

Issue 02
Fall 2011

**For Families of
Children and
Youth with
Special Health
Care Needs**

Innovative Approaches Newsletter

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What Innovative Approaches is Working on...

- ◇ Additional parent workshops about resources available in the community and how to access them.
- ◇ The development of a website so that resource and transition information is readily available and accessible to parents and professionals.
- ◇ In conjunction with community partners, the development of activities for youth with special health care needs related to self-advocacy, support and/or recreation.
- ◇ The development of a parent/educator training series, with topics such as transition, specific diagnoses, behavioral issues, etc.
- ◇ Follow-up focus groups for parents next spring to address progress towards the overall IA goals below:
 - **Improve access to services.
 - **Improve coordination of care within the Medical Home.
 - **Increase family involvement and participation regarding services.
 - **Improve transition services (NICU to home, early intervention to preschool, preschool to kindergarten, high school to adulthood, and pediatric to adult medical care).
 - **Increase screenings for special needs and referrals for intervention at an earlier age.



The Right Call Every Time. Your Medical Home.

What is a Medical Home?

A medical home is a doctor's office, clinic or health department where the staff knows you, your child and your child's health history. It is the one place you take your child for their health care:

- Checkups
- Sick visits
- Accidents
- Special health care needs
- Shots

*Choosing a quality medical home is **IMPORTANT!** You want to take your child to someone you trust, someone who respects you as a full partner in your child's care.*

Some questions to ask:

1. Do you accept my health insurance?
2. What are your regular office hours? What if my child needs care at night, on weekends, or holidays? Do you have an advice line I can call?
3. If I have concerns, may I schedule a longer appointment?
4. Will you regularly check my child's developmental progress?
5. Will you tell me about and help me contact health and community resources?
6. How familiar are you with my child's special health care needs?
7. I like talking with other families who have had similar experiences. How do you use families as resources to your practice?

Medical Home versus Emergency Room

Contact your Medical Home

- When your child looks or acts sick with common illnesses such as fever, flu, sore throats, or coughs.
- For problems that need care now such as infections, asthma, vomiting, injuries, sprains, or cuts that need stitches.
- And as always for checkups, shots, and help with long-term illnesses or conditions.



Go to the Emergency Room

When a child could die or risk their health without help NOW!!

- When bleeding won't stop.
- When breathing is very hard.
- After a serious accident.
- After a convulsion
- If appropriate, after calling the Carolinas Poison Center at 1-800-222-1222.

If your child is going through a mental health crisis, call PBH Access. Counselors are available to speak with you 24 hours a day, 7 days a week, 365 days a year.
1-800-939-5911

DID YOU KNOW ?

You can register your address with emergency responders to help them be better prepared to assist you in an emergency. You can call to register your child's disability with 911. When a registered address has an emergency call, that information will automatically pop-up in the responder's information. Whenever possible, callers should also identify their disability to the dispatcher during an emergency call.

Cabarrus County Residents should call: 704-920-3000

If you live in the City Limits of Concord, you should also call: 704-920-5580
If you live in the City Limits of Kannapolis, you should also call: 704-920-4017

Wrightslaw

Parents, educators, advocates, and attorneys go to **Wrightslaw** for accurate, reliable information about special education law, education law, and advocacy for children with disabilities.

GO TO WWW.WRIGHTSLAW.COM TO LEARN MORE AND GET INFORMATION ON A VARIETY OF TOPICS SUCH AS:

- *IEPs*
- *Advocacy*
- *Laws Relating To Special Education*
 - *Specific Diagnoses*
 - *Transitions*
 - *And Much More!*

*"Go as far as
you can see,*

*when you get
there, you'll
be able to see
further."*

*~Thomas
Carlyle*

★ Transitions Are Important ★

There are many transitions in the life of a child with special needs and their family. The following are some important transitions to think about:

⇒ From NICU to home

(Transition Packet given upon discharge from CMC Northeast Hospital.)

⇒ Entering Preschool

(Transition Packet given at the Transition Planning Conference when child is 2 1/2 enrolled in the Infant Toddler Program at the CDSA.)

⇒ Entering Kindergarten

(Transition Packet given at the child's last IEP meeting before entering Kindergarten or at the child's first IEP meeting if they were not enrolled in the Preschool Program.)

⇒ Entering Middle School

(Transition Packet given at the child's last IEP meeting before ending 5th grade.)

⇒ Entering High School

(This Transition Packet is being developed.)

⇒ Leaving High School and entering Adulthood

(Transition Packet given at the IEP meeting when the transition plan is added at age 14.)

⇒ From Pediatric to Adult Medical Care

(This information is included in the "High School to Adulthood" Transition Packet. There is a health care transition guide for youth and parents included.)

Through our Innovative Approaches project, we have been looking closely at important transitions. Transition Packets are being developed for each transition. To request one of these packets, contact Debbie Biggerstaff at 704-933-9344 or Amber Pierce at 704-262-1063.



Headed Back To School

By Linda Jorgensen

Special Needs Resource Project www.snrproject.com



In addition to the usual lists of classroom supplies, Special Education programs will have other requirements depending on the specific needs of your child. The following are just a few of the things that may need to be accomplished before heading back to school.

1. Communication Notebook

Develop a communication system that works well for you, the teaching staff, and your child. This might be a simple notebook with dated entries by the parent and teacher carried back and forth in the child's backpack or a 3-ring binder complete with medication forms, therapy notes, notes from home, etc. Find a method that works best for you.

2. Personal Supplies

These are items your child will need to get through the school day. Many of these items are specific only to your child and will need to be provided by you, the parent. These items should be stored in an appropriate container labeled with your child's name.

- * Classroom supplies as requested by your child's teacher
- * Personal hygiene products, wipes
- * Disposable medical equipment (gloves, syringes, extra oxygen, tubing, cannulas, etc.)
- * Specialized diet/food items
- * Required Medications (New, not expired)
- * A Seasonal change of clothing

3. Medical Preparation

- Schedule an Annual physical exam by your family pediatrician. Update shots, medications, and evaluate your child's current medical needs.
- Send medical equipment such as wheelchairs, nebulizers, etc. for annual maintenance BEFORE school starts if at all possible.
- Check other medical equipment such as standers, walkers, foot/ankle braces, etc. for fit and/or repair.
- Contact your school nurse when school starts regarding any specialized medical treatment or medications your child may need.

4. Transportation Requirements

For children in wheelchairs or who need modified seating, contact your local transportation office to ensure your child's personal equipment can be safely transported on a bus. Not all buses use the same system. You may want to contact your school before school officially starts to discuss transportation and transporting of equipment.

5. IEP Preparation

Most IEPs (Individual Education Plans) are updated after 4-6 weeks of school. This allows teaching staff time to observe and evaluate your child's current learning levels and status for changes that may have occurred over the summer. Begin planning for this meeting early and you'll find the process generally goes much smoother for all involved.

- Update your current IEP Notebook *(If you do not have one, make sure you read the next article on how to prepare an IEP Notebook.)
- Review your copy of last year's IEP, any evaluations completed over the summer, Handbook on Parent's Rights, etc.
- Consider goals that may need changing. Make notes of any changes that need you feel need to be made.
- Begin gathering documentation from care providers/therapists and other sources that may be needed to complete an IEP for the upcoming year.





Creating An IEP Notebook



Managing the needs of your children with special needs is a full time job. Add to that the mountain of paperwork that comes from doctors, evaluations, schoolwork, and IEPs, and you can quickly find yourself overwhelmed. As the parent, you are the most knowledgeable person about your child, and creating your own file can be instrumental in advocating for your child. The notebook is a very powerful tool in reviewing your child's history, recording what other professionals have said about your child, and keeping an accurate record of what the school has committed to and what they have actually done. Written evidence will speak for itself, removing you from the middle.

Materials to get you started

The first thing you'll need is a 3-ring binder, divider tabs, and a 3 hole puncher. Next you'll need to gather up all of your child's paperwork.

Here are a few suggestions:

- IEP or 504 Plan
- Medical and or Psychological evaluations and testing
- Diagnostic reports
- Academic evaluations
- Recent report cards & progress reports
- Written correspondence with teachers
- Contact info for doctors and therapists
- Samples of your child's work, showing strengths and weaknesses, including classwork, homework, and tests
- Standardized test results

A Few Tips on Documentation

Always keep the original document in your notebook. If you want to keep extra copies, create a box or filing system - this helps keep your notebook from filling up too quickly.

Dates are important! Every piece of paper should have the date you received it - mark the date yourself if needed.

It is important to note the following dates:

- Meetings with anyone at the school,
- When you send or receive any key documents,
- When you tell the school specific information such as, "My child is spending hours on what should be a 15 minute assignment,"
- Anytime your child is disciplined or suspended.

If it is in your notebook, it needs to have a date on it. This is very important when you need to establish a timeline.

Putting it all Together

There are two schools of thought in organizing all of this information:

- One method is to create categories such as Evaluations, Work Samples, Correspondence, IEP, etc. You can buy a kit with a notebook, dividers, and tips to help you put it all together at www.organized4kids.com.
- The other method, which is recommended by www.WrightsLaw.com, is chronological. You create a master list of documents at the front of the notebook to easily locate the contents. When you add a document to

the notebook, you simply add it to the master list, which functions as your table of contents. One benefit of the chronological method is that as you acquire papers, you simply add them to the notebook and the master list, without worrying about categorizing.

There is no right or wrong method to organizing the information. What matters is that it makes sense to you and that you are able to access what you need quickly.

You may want to keep your IEP binder in a tote bag where you also include supplies like pencils, pens, highlighters, and an IEP guide book. When you arrive at your next IEP meeting, you will know you have all of the tools you need to advocate for your child, as well as a renewed sense of confidence that you are organized, knowledgeable, and prepared.

This information was derived from an article written by Amy Perry published in the newsletter of the Autism Society of North Carolina.

Upcoming Events



Sibshops

For boys and girls 3rd – 9th grades that have a brother or sister with a disability. First meeting for this school year is Saturday, September 24th, from 10:00 until 2:00 at Epworth United Methodist. Please call Carol Cranford at 704-788-1616 for registration information.

Parent Network Support Group

For families of children with multiple disabilities, birth to middle school. Meets the 2nd Thursday of the month from 6:30-8:00 during the school year at the Mary Frances Wall Center. Child care is available upon request. Please call Carol Cranford at 704-788-1616 for details.

Bayada Nurses presents the Special Needs Story Time

*September 24th at 11:00 a.m.
For location and more information, contact Margarete Moose at 704-797-2993.*

ECAC IEP Institute

*Saturday, September 10, 2011 from 8:30–2:00 p.m.
Orange United Methodist Church, Chapel Hill, NC
To register, contact Margarete Campbell at 1-800-962-6817 ext. 317
Registration deadline is September 7, 2011*

23rd Annual Leo M. Croghan Conference on Early Intervention

*Monday, December 5, 2011 at Sheraton Imperial in Durham, NC
For more information and registration, go to <http://CroghanConference.org/>*

**For more information on this project or to get involved,
please contact:**

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Innovative Approaches

Innovative Approaches™ is a grant funded project working to improve the system of care for children and youth with special health care needs up to age 21, through the collaborative efforts of parents, our community providers, and organizations.