

Claire's Transition Story

My name is Lynn Havemann and I work at the Waisman Center at UW--Madison in the Early Intervention Program. I've been working here since September 2003—coordinating trainings for B-3 personnel, working on the State Improvement Grant and focusing on pre-service training of emerging professionals through the ID Train program.

To learn more about the Waisman Center visit:

<http://www.waisman.wisc.edu>

Prior to my Waisman Center job, I had a full-time unpaid position as a stay-at-home mom for my three charming, sticky-fingered, fun-loving kids—Owen, Claire and Bess. I had not planned on staying at home and in fact had worked after Owen's birth, but when Claire came along three years later our life took a turn in a direction we hadn't anticipated. We found ourselves in the unfamiliar situation of loving and raising a child with special needs.

Here's a glimpse into our family's life—through our attachment to our beloved early interventionists and the daunting emotional period of three year old transition. But first, a little background. When Claire was an infant and toddler, she was a fairly medically-complicated child. She was born with meconium aspiration syndrome (she ingested her first stool into her lungs making it impossible for her to breathe) and then was diagnosed with a host of other birth anomalies—coarctation of the aorta, displastic kidneys, hypothyroidism, mild cleft palate, mild hearing loss, severe reflux, hypotonia. She required 4 months of medical intervention in the neonatal intensive care unit after she was born and finally came home to us with a trach and ventilator, apnea monitor, supplemental oxygen, g-tube, nebulizer, glucose monitor, blood pressure cuff, hourly meds, medical charts and in-home nursing care.

Children with Special Health Care Needs (CSHCN) may be helpful when navigating through the various services and resources available for children with chronic health issues.

Visit http://www.dhfs.state.wi.us/dph_bfch/cshcn/index.HTM for more information.

Claire was also significantly developmentally delayed. We were put in contact with the Birth to 3 program while she was still in the hospital and

once home we received weekly services from a host of therapists and educators. We were blessed with a group of interventionists who included our family in their work with Claire, who were optimistic, who saw Claire's potential and who week after week supported us through the ups and downs of Claire's progress.

To learn more about Wisconsin's Birth to 3 Program visit:
<http://dhfs.wisconsin.gov/bdds/birthto3/index.htm>

When Claire was two and finally strong enough to get rid of her tracheotomy, ventilator and oxygen. She was also healthy enough to start "going out" and socializing. We wanted her to have periods of "play time" with social peers so we enrolled her at the preschool located here at the Waisman Center for three half days a week. The teachers were willing to learn how to do g-tube feeds and learn her signs and did a marvelous job of including her in all activities with her peers who were typically-developing. They also played a pivotal role in teaching her to walk and getting her comfortable with water and other textures. Claire loved school!

During our time with Birth to 3, we were blessed to have a great service coordinator, Mary, who was always helpful to me—patient with my questions, providing resources, supporting our family, prepping me for upcoming meetings. She helped facilitate really productive IFSP meetings and helped put together a great team of therapists for Claire and our family.

So we continued on with our routines and while I knew in my head that our time with B-3 ended when Claire turned 3 (I'm glad that's in the name as a reminder...), our day to day lives were so filled with doctor appointments, therapies, medicine, supply orders, glucose checks, g-tube feeds, and sleep deprivation that it was really hard for me to deal with future changes. So I chose not to think about it.

For resources relating to the transition process from Birth to 3 visit:
<http://www.collaboratingpartners.com/transition/index.htm>

I vaguely remember our service coordinator, Mary, mentioning at one of our IFSP meetings that Claire would turn three on April 1, 2002 and so our services would move from Birth to 3 to the school district. This was around Claire's 2nd birthday. I'm imagining Mary could tell I was in no shape to begin conversations about our options for Claire, but slowly over the next

six months, she brought up the topic again and again, gently nudging me towards accepting the fact that changes were to come. Mary gave me a Transitions publication (a brochure of some sort which explained options) and a video to watch. She told me the Transition “steps” but also wrote these down so I could refer back to them. Having all these materials in so many forms served to deluge me with helpful information we needed to make decisions about the future.

Wisconsin Family Assistance Center for Education, Training, and Support (FACETS) can be helpful in supporting families through the transition process. Visit their website at: www.wifacets.org

It was important to me that Mary understand that our attachment to B-3 was not merely just a “provider of services” like a department store or supermarket. It was an emotional connection to a place and people who supported Claire and our whole family through a crazy and emotional time. The prospect of losing this support was frightening. Mary seemed to “get this” so didn’t belittle my attachment and reassured me that all would be okay.

In early December (3 ½ months before Claire’s 3rd birthday), two school district reps came to my home for our Transition Planning Meeting along with Mary. We discussed more specifics about our options for Claire and reviewed the forms I needed to complete and submit. We discussed that Claire could continue in her current pre-school program or would be eligible to attend the ECP. I was interested in exploring the ECP option so we put this in our plans. We designed an “action plan” including who was going to do what by when and thus began the 90-day timeline.

One of the main issues my husband and I were trying to decide was whether to use the school district’s Early Childhood Program or continue Claire in her preschool. Mary discussed the ECP option with us and then scheduled two appointments at schools Claire might attend. Mary and I visited the classrooms and chatted with the teachers. It was a great opportunity to actually see how these classes work. And it was nice that I didn’t have to do any of the coordination!

At www.preschooloptions.org you’ll find helpful information on providing a continuum of options to preschoolers with special needs.

Mark and I decided for a variety of reasons that we would finish out the summer in Claire's current preschool and then in the fall try the ECP.

We set our initial IEP meeting for early March 2002. Mary took care of all of the details—invitations, dates/times, etc. We had our official IEP meeting in our home. I wanted to have the meeting someplace I was comfortable in and I wanted Claire to be around since the meeting was about her. Mary asked Claire's birth to 3 therapists to try to connect with the school district personnel assigned to our meeting to talk before hand so they got a sense of Claire. A couple of the therapists went to Claire's daycare to meet her and all the therapists talked with her current staff. There were about 18 people crammed in my small living room—2 PT's, 2 OT's, 2 SLP's, 2 of Claire's teachers from the daycare she was currently attending, 2 Audiologists to discuss Claire's mild hearing loss, Mary our service coordinator, 2 school district reps, a school nurse and Mark (my husband) and myself. It was a lot of bodies but it felt great that all these folks were focused on providing support for my daughter.

Claire was actually asleep for most of the meeting but at the end, she came downstairs and the new school providers, who had not yet met her, were given the chance to put a name and face together. Claire's pretty social so she loved all the attention!

For the remainder of the school year, Claire received itinerant teaching through the school district. Katy came into Claire's classroom and worked in concert with her teachers to provide her additional support.

Before the new school year began, Claire and I went to her ECP to meet her new teacher, Karen, review the IEP goals, learn about classroom routines, share resources and information particular to Claire and generally to get acquainted. Once the new school year began, Claire started boarding the Laidlaw bus that came to our house four times a week. Karen became my contact for questions, concerns and items to be followed-up on. Claire had a great year.

To learn about programs who offer special education services in inclusive settings, visit: www.collaboratingpartners.com

Over the course of the year, our home life was stable enough, and I missed professional work so when a Waisman Center position opened up, I applied

for and was offered it. We therefore needed a preschool that offered longer day options five days a week and we were interested in having Claire have more “typical” peer models so the preschool at Waisman once again felt like a good fit. Claire received itinerant teaching through the school district again—a great resource for her, the teachers and myself and she received PT through the school district as well. She also received services through CASC (communication aids and systems clinic) once a week. Ericka, her CASC therapist, provided augmentative devices to help Claire in communicating in her daily life. Ericka alternated working with Claire in the clinic and in the classroom, thereby supporting her teachers and supporting Claire in the devices she is able to use.

Wisconsin Assistive Technology Initiative (WATI) is a statewide project to make assistive technology devices and services more available to children with disabilities. Visit www.wati.org for more information.

So Claire is now almost 6 and done with her medical “accessories”—no more trach, g-tube, monitors, etc. We still have a lot of doctor and clinic appointments but these are slowly diminishing. Claire is thriving in her preschool—she loves her teachers and friends and is growing by leaps and bounds. Now, in the fall, we face the transition to Kindergarten. I’m still deep in denial about this but have faith that someone will come along at some point to nudge me along...

*I’ve really enjoyed my work and serving as a parent “voice” in training—so much so that I was excited to take on the **Parent Consultant Directory**. This is a directory of parents with children with special needs who are willing to help with professional and pre-professional training—knowing that our perspectives on raising and loving a child with disabilities is a unique and valuable voice. Please contact me more information about the Parent Consultant Directory: Havemann@Waisman.wisc.edu*