# Parent Time

**A Newsletter for MoSPIN Parents**

**Volume 16, Issue 1** **February 2011**

## Editors Corner:

Hello!
Welcome to all the new families that have joined MoSPIN and hello to the ones who have been with us for a while now. My name is Stacy Meyer. I am a wife and mother of four beautiful children. I have two teenage daughters, Katrina (17) and Jessica (14), and two little boys, Lucius (4) and Gabriel (2 months). We have been with MoSPIN for four years now. They have been key in helping us with learning materials for both our family and Lucius as an individual.

Lucius is our child with visual impairment. He is four now and goes to preschool. He has Hypopituitarism and with that came Optic Nerve Hypoplasia, a fancy title for small optic nerve with a whole range of outcomes from perfect vision to total blindness. He was diagnosed at birth. Lucius has light perception (he can see light). He can see some colors; red, black, white, mostly dark bold colors. He does not see any detail that we are aware of yet, but he manages to get around and pilfer just fine anyway. Everyone in the house works to teach Lucius about his home and the world around him.

He is curious and mischievous like most boys his age. Since he has the visual impairment he plays differently than most kids. What other kids learn in minutes may take him months, but he loves to learn. He rides a bus to and from school (one of his favorite things to do). He loves to play with the other kids. They all seem very fond of him as well. He has an excellent paraprofessional who is with him during the day at school. She is key in helping him get around at school and interact with the other kids. We have a great team at the school to work with. We recently revised Lucius' IEP to have an extended day at school. He has several therapies per week to help him communicate and travel on his own. He has Speech and Language therapy to help him communicate about his world. O & M (Orientation and Mobility) therapy helps him learn to navigate on his own with a cane. He is doing very well at this. OT (Occupational Therapy) helps him learn to dress, feed, and feel the things around him and identify them. This one seems to be the hardest for him. OT also helps with learning pre-braille concepts so that he will be able to eventually read and write Braille*. We are lucky and thankful that we are in the school district we are in. They work very hard to make sure Lucius has every opportunity and resource needed to learn and thrive like the rest of the students in his school.

We are still potty training. It is much harder with a child who doesn't see than with one who does. All the things we take for granted about doing everyday things become very evident. He can do almost all of it on his own, but he is still having trouble getting to the bathroom by himself. He knows when he has to go, but like most kids his age, if he is playing or otherwise occupied, he will have an accident. I am hoping this will change soon as pull-ups are expensive!

Recently, Lucius was introduced to his new baby brother. When I found out I was pregnant, I started telling Lucius about the baby (anything I could think of). I would tell him how the baby was in my tummy, like he used to be. We played with baby dolls to try to get the concept across to him. We took him to friends' houses that had babies or much smaller children to try to give him another input on what was coming. As I got further along and could feel the baby move, I would put Lucius' hand on my tummy to feel the baby move. He wasn't very thrilled at first, but as time got closer he started to say "baby Gabriel" and pat my tummy. When Gabriel was born, I was in the hospital longer than expected.

When I came home, Lucius seemed mad at me. He didn't want anything to do with me for the first night. I let him have his space, but let him know I was there, just like I had always been. He has since warmed up to Gabriel. He likes to feel his feet and hands. We rub the baby's head and pat his back together. He now says, "my brother'. I think for the most part he understands that aspect. He does still have his moments of jealousy but we try to work around that.

We are so very proud of Lucius and the progress he has and is making everyday. We look forward to the many challenges he will overcome as he gets older.

This issue of Parent Time has a focus on transition. Our family just went through a transition with the birth of our second son. Earlier we went through a transition when Lucius went from First Steps to Preschool at age three. You can read more of that process in my article on page 3.
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*A teacher of the visually impaired (TVI) will be the professional responsible for providing Braille instruction.

## It's IEP Meeting Time

Usually the IEP (Individual Education Program) process goes well for families but sometimes the IEP meetings can be a challenge. If you've ever wished you had just the right response during IEP discussions, read on. The National Center on Severe and Sensory Disabilities has developed a very helpful "Pop-Up IEP" and here is how they describe it:

With the help of parent organizations across the country, the NCSSD has developed a series of disability specific help guides for parents, teachers, and administrators. Each one contains a series of commonly heard objections (for example, "We've never had a child like yours in our school" or "We can't get a certified teacher of the visually impaired…to come out here") followed by some possible responses and the law that justifies those responses. Go to

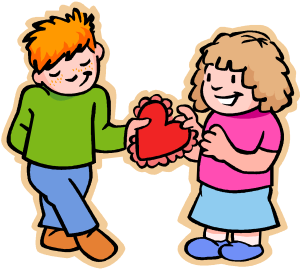
http://www.unco.edu/ncssd/resources/popup.shtml and click on the Blindness and Visual Impairment version or the Significant Support Need version for more information.

# Hold the Date!

## Facilitating Friendships and Positive Self-Esteem

*Social relationships and friendships don't always occur naturally for children with sensory impairments. In an upcoming workshop, Maurice Belote from the California Deaf-Blind Services will provide information on ways to facilitate school and community participation and build positive self esteem. Some strategies are applicable to all children while others will be specific to helping children with vision and hearing issues build and maintain rich, ongoing social networks. Maurice believes that moving from* ***the ways things are now to the way you would like them to be*** *sometimes takes just a few small steps. His goal is to help children have the kind of life that many of us would choose for ourselves.*

*Are you interested in hearing more?? Then mark* ***Saturday, April 16*** *on your calendar so you can attend a special presentation in St. Louis for Missouri families. More information will be sent to you in a special mailing, but MoSPIN families will want to "hold the date". We are even working on how we can provide financial support for travel for families outside the St. Louis area for this Saturday workshop.*



## Transition Times for MoSPIN Families

Transition usually refers to a move from one phase of life to another. These transitions can be exciting, sometimes challenging, but certainly inevitable. Two major transitions that MoSPIN families face are at age 3 when your child moves out of First Steps usually to a preschool program and after age 5 when you prepare for your child to move to Kindergarten or a new educational program. The following articles will provide information and resources to help you prepare for these transitions. In addition, two parents share their experiences and ideas for a smooth transition for you and your child. And don't forget, you may always ask your Parent Advisor for information and resources as you prepare for an upcoming transition or IFSP (Individualized Family Service Plan) or IEP (Individualized Education Program). You may also contact Ginny Williams, Lead Parent Advisor, at ginwilliams@aol.com or 573-295-4808.

# Transition Information for Families of Children Under 3

### Transition from First Steps to Early Childhood Special Education (ECSE)

"The period of time an infant/toddler is in First Steps is relatively short; therefore, it is important to plan for transition from the time the child enters First Steps.

The discussion of transition prepares the family for a smooth transition as their toddler leaves First Steps to attend a preschool, child care, Early Childhood Special Education (ECSE) or other community program.

Steps toward transitioning out of the First Steps program must be addressed at every Individualized Family Service Plan (IFSP) meeting, regardless of a child's age.

Many documents have been developed to assist with educating service coordinators, providers and parents about the importance of a successful transition from First Steps."

These documents may be found at: http://www.dese.mo.gov/divspeced/FirstSteps/Transitionindexpg.htm

This article and more may be found on the Department of Elementary and Secondary Education (DESE) website at: www.dese.mo.gov

### Transitioning From First Steps: A Parent's Perspective

*(NOTE: Stacy, your parent editor, wrote this article in 2009 to share her transition experience as Lucius moved from First Steps to the local school district's preschool program at age three. She describes the evaluation process, the development of the IEP (Individualized Education Program), how Lucius reacted to all of the changes, as well as her reactions and thoughts about transition.)*

This fall has been a busy one. My son Lucius turned three, graduated from Delta Gamma for Visually Impaired Children and transitioned from First Steps into preschool. I was so nervous about the whole process. I was excited about him going to school, but there seemed to be so much that needed to be done first and there was.

As we approached his third birthday, dates were scheduled for evaluations at the school he would attend. I wanted to make sure he would be okay when he went to school and had to stay there several hours without me. So, from time to time, we would visit the school and the various teachers he would be working with and classrooms he might be in. Since he is visually impaired, I wanted to know how they were going to assess his developmental abilities. After all, most of the kids in school see. Turns out, there are tools the schools can use to assess children like mine. They often use the "Oregon". It is designed for children with visual impairments that would make it difficult to assess them otherwise. They also ask the parents a lot of questions. Answer these as honestly as you can. It benefits your little one in the long run.

They evaluated Lucius's gross motor skills, fine motor skills, orientation and mobility skills and his verbal skills. Since Lucius doesn't talk for everyone else like he does me, it was mostly a "Mom, does he do this or say this?" type of questioning. It took two separate evaluation meetings to cover everything. I was lucky; they were very thorough. I asked lots of questions and the teachers and therapists involved answered them freely. Never be afraid to ask questions.

After the evaluations the information they gathered was put into a system for calculating where my son is developmentally and cognitively. I wasn't too worried about the developmental part of it. I knew he was ahead in gross motor skills but behind in fine motor skills. It just takes him longer to put things together. The cognitive is what got me. He is three and very bright, but because he didn't talk for them and wouldn't answer simple questions, he scored as if he were 18 months old. It stung a little (okay, a lot). As prepared as I thought I was, I was not ready to be told my son was behind in the thinking department. The head of the Special Education department even told me that he would score low because he wouldn't talk for them but not to worry about it. It is hard not to worry. I started to question if I had done enough. What did I miss working with him on? Then I took a deep breath and decided I had done enough and he would be fine.

The next step was the IEP. This is where you sit down with the teachers and therapists, focus on goals, and work out a schedule for the services your child will need. Lucius does OT for his fine motor skills, orientation and mobility with a Certified Orientation and Mobility Specialist and language with a speech therapist. (Language is to teach him to use his words). This is also where we decided what equipment the school would need to get for him; things like a Braille writer, light box, a personal aide for him and any computer based aids like Intellikeys. They also discuss where you would like to see your child go educationally. I want Lucius to excel, of course. They will also determine how many days a week your child will need to go. Lucius goes three days a week for four hours each day. Next year maybe more.

So far he loves preschool. The teacher is very good with him. She makes sure that whatever they are working on she modifies for Lucius to do as well. I am very lucky to be in the school district that I am. They are very much geared towards making sure children like Lucius get their educational needs met. The children in his class have warmed up to him and even like to play with his special toys and equipment. I personally think this is great because they are learning early on that some people have differences but they are still the same as everyone one else.

Since starting school, he is talking more. Sometimes I can't quite understand what he is saying, but he knows. He has actually started using his cane to get around in unfamiliar places. (I tried to get him to do that for two years.) He plays on the playground with the other kids and his personal aide, of course.

So even though transitioning can be nerve-racking, scary and even overwhelming, ask lots of questions and stand up for what you know your child needs and should have.

# Transition Information for Families of Children Turning 5

When your child nears the age your school district sets as the starting point for Kindergarten -- most likely, five years old -- it's time again to think in terms of another transition. For most children with special needs, this will mean a transition from a preschool program (ECSE) to a Kindergarten program. It may also involve a transition from a partial day to a full day, from one school to another or from one type of educational program to another.

## Transitioning from Preschool (ECSE) to Kindergarten: A Parent's Perspective

*(NOTE: Kristin, a previous parent editor, wrote this article in 2008 to describe her preparations for Nathan's transition to Kindergarten. She shares thoughts, useful websites and transition ideas for parents and children.)*

Transition time is coming near for my family as Nathan turned five in December. Not only will he be transitioning out of MoSPIN, Head Start, and ECSE (Early Childhood Special Education), but will be transitioning into Kindergarten this fall. I believe transition out of any program that supports you and your family into a new unknown setting can be scary for parents but also for our children.

To help in these transition periods, I think we as parents need to educate ourselves as much as possible about what to expect at Kindergarten or any other grade level. You need to talk to your school district to see what the expectations are for each grade level.

Nowadays Kindergarten has become the First Grade that many of us grew up with, where our children are learning basic math and reading skills on top of developing their social skills.

The Missouri Department of Elementary and Secondary Education (DESE) has a great handout on their website to help parents prepare their kids for school. It gives ideas for transition activities that parents and educators can do to help children have a smoother, less stressful transition into the Kindergarten setting.

The website link is:
http://www.dese.mo.gov/divimprove/fedprog/earlychild/pdf/PrepareKids.pdf.

They also have another handout that gives parents ideas to help their child in the area of Early Social and Emotional Development, that can be located at:

http://www.dese.mo.gov/divimprove/fedprog/earlychild/reK_Standards/Social_Parent.pdf

The next articles contain some ideas that I hope will be helpful for you and your child when transitioning into Kindergarten.

### *Transition Ideas for Kids*

**-** *Visit the school, the classroom and playground before the first day to get your child used to the environment and how to navigate around the building.*

*- Read books and tell stories about what to expect the first day of school.*

*- Familiarize your child with their Kindergarten teachers by reviewing their names, showing pictures and discussing what the classroom will be like.*

*-Talk to your child about what types of rules will be expected while they are in the classroom.*

### *Transition Ideas for Parents*

*- Meet with your child's Kindergarten teacher before school starts and describe your child's interests, likes, dislikes, special strengths and how your child best learns.*

*- Find out what the expectations of the Kindergarten teacher are and how those expectations can be adapted to meet your child's needs.*

*- Provide opportunities for your child to interact directly with their anticipated Kindergarten teachers by arranging visits to Kindergarten classrooms during story time, center time, recess, or a special school function.*

*- Introduce your child to other children that are expected to be in the same classroom or school as your child.*

*- Role-play with your child. Start getting a home routine that you will use during the school year.*

*- Know special education laws in regard to your child's rights. MPACT offers several free trainings though out the state.*
*www.ptimpact.com*

*- Make sure a current IEP document is in place before starting Kindergarten. All of your child's needs and supports should be written in the IEP. If it is not written into the IEP then it doesn't exist.*

### *Need Web Assistance?*

*Many of the articles in this issue of Parent Time refer you to websites. If you do not have access to the internet, just ask your MoSPIN Parent Advisor to assist you. I am also available to provide information or hard copies of resources. You can contact me at 573-295-4808 or at 800-622-5672 (to leave a message).*

*Ginny Williams*
*Lead Parent Advisor for MoSPIN*

# Parents' Bill of Rights

***The following document is available on the Missouri Department of Elementary and Secondary Education (DESE) website for parents to understand their rights during the IEP process.***

***This document does not confer any right or rights beyond those conferred by federal or state law and is intended for in for informational purposes only.***

***For additional information, contact the Department of Elementary and Secondary Education, Division of Special Education at (573) 751-0699 or*** ***webreplyspeco@dese.mo.gov***

As a parent of a child with a disability, you have the right to:

1. Attend individualized education program (IEP) meetings and represent your child's interest.

2. Have an advocate or expert present at individualized education program (IEP) meetings.

3. Receive a copy of your child's evaluation, disagree with it, and request one independent educational evaluation at public expense.

4. Provide a written report from outside sources as part of the evaluation process.

5. Examine all education records pertaining to your child and be provided with a copy of the individualized education program.

6. Disagree with the decision of the individualized education program (IEP) team and pursue complaint procedures, including filing a child complaint with the Department of Elementary and Secondary Education, state paid mediation, have an impartial due process hearing, and appeal the due process decision to the court.

7. Participate in reviews of the individualized education programs (IEPs) and in any decision to change any aspects of the IEP, as well as receive a written notice of action before a change in your child's educational placement or the provision of a free appropriate public education.

8. Have your child placed in the least restrictive environment and in a general education classroom to the greatest extent appropriate.

9. Request an accommodation to provide effective communications if you have limited English language proficiency.

10. A free appropriate public education for your child with an individualized education program designed to meet your child's unique needs, which may include but not limited to, special education and related services, such as assistive technology devices and services; transportation; speech pathology services; audiology services; interpreting services; psychological services; including behavioral interventions; physical therapy; occupational therapy; recreation, including therapeutic recreation; counseling services, orientation and mobility services; school health services; school nurse services; social work services; parent counseling and training; and, medical services for diagnostic or evaluation purposes.

# “Spotlight on Visual Impairment”

## Aniridia

Aniridia means “without an iris.” A child born with this condition has only a small portion of the peripheral iris, which is the brown or blue portion of the eye. The pupil may look larger than normal due to the absence of the iris. There are two forms of aniridia. In one form, a parent has the condition and carries the gene. The other form occurs sporadically, meaning that it occurs with no previous genetic history and, quite often, will not be transmitted on to future children. For a child with sporadic aniridia, there is a condition called a Wilms’ tumor, which is a tumor of the kidney and the child, will need to be examined for Wilms’ periodically as they grow up. Aniridia is accompanied by nystagmus (rapid, involuntary eye movement). As an individual becomes older, there is a risk of glaucoma developing. Therefore, a child with aniridia needs to be monitored periodically to watch for glaucoma. Also, as the child becomes older, cataracts may develop. If the cataracts are mild, no treatment is indicated. However, if the cataracts become significant to the point of decreasing visual acuity, surgery may be indicated.

A child with aniridia typically has a visual acuity in the 20/200 range. This is true even if the child needs glasses, meaning that the condition may not, generally, be improved beyond the 20/200 level even with glasses. Occasionally, there are children who see better or worse than this, but 20/200 is a normal visual acuity for a child with aniridia. As a child with aniridia becomes older, she may find the use of reading glasses and/or telescopic lenses helpful.

Sensitivity to light is characteristic of an individual with aniridia as the iris is responsible for controlling the amount of light entering the pupil. Sometimes “pinhole” contact lenses are prescribed to control the amount of light entering the eye. Glare control is also important for a child with aniridia. The child should not be seated facing windows or positioned under a light which is casting glare on a surface like a table or lap tray. Those working with a child with aniridia should avoid positioning themselves in front of light or windows, which require the child to look directly toward light sources. When turning on room lights, after the room has been dark, it might be helpful to the child and reduce the potential for discomfort, if light could be reintroduced gradually (using a rheostat) or if the child could be positioned away from the light and/or have the eyes shielded. If the child demonstrates sensitivity to sunlight, she might benefit from wearing a cap with a visor. The child’s eye care physician may recommend sunglasses.
Resources:

http://www.tsbvi.edu/curriculum-a-publications/969-aniridia

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IDEAs that Work
Office of Special Education Programs

The Department of Elementary and Secondary Education does not discriminate on the basis of race, color, national origin, sex, disability, or age in its programs and activities. Inquiries related to Department programs and to the location of services, activities, and facilities that are accessible by persons with disabilities may be directed to the Jefferson State Office Building, Civil Rights Compliance (Title VI/Title IX/504/ADA/Age Act), 5th Floor, 205 Jefferson Street, Jefferson City, MO 65102-0480; telephone number 573-526-4757 or Relay Missouri 800-735-2966.