

Individualized Education Programs (IEPs): Making Sure Your Child's Needs Are Met

Sha Clark, LISW-S, CP Clinical Social Work Coordinator

Sending your child to school for the first time can be very difficult as a parent. Parents often worry about their child making friends and how they'll do in the new structured environment. If your child has a disability, you probably have these worries plus many more. You also quickly realize that you have to learn a whole new language around your child's special education services.

The Individuals with Disabilities Education Act (IDEA) is a federal law that sets guidelines and rules for the education of children with disabilities. This law requires school districts to identify and evaluate children who may be in need of special education. For those children who qualify for special education services, the school district is required to provide a "Free and Appropriate Education (FAPE)" in the "Least Restrictive Environment (LRE)." These two terms are very important in helping determine the most appropriate education services. **Special education is a service not a placement.** In other words, just because a child has some identified needs does not mean that the child cannot learn in the regular education classroom (considered the least restrictive environment).

Once a child has been found eligible for special education services, an Individualized Education Plan (IEP) is then developed. This plan lays out the educational goals for your child and how the school is going to help the child meet these goals. The word "Individual" in IEP is very important because it needs to be developed with your child's specific needs in mind. There are many school staff who are a part of the IEP team, but the most important person on the team is you, the parent. An IEP cannot be implemented without your input. Do not sign the IEP if you do not agree with everything in it. Do not be afraid to discuss areas you do not agree with and provide other suggestions. If you and the school staff cannot come to an agreement, then you will need to discuss the grievance and appeal process.

The more familiar you become with how your school district educates children with disabilities and the laws that govern this, the more comfortable and confident you will become in advocating for your child's needs. Remember, you know your child best and are the most important person on your child's education team.

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A Parent's View of IEPs

Allison Kingsley, Family Advisory Council Past Chair

In the fall of 2007 we received our son's diagnosis of Spinal Muscular Atrophy. We were shocked, stunned and overwhelmed by his terminal diagnosis. Over time we accepted his disease and we were determined to give him the fullest life possible without any regrets.

We became his advocates for his care and well-being. We learned the medical and insurance world fast while also partnering with his physicians, nurses and therapists. Collaboration was essential and we all see the potential in him and not just his diagnosis.

When I registered him for kindergarten, several tests needed to be performed. We had no fears. Our hopes for him are the same as for our other two children. We want him to receive a good education and go to college to pursue his dreams.

We knew he would continue to be on an Individualized Education Program (IEP) due to his medical condition. It would just become a more elaborate IEP from his itinerate preschool days. Our relationship with the school district would need to build.

Unfortunately, our first kindergarten IEP meeting was eye opening. Intimidating is a good word to describe it. The school seemed to see his disease and not his potential. I felt like it was us vs. the school. The team atmosphere we were used to was missing. Evaluations and goals were discussed but they all seemed negative. I felt emotional and not empowered. I felt small and not strong. I felt belittled and not valued. Most importantly, I felt like I had failed our son.

I learned we needed to know more than medical terminology. We needed to know the laws regarding our son's education. A social worker at Nationwide Children's Hospital recommended a Wright's Law seminar. It turned out to be the best drive I have ever made! I left the seminar with a platform to stand on. I am still learning, but our son's last IEP meeting

for second grade went well and was not stressful. I felt stronger, a little more empowered and even more valued. Our son's educational team is slowly taking form. The trust is building.

I have learned to ask a lot of questions (who, what, where, when, why, how and explain), never go to an IEP meeting alone and never get emotional. If used correctly, questions can make the school's staff feel like they are in control. Have them read and explain the statement in question and then you can reference a law and have them explain the law as it relates to your original question. They will see the error on their own and correct it. It is also essential to bring someone with you. Bring a therapist, spouse or social worker. Someone that can help you advocate for your child and preferably someone that knows the educational laws. Last but not least, never get emotional. If you are about to cry, cough. It immediately stops the tears.

As parents, we know our child's potential and only seek the best education for them in order to meet their unique needs. Yes, it is another challenging road to master, but with a little training, we can all build a trusting relationship with our school districts.

Tips for Avoiding the Seasonal Flu

Seasonal influenza (the flu) is a respiratory illness caused by a virus. The flu can cause moderate to severe illness, and at times even lead to hospitalization. The flu is contagious, meaning it spreads from person to person by coughing, sneezing or talking. Children, especially those with chronic medical problems, are particularly at risk for complications from the flu.

Nationwide Children's Hospital recommends everyone 6 months and older receive a flu vaccine every year to reduce the chance of becoming sick from the flu. Getting a flu

vaccine is the best way to protect your children, yourself and everyone around you.

Here are some other steps you can take to help keep yourself and your family from getting sick.

- Good hand washing is key to preventing the spread of germs.
 - ✓ Wash for at least 15 seconds with soap and water.
 - ✓ Turn the faucet off with a paper towel.
 - ✓ Alcohol-based hand rub is also effective.
 - ✓ Wash your hands often throughout the day.
 - ✓ Always wash your hands after using the bathroom, after you cough or sneeze, and before eating.
- Avoid touching your eyes, nose or mouth. Germs spread that way.
- Cover your nose and mouth with a tissue when you cough or sneeze. Throw the tissue in the trash after you use it.
- Stay home if you get sick. The Centers for Disease Control recommends that you stay home from work or school and limit contact with others to keep from infecting them.
- Give your immune system a boost by:
 - ✓ Getting plenty of sleep
 - ✓ Getting plenty of exercise
 - ✓ Eating healthy foods
 - ✓ Drinking plenty of fluids

Learn more about the flu and watch videos related to the information above by visiting www.NationwideChildrens.org/flu.

Autism Expansion Planned for 2013

Amy Hess, Autism Treatment Network Site Coordinator

The Child Development Center (CDC) in Westerville is about to expand!

The CDC completes approximately 3,500 developmental screening assessments annually and provides a comprehensive, coordinated, multi-disciplinary care model for children with Autism Spectrum Disorder and other neurodevelopmental disabilities and their families. To accommodate such growth, the CDC includes a robust staff of more than 60 professionals including Psychology, Psychiatry, Developmental and Behavior Pediatrics, Speech and Care Coordination who have experience training and expertise in autism.

The CDC is also part of the Autism Speaks Autism Treatment Network (ATN) providing coordinated care to families, clinical research and autism outreach to the local and state community. This network of 17 sites includes hospitals, universities, clinicians and families from across the United States and Canada. The collaborative nature of the network allows the CDC access to leading experts in autism and site collaboration in research and resource design. The ATN Model of Care promotes the inclusion of children and parents during the diagnostic and treatment process to best suit the needs of the child and family.

The expansion was initiated with a new waiting room (picture on next page) which enables more seating for families. This also adds an additional 7,500 square feet which include clinical offices, conference rooms, exam rooms and meeting space. Due to the volume of children seen at the CDC, many families have been scheduled at other offsite locations (Dublin and Westerville *Close to Home*SM) to accommodate the need. The expansion will allow the CDC to once again be united under one roof.

Thank you to all who have helped to make this expansion possible! Construction begins in August and will be completed in November 2013. We hope you will stop by and visit once construction is complete to see our new space. It is an exciting time at the CDC!

For more information about the CDC/ATN, please visit our webpage www.nationwidechildrens.org/autism-treatment-network.



Two Years Strong for the Nationwide Children's Hospital Columbus Marathon & 1/2 Marathon

Nationwide Children's Hospital is honored to be the title beneficiary for the Nationwide Children's Hospital Columbus Marathon & 1/2 Marathon for the second year of a three-year partnership. This race is about much more than running or walking an incredible distance. It's about 24 Miracle Mile Patient Champions who have shared their stories to inspire. There will be one Angel Mile to honor, remember and celebrate those who have already finished their race. And one Encore Mile, for the patients who

lined the inaugural Nationwide Children's Hospital Columbus Marathon & 1/2 Marathon in 2012.

26.2 miles, each with a different story, a new inspiration and another reason to keep running. These miraculous kids will be on each mile of the marathon on October 20th, supporting race participants every step of the way. Become a Children's Champion and fundraise at www.NationwideChildrens.org/WhatMovesYou Learn more about our Miracle Mile Patient Champions at www.NationwideChildrens.org/Marathon-Miracle-Mile-Patients. Questions? Reach out to Haley Flowers in the Foundation at Nationwide Children's at (614) 355-0855.

Partners in Care, Partners in Hope Award

Do you know an employee at Nationwide Children's Hospital that exemplifies family centered care practices? Have you considered nominating them for this year's award? Nomination forms are available in the Family Resource Center, may be downloaded in a printable form for mailing, or can be completed online.

This year marks the 8th year for the Partners in Care, Partners in Hope award. Each year an employee is shocked, surprised and speechless when their name is announced at the annual employee recognition banquet. It is also the only award of the evening that comes from a family.

Selection will be by the Partners in Care, Partners in Hope Award Committee composed of patients, caregivers, family members and select staff members. Nominees are judged by the following criteria:

Dignity and Respect – Health care practitioners listen to and honor patient and family perspectives and choices. Patient and family knowledge, values, beliefs and cultural

backgrounds are incorporated into the planning and delivery of care.

Information Sharing – Health care practitioners communicate and share complete and unbiased information with patients and families in ways that are affirming and useful. Patients and families receive timely, complete and accurate information in order to effectively participate in care and decision-making.

Participation – Patients and families are encouraged and supported in participating in care and decision-making at the level they choose.

Collaboration – Patients and families are also included on an institution-wide basis. Health care leaders collaborate with patients and families in policy and program development, implementation and evaluation; in health care facility design; and in professional education as well as in the delivery of care.

Past recipients of the award include:

Chris Bunge, RN - 2006

Dr. Jane Balint - 2007

Dr. Richard Shell - 2008

Dr. Alfred Gest - 2009

Dr. Richard Kang - 2010

Christy Plank, RN - 2011

Beth Mohler, RN - 2012

The deadline for 2013 submissions is Friday, December 6.

Patient and Family Centered Care EXPO- New Location

Join us for the 2013 Patient and Family Centered Care Expo on August 28. There will be poster presentations from 11 a.m. to 1 p.m. in the Commons (outside the Cafeteria) showcasing patient and family centered care initiatives within Nationwide Children's Hospital.

The presentations will help recognize, celebrate, educate and inspire further advances in patient and family centered care. Please contact the Family Resource Center at (614) 722-2252 with questions.



Where Are They Now?

Jill Rako, Former Family Advisory Council Member

On July 8, 1997, we received the unthinkable news: our unborn child has spina bifida, severe hydrocephalus and a litany of other medical challenges that are quite alarming. The situation was grave to say the least. In fact, one expert physician told us our son would not have any purposeful, cognitive function. Fast forward 16 colorful years and 21 surgeries later, Daniel Rako continues to beat insurmountable odds.

Thanks in large part to the care we received from the hospital teams, Daniel isn't just "functioning" – he is *flourishing*. An avid sports fan, Daniel is a sophomore at New Albany High School. In addition to rooting for his favorite teams (Buckeyes, Reds, Bengals and – of course – the Eagles), he is the Team Manager for the New Albany Eagles varsity football team. He was part of the team's journey to the state "Final Four" last fall. He also enjoys being part of the high school's drama department. His "big debut" was in the school's fall production of "Legally Blonde" as a chorus member.

Make no mistake: Daniel's medical issues can interfere with his quality of life more often than we'd like. He has a list of health issues that runs a mile long identifying everything that is "wrong" with him, but that's never his focus. He doesn't let his health challenges and list of maladies define him. Instead, he serves as a living example of both courage and perseverance.

A perfect example is Daniel's participation in Special Olympics. Once he was cleared from his last spine surgery, two of his teachers encouraged him to join the basketball team. That led to his participation in the New Albany chapter's track and field events. After a lot of hard work and excellent coaching, Daniel qualified and competed in the 2013 Ohio Special Olympics Summer Games where he earned a silver medal in the 25-meter wheelchair race and a bronze medal in his division of the boys' softball throw.

The care Daniel has received for the past 16 years at Nationwide Children's Hospital has helped to set the foundation for his future. The spectacular family-centered care has been a blessing to ALL of our family members, not just Daniel. The good folks at Nationwide Children's were practicing family-centered care principles before it became the industry norm, simply because it was the right thing to do.

Suffice it to say, Daniel enjoys an extreme love for life, family and friends that is beyond measure.



Who Are We?

Suzi and her husband, Tim, are the proud parents of two beautiful daughters, Caitlin and Isabella. Their youngest daughter is how they became partners with Nationwide Children's Hospital. She was inpatient and in the need of a foster family. Little did they know as they met this darling little bundle of joy for the first time that she would steal their hearts and become a member of their family.

Isabella still sees physicians and therapist at Nationwide Children's, but she has come a long way since the first time they met. She no longer has a trach and g-tube, but still has therapies and on-going medical appointments. She continues to make amazing progress.

Through all their families' positive experiences with the hospital, Suzi felt the need to give back. She has now been a member of the Family Advisory Council for four years and is a new presenter for the Family As Faculty program. She also actively participates in the Hospital Experience Committee and wants to help promote family centered care practices throughout all aspect of the hospital.

