynne Carter, is comprised of students of all abilities; their performance left the audience both moved and entertained. The evening concluded with a comedy routine by Patty Ross, a national entertainer.

Mark your calendars now for next year’s Gala on May 21, 2010. We hope to see you there.
Welcome, MassPAC

By Amanda Green, Parent Training and Information

The Federation for Children with Special Needs is delighted to welcome the Massachusetts Association of Special Education Parent Advisory Councils (MassPAC) into our family of activities. MassPAC is the statewide organization providing information, training, and networking opportunities to Massachusetts special education parent advisory councils (PACs) and the professionals who collaborate with them.

Since MassPAC’s inception in 1998, the Federation has encouraged and supported MassPAC’s outstanding work with parents and school districts. In particular, the Federation commends MassPAC founder Suzanne Gervais for her longstanding innovation and leadership in the creation and development of MassPAC as a widely recognized name in special education parent leadership.

MassPAC is a natural fit for the Federation, since both organizations seek to inform and empower families. The Federation’s Parent Training and Information Center (PTI) is well known for providing more than 600 parent workshops statewide per year and responding to hundreds of parent calls and emails about special education topics every week. Over the past six years, the Federation has also developed special expertise in training PAC leaders through the Advancing Parent-Professional Leadership in Education (A.P.P.L.E.) Institutes, which assist local PAC leaders in establishing collaborative relationships with their district administrators and in improving parent involvement within their districts. Staff member Amanda Green, who has 10 years of experience as a PAC Chair, will coordinate MassPAC at the Federation. Amanda also created and taught the Federation’s first online graduate course for school professionals on the topic of parent-professional partnerships.

Going forward, the Federation will ensure that MassPAC continues to assist PAC leaders to maximize their effectiveness in partnering with schools and parents and in sharing resources and ideas with other PACs. We welcome your input. For more information, or to offer comments and suggestions, please contact Amanda Green at agreen@fcsn.org or 617-236-7210, ext. 307.

Newsline Online

The flagship colors of Newsline may be blue and white, but the Federation is going green! In order to cut down on paper waste, and the significant cost of our quarterly publication, the Federation now provides an easy to navigate, on-line version of each edition. If you are reading this as hard copy, we invite you to check out the current issue at www.fcsn.org. Same great news, delivered faster and cheaper. Sign up at http://fcsn.org/publications_resources/newsline/newsline_subscriber.htm.
The economic downturn has made this a challenging year for many non-profit organizations, including the Federation. The fiscal crisis coincided with the start of our current budget year. We had no idea what this would mean. Would there be abrupt funding cuts? Would we have to eliminate activities? How would we continue to provide support and services to families raising children with special needs? There were no concrete answers for these troubling questions.

A week before our Spring Gala, we were worried that expected attendance and financial support would be less than we hoped. Many of our longtime corporate supporters, while iterating their support of the Federation and our mission, regretted to inform us they were not able to sponsor us as in previous years. It appeared that our Gala support might be 30 – 35% below our hoped-for goal.

This unfortunate news spread among our board members and long time supporters, and their response was overwhelming! Due to their efforts, we not only met, but also exceeded our attendance goal. Our more than 350 guests boosted the Silent Auction proceeds 25% over last year, and we were only 7% below our overall fundraising goal! When I reflect on these statistics, I am reminded that it is the families we serve and our very generous supporters who make the Federation the dynamic organization it is. We could not exist without each of you.

The vital work of the Federation is and always has been funded by grants. (Please read the grant announcement for the Parent Training and Information Center on page 4.) Unfortunately, grant opportunities in these times are few. In recent years, we have attracted foundation and corporate support. However, when the economy crashes their support goes away. The truth is that no one remains more committed to our mission than you, the families we serve. We simply cannot do the job without each of you.

Please know, your support, whether $5 or $5,000, ensures that when the phone rings or the email box pops up with a new family request, we will be there to answer it. Clearly that’s what has made the difference this year.

Please accept my deepest thanks,

Rich Robison

Rich Robison

Executive Director
FEDERATION FOR CHILDREN WITH SPECIAL NEEDS

News from Family TIES of Massachusetts

By Mary Castro Summers, Family TIES of Massachusetts

Family TIES of Massachusetts is the statewide information and support network for families of children with special needs. It is a project at the Federation for Children with Special Needs, funded by the Massachusetts Department of Public Health, Division for Perinatal Health, Early Childhood and Special Health Needs. We provide information, referrals, parent-to-parent support and training to families of children with special needs.

The core activity of our program is parent-to-parent support. As a member of P2P USA, Family TIES of Massachusetts is one of 36 statewide programs in the U.S. established for the express purpose of helping parents of children with special needs make meaningful contact with other parents who share similar life experiences.

P2PUSA is a nonprofit organization committed to promoting access, quality, and leadership among parent-to-parent programs. Their guidance, research, and coordination of our programs ensures that families all across the country can participate in satisfying relationships that offer emotional and informational supports and technical assistance from trained support parents, who have had similar joys and challenges in caring for and raising children with special needs.

Recently, Linea Luck Pearson, our Parent-to-Parent Coordinator, and I attended a two-day conference sponsored by P2P USA. We met with representatives of 24 member P2P programs.

Discussions focused on assuring satisfaction among parents who have called us, wanting to have conversations on important aspects of special needs-childrearing, such as: how do I help my son accept his diagnosis, will I ever resolve my worries about my daughter’s future, how can we face another surgery, when is there time for me? We talked about the changing “face” of finding support through social networking sites and listservs, and about the need for more research that would demonstrate the importance and enlightenment that comes from these powerful parent connections.

Caring for children with special healthcare needs, like my son Matthew, is truly a blessing. Without this impetus, how likely would it have been that any of us would have taken the road less traveled? How much would we have missed by not connecting with the generous, unselfish community of families that provides meaningful support through difficult times and shares in the celebrations of every achievement that we, as parents, enjoy? What’s so special about this type of relationship? To me, it has meant the world!

To learn more about the Family TIES of Massachusetts Parent-to-Parent Program, call your Regional Coordinator at 1-800-905-TIES (8347) or visit our Web site at www.massfamilyties.org where you can download the Match Request form and start the parent-to-parent process. Remember, we are always looking for experienced parents who would like to share their wisdom and lessons learned with parents who are seeking a Match. Speak with Linea at 508-792-7880 for more information about upcoming Listening & Learning workshops to become a trained Support Parent.

Five More Years: Federation Awarded PTI Grant

On July 7, 2009, the U.S. Department of Education/Office for Special Education Programs (U.S. DOE/OSEP) named the Federation for Children with Special Needs as the Parent Training and Information Center (PTI) for Massachusetts for the next five years. The Federation was the first ever PTI in the nation. For 35 years, our parent-run organization has trained parents and professionals to support educational and life outcomes for children with special needs/disabilities and their families, while at the same time developing collaborative partnerships with educational professionals at national, state, and local levels. We are delighted at the opportunity to continue to serve families and our professional partners in Massachusetts.

The PTI is funded by the U.S. DOE/OSEP. We offer workshops, parent consultant trainings and individual technical assistance. We provide workshops at various locations throughout the state. Learn more about our workshops topics, find a workshop near where you live, and register at www.fcsn.org/pti/. Can’t get to a workshop? Our presentations are posted on our Web site.

Individualized technical assistance is available in English, Spanish, Portuguese and Cantonese. Call the Federation at 1-800-331-0688, ext. 784 for free assistance about state and federal special education laws, your child’s rights to a free and appropriate public education, and more. We look forward to hearing from you and working with you.
Summer's Over: Preparing for the School Year

By Janet Vohs, Director of Publications, Mass Parent Information & Resource Center (PIRC)

Summer is quickly winding down. Back-to-school preparations are taking center stage. Parents of children with disabilities should review IEPs and accommodations their children need to participate fully in the academic and social life of the school. They also need to update medical information so school personnel can ensure their child’s health and safety.

At the same time, families of children with disabilities need to attend to a host of other issues that affect all kids and families. Here are some suggestions for smoothing the transition from those lazy days of summer to the rigors of a new school year.

Set the stage for learning at home.

• **Reset internal clocks.** Just as we need to reset our clocks when traveling to a new time zone, shifting from a less structured summer schedule to the highly structured school year requires adjustment. Staying up late, sleeping in, and hanging out in pajamas must give way to new bedtime and morning routines. A few weeks before school starts, introduce earlier bedtimes and earlier wake ups. Figure out how long it will take your child to get up, dressed, eat breakfast, and get to school.

• **Make a homework plan.** Work with your child to pick a homework spot and stock it with paper, pencils, calculators, and other supplies. Generally, doing homework earlier in the afternoon is better than waiting until later in the evening. Encourage your child to organize books and homework at night so backpacks, lunches and other necessary items are ready to grab on the way out the door in the morning.

• **Look for the “Parent-Guardian MCAS Report.”** In late September/early October, families whose children took the MCAS the previous spring will receive their child’s performance report. Be sure to note your child’s strengths and areas of concern, as well as any discrepancies with other school reports. Parents and teachers can work together to address those needs.

Set the stage for partnership at school.

When families and educators work together as partners to support children’s learning, children do better and so do the schools. Good communication is the building block of successful partnerships. Here are some tips:

• **Meet your child’s teacher early in the school year.** Let the teacher know you want to help your child learn. Ask the teacher to let you know about any concerns immediately.

• **Attend open houses** to get a sense of the whole school and the classroom your child will be attending.

Mais Cinco Anos: Federação Premiada com PTI Grant

No dia 7 de julho de 2009, o Escritório para Programas de Educação Especial (OSEP), nomeou a Federação para Crianças com Necessidades Especiais, como o Centro de Treinamento e Informação para os Pais (PTI), para Massachusetts, para os próximos cinco anos. Por 35 anos, a Federação – uma organização dirigida-pelos-pais – tem treinado pais e profissionais no apoio educacional e nos futuros resultados de vida para as crianças com necessidades/deficiências especiais e para as suas famílias, enquanto ao mesmo tempo, vem desenvolvendo parcerias em colaboração com profissionais educacionais a nível nacional, estadual e local. Nós estamos encantados com a oportunidade de continuar a servir as famílias e os nossos parceiros profissionais em Massachusetts.


A Assistência Tecnológica Individualizada encontra-se disponível em inglês, espanhol, português e cantonês. Ligue para a Federação no telefone 1-800-331-0688 e peça para falar com um Especialista de Informação no PTI, para obter assistência gratuita sobre as leis federais e estaduais de educação especial, um direito de seu filho/sua filha a uma educação pública gratuita e apropriada, e mais. Aguardamos com interesse ouvir de você e trabalhar com você.
Summer’s Over: Preparing for the School Year (continued from page 5)

• **Join your school’s parent-teacher association or organization (PTA or PTO).** These meetings are a good way to compare notes with other parents and to work together to improve the school.

• **Join the School Council.** Massachusetts law requires that each public school establish a School Council as a way to ensure that families have a meaningful role in shaping school policies and programs. Parents of students with disabilities and of English language learners bring important voices to these Councils. While many parents join the Special Education Parent Advisory Council, participation on the School Council is also an important way to help shape school policies that address all students’ needs.

**Make the most of options available under the No Child Left Behind Act (NCLB).**

Before the first day of school, parents of children in Title I schools should receive a notice if their child’s school has been “identified for improvement” or has an “accountability status.” Both of these terms indicate that a school has not met state improvement goals. This notice must give clear timelines and contact information and will explain the following:

• What the accountability status means. It should identify the subject areas where the school did not meet state goals and how the school plans to improve student achievement.

• Parents of children in Title I schools must also be informed if their child’s school must provide one or both of the NCLB options below. Students with disabilities and students who are English language learners have the same right to these opportunities as all other students.

Many Massachusetts school districts give parents Public School Choice, an opportunity to choose among schools in the district. NCLB expands the school choice opportunity for students in underperforming Title I schools. SES means schools provide free tutoring or other instructional services that take place outside of school time. Low-income students in Title I schools may be eligible for SES if their school has not met improvement goals for three years in a row. **Students with disabilities and students who are English language learners have the same right to these opportunities as all other students. For more information about Public School Choice or SES, please call the Massachusetts PIRC at the number below.**

The special needs and concerns of students with disabilities make it easy to overlook general rights and opportunities that apply to all families. Yet, as students continue to take their rightful place as members of the whole school community, it becomes more important to know about opportunities parents have to participate in shaping their children’s education and the school environment.

For more information about helping your child transition back to school, and parent-school partnerships, call the Mass PIRC at 1-877-471-0980 or visit www.masspirc.org.

**Cinco años más: la Federación recibe subsidio como Centro de Capacitación e Información para Padres**

El 7 de julio de 2009, la Oficina de Programas de Educación Especial (OSEP, por sus siglas en inglés) nombró a la Federación para Niños con Necesidades Especiales (Federation for Children with Special Needs) como Centro de Capacitación e Información para Padres (Parent Training and Information Center, PTI) en Massachusetts durante los próximos cinco años. La Federación, una organización operada por padres, lleva 35 años capacitando a padres y profesionales para promover el éxito educativo y en la vida de los niños con necesidades especiales o discapacidades y de sus familias, y desarrollando simultáneamente relaciones de colaboración con profesionales de la educación a nivel nacional, estatal y local. Estamos muy complacidos por la oportunidad de seguir sirviendo a las familias y a nuestros asociados profesionales en Massachusetts.

El Centro de Capacitación e Información para Padres es un proyecto financiado por el Departamento de Educación de los Estados Unidos. Ofrecemos talleres, sesiones de capacitación para padres consultores y ayuda técnica individual. Los talleres se llevan a cabo por todo el estado. Aprenda más sobre los temas de nuestros talleres, encuentre uno cerca de usted y anótese en www.fcsn.org/pti/. ¿No puede llegar a un taller? Las presentaciones pueden verse por Internet en nuestro sitio web.

La ayuda técnica individualizada está disponible en inglés, español, portugués y cantonés. Llame a la Federación al 1-800-331-0688 y pida hablar con un Especialista en Información del Centro de Capacitación e Información para Padres (PTI) para recibir ayuda gratuita en lo referente a las leyes estatales y federales de educación especial, los derechos de su niño a una educación pública gratuita y apropiada, y otros temas. Por favor, llámenos. Esperamos con interés la oportunidad de trabajar con usted.
MassHealth Launches New Behavioral Health Services for Children and Young Adults

By Jack Simons, PhD, Assistant Director of the Children’s Behavioral Health Initiative

The Children’s Behavioral Health Initiative (CBHI) is an interagency effort of the Commonwealth’s Executive Office of Health and Human Services. CBHI’s mission is to strengthen, expand and integrate Massachusetts state mental health services into a comprehensive community-based system of care, to ensure that families and their children with significant behavioral, emotional and mental health needs receive the services necessary for success in the home, school and community.

CBHI is pleased to announce several new community-based services for children and youth, under age 21, who are enrolled in MassHealth, the state Medicaid program that provides health care benefits for individuals with low income and individuals with disabilities of any income, living in Massachusetts. In these new services, parents and caregivers play a strong and active role in deciding about treatment for their child.

On June 30, 2009, MassHealth began covering three new behavioral health services for children and youth:

**Intensive Care Coordination:**
A model of care coordination using the “Wraparound” team approach for children with Serious Emotional Disturbance or “SED”.

**Family Support & Training:**
A care model that links parents with a “Family Partner,” a person with life experience as the parent or caregiver of a child with behavioral health needs, who has been trained to provide support, and helps parents navigate the system.

**Mobile Crisis Intervention:**
A behavioral health intervention for children who are in crisis. A Mobile Crisis team goes to the location to help stabilize the child or youth; the team can remain involved up to 72 hours.

Beginning this fall, MassHealth will provide coverage for three additional behavioral health services. These services include:

Continues on page 12
35th Anniversary Gala Spectacular

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Comedian Patty Ross closed the evening with a brilliant performance.

Federation staff members Gisel Pimentel (l) and Wanda Morton (r).

Guests mingled and cast their bids during the Reception and Silent Auction.

Faberge Necklace, one of many items donated to the Silent Auction.

SAVE-THE-DATE
Mark your calendars and plan to be in attendance at next year’s Gala on Friday, May 21, 2010!
On Thursday, June 25, 2009, the Federation hosted a first ever House Concert Benefit. It was an evening to remember, thanks to our gracious and generous hosts, Mike Walsh and Maureen Manning, and our fabulous entertainers, singer/pianist Kira Small and her husband, famed bassist Bryan Beller. Kira’s smooth and soulful sound and her vibrant energy wowed the audience and left us all wanting to hear more.

The setting couldn’t have been more perfect, from the beautiful grounds to the break in the rainy weather. Somewhere amid the mingling, the music and the delicious RedBones barbecue, parents of children with special needs made powerful connections with each other. This was also an opportunity for families to learn about the resources, programs and supports offered by the Federation. The evening was fun, and was as much a celebration as it was informative.

Special thanks to the following people for their volunteer work and contributions:

- Ingrid Bassett
- Sarah Commerford
- Susan Cory and Dan Tenney
- Susan Dee
- Martin and Karen Fioretti
- Lisa and Louis Frolio
- Katie Glerum
- Katherine Gross
- Valia Kattar
- Ellen Kolton
- Duncan and Diana MacArthur
- Janet Mausteller
- Paul and Jen Nahass
- Madhvi Patil and Mike Nakagawa
- Joe Petner
- Ricky Sheaves
- Kira Small and Bryan Beller
- Jess Spaude
- Mike Walsh and Maureen Manning
- Donald Wexler and June Mendelson

**This first House Concert was so successful, the Federation decided to plan more! If you’d like to host a concert, please contact Selena at 617-399-8374.**

Rehabilitative vs. Habilitative: When is Therapy Medically Necessary?

*Information from the Massachusetts Family-to-Family Health Information*

If you’ve tried to get your health insurer to pay for physical, occupational or speech and language therapy for your child with a disability, and had the service denied because it was not “rehabilitative” and therefore, not medically necessary, you are not alone. Many health insurers deny these therapies for children with physical or developmental disabilities. They state the child never obtained the skill in one or more of these areas, therefore, the therapies are not rehabilitative. Currently, individuals only receive these therapies when, for example, they were able to walk, hold a pencil, and talk, and then lost that ability due to illness or injury. The therapy is rehabilitative because it helps the person regain a skill they used to have.

However, children with disabilities may need habilitative therapies in order to reach developmental milestones. Many benefit from the help of a physical or occupational therapist, or speech and language pathologist to learn, for example, to walk, talk or hold small objects, like a spoon, so they can feed themselves.

It’s not a matter of rehabilitation – it’s about quality of life, and helping children with disabilities become as independent as possible.

In January 2009, Massachusetts State Senator Karen Spilka of the second Middlesex and Norfolk district presented Senate Bill # 70: An Act to Provide Habilitative Services to the Children of the Commonwealth, to the Massachusetts House and Senate. Additional supporters include Representatives David P. Linsky of 5th Middlesex, Tom Sannicandro of 7th Middlesex, and Benjamin Swan of 11th Hampden. The goal of this bill is to have health insurers cover medically necessary habilitative services for children younger than 19 years old.

Read the text of Senate Bill #70 at [www.mass.gov/legis/bills/senate/186/st00pdf/st00070.pdf](http://www.mass.gov/legis/bills/senate/186/st00pdf/st00070.pdf), and speak to your state legislators about what this legislation, if passed, might mean to your child and family. Find your state legislators and contact information at [www.usa.gov/Contact/Elected.shtml](http://www.usa.gov/Contact/Elected.shtml).

More information about Senate Bill # 70 is available on the Family-to-Family Health Information Center Web site at [www.massfamilyvoices.org](http://www.massfamilyvoices.org).
Joining Voices 2009: A Day of Learning & Networking for Families 
Raising Children & Youth with Special Healthcare Needs

The Massachusetts Family-to-Family Health Information Center at the Federation is pleased to announce this year’s Joining Voices conference. This event is an opportunity for families raising children & youth with special health care needs (CYSHCN) to learn specific skills to advocate effectively for their children, make informed decisions about healthcare services and supports, and ultimately be better partners in decision-making with health care providers, other providers, systems of care, and with policymakers.

This year’s conference is:

**Wednesday, November 4, 2009**
9 am – 3 pm

**Hoagland-Pincus Conference Center**
Shrewsbury, MA

Amy Rosenthal, Project Director at Community Catalyst, will give the keynote presentation about health reform and the implications for individuals with special health needs. In response to feedback from last year’s attendees, breakout sessions are longer. Topics include effective communication with healthcare professionals, supports for children with behavioral health needs, health information technology, sustaining adult relationships when you have children with special health needs, the MassHealth Premium Assistance programs, and the MassHealth Adult Family Care program.

Last year, we provided an opportunity to participate in round-table discussions over lunch. This feature was so popular, we have once again invited experts in various fields to facilitate discussions about respite, oral health, parent-to-parent matches, transition, the Children’s Behavioral Health Initiative Mental Health Services, and tips for getting and staying organized.

The conference is free for family members of individuals with special health needs. The conference brochure and on-line registration will be available the first week in September. Visit the Web site at www.massfamilyvoices.org for updates or call 1-800-331-0688, ext. 210 or e-mail massfv@fcsn.org for more information now. We look forward to seeing you at this year’s Joining Voices conference.
In-Home Behavioral Services:
Behavior therapy provided in the home or community for children and youth with specific problem behaviors. This new service provides special behavior plans for children who might not be helped by other therapeutic approaches. Services are provided by behavior therapists skilled in understanding and treating problem behaviors and by paraprofessionals who help family members implement the child’s or youth’s behavior management plan. Start date is October 1, 2009.

Therapeutic Mentoring Services:
A therapeutic mentor works one-on-one with a child or youth who, because of their behavioral-health needs, requires support and coaching to learn social skills, including better ways to communicate and get along with others. Start date is October 1, 2009.

In-Home Therapy Services:
Intensive therapy is provided for a child and family to treat the child’s or youth’s behavioral-health needs and help the family support him or her in the home. Start date is November 1, 2009.

These new services are available to children and youth under the age of 21 who are enrolled in MassHealth Standard or CommonHealth*. Mobile Crisis Intervention and In-Home Therapy are available to all MassHealth coverage types.

Referral for these services can begin with a behavioral health screening performed by the child’s pediatrician or primary care doctor or nurse, or the MassHealth member (or parent/caretaker) can apply for services directly from a provider.

To learn more about MassHealth Standard or CommonHealth eligibility, call MassHealth Customer Service at 1-800-841-2900 (TTY: 1-800-497-4648 for people with partial or total hearing loss) or call the Massachusetts Family-to-Family Health Information Center at the Federation at 1-800-331-0688, ext. 210 or e-mail massfv@fcsn.org.

[Editor’s note: *CommonHealth provides healthcare benefits similar to MassHealth Standard to children, youth and adults with disabilities/special health needs who are not eligible for MassHealth Standard due to income. There is a sliding scale premium for CommonHealth.]

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Dr. Nadine Gaab is an Assistant Professor of Pediatrics at Children’s Hospital Boston and Harvard Medical School. She conducts her research at the Labs of Cognitive Neuroscience at Children’s Hospital. In the interview below, she graciously shares her expertise about dyslexia, a learning disability that affects more than 5% of elementary school students.

**What is dyslexia?**

Dyslexia is not defined by what it is, rather by what it is not. If a child’s reading difficulties are not caused by eye and ear problems, the child has average to above average IQ, and is still struggling to read, the likely diagnosis is developmental dyslexia.

**What are the signs of dyslexia?**

The early signs are problems with manipulating sounds, difficulty repeating multi-syllable words, problems with rhyming, and an inability to pronounce made-up names. Often a child will score normal or above average IQ on neuropsychological tests, yet reading difficulties persist.

**How early can dyslexia be diagnosed?**

There may be signs as early as preschool, or even earlier, but most children are diagnosed in second grade. Dyslexia cannot be diagnosed in pre-readers, but children can be identified as children at risk.

**What tests are used to diagnose dyslexia?**

A good neuropsychological evaluation. A good psychologist can also help with the diagnosis.

**Do children with dyslexia also have other disabilities?**

It is estimated that approximately 40% of all persons with dyslexia will also have ADD or ADHD.

**Do children with dyslexia have difficulty in other subject areas?**

Reading is integral to every subject, so children with dyslexia often have trouble in other areas. For instance, a student may be gifted in math, yet be unable to complete word problems. Science and social studies also require larger amounts of reading. Additionally, social difficulties can arise from lack of confidence and self-esteem directly related to the disability.

**What is the recommended remediation strategy for dyslexia?**

Every child is unique; remediation must be individualized for each child. The type of remediation will depend on the outcome of the neuropsychological evaluation, and how the child responds to a particular intervention. 

Continues next page
**Do you recommend specific reading programs?**

My recommendations depend on the child’s neuropsychological profile. There are a lot of good programs out there, and while one might work best for one child, it may not for another. There is also a misconception that the most expensive is the best. I do not believe this to be the case. Again, the strategies used will depend on the individual child.

**If a child with dyslexia receives optimal services/ remediation throughout the elementary school years, would you expect that they could go on to high school and college without further supports?**

It depends on the child. Some will succeed without supports, some will not. I see support as a good thing, not a bad thing. It’s okay if a student needs to continue with supports. The parents have put up a long fight for supports and services; use them.

**Is there an ideal school situation for students with dyslexia?**

If a school that specializes in dyslexia is not available, then work with the school to put supports in place as early as possible. Optimally, these supports should consist of strong social and psychological supports and teachers with experience with learning disabilities.

**Why is a neuropsychological evaluation important?**

The tests are comprehensive and generally include: language assessment, rapid naming, writing, phonological language, fluency and comprehension. These evaluations offer insight and can provide the blueprint for doctors and therapists to develop a plan that will fit your child.

**What resources may help parents support their student with dyslexia at home?**

Proust and the Squid by Maryanne Wolf is a great book; Useful Web sites include LD Online at www.ldonline.org and the National Center for Learning Disabilities at www.ncld.org.

**Do you have any words of wisdom for families who are struggling to support their child with dyslexia?**

Get the neuropsychological test! And, even more important, create a comfortable, loving environment where your child can be happy. Let your child know he can still be a strong person! Teach her to be proud of who she is; it can prepare her for dealing with other challenges in life!

Read about Dr. Gaab’s research and contact her through the Web site at www.childrenshospital.org/research/gaablab.
**Book Reviews**  
Reviewed by Beth Dworetzky, Massachusetts Family-to-Family Health Information Center

**Children with Spina Bifida: A Parents’ Guide**

Edited by Marlene Lutkenhoff, R.N., M.S.N.  

As in the first edition, professionals and parents contributed material to this second edition, with the goal of helping other parents navigate the medical, educational, and legal issues of spina bifida or meningocoele. With a foreword by Drake Crittenden Ash, a parent who shares how important it was to her family to connect with others whose children have the same diagnosis, this new edition includes updated research and medical developments. Ms. Crittenden notes that even for the most organized families, it’s easy to become overwhelmed by the number of medical professionals involved in a child’s care. She encourages parents and other caregivers to understand the diagnosis, as it will help them advocate on the child’s behalf.

The chapters provide information about preparing a child for a hospitalization, the surgeries, urologic and bowel concerns, the importance of diet and nutrition, orthopedics and physical therapies, as well as assistive devices a child may need to help build strength.

Each chapter ends with parent statements. Parents also contributed chapters about coping, finding support for themselves and their other children, and maintaining good communication with medical and educational teams. In addition, they share strategies for helping their child be emotionally healthy and self-confident.

There is an in-depth discussion about the federal laws that protect the educational and civil rights of children with disabilities. There is also information about planning for the future, and a chapter written by a young adult with spina bifida.

**Teaching Motor Skills to Children with Cerebral Palsy and Similar Movement Disorders: A Guide for Parents and Professionals**

By Sieglind Martin, M.S., P.T.  

Who hasn’t heard the phrase, “You have to learn to crawl before you walk?” This maxim helps everyone make step-by-step progress in learning new activities. For children with cerebral palsy and other movement disorders, it is absolutely necessary. And this book is a must read for parents who want to understand the sequence of gross motor development, what physical therapists do and why they do it.

There is an explanation of the different types of cerebral palsy, and a discussion of the medical conditions and developmental delays, which may co-occur. This book doubles as an easy-to-read guide for parents who want to participate in their child’s gross motor progress. There are photos that illustrate positions, tips to make activities fun, and ideas that have worked for other families. There’s also a comprehensive list of organizations that provide recreational opportunities for children with physical disabilities.

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