



TEAM

TOGETHER EVERYONE ACHIEVES MORE

3rd Year Resident Journal Selections August 2004 – May 2005

PT/OT/ST

- Another good example of care coordination.
- How fascinating to see them at work and the connections they make with their patients.
- I am impressed that every game, every question, every movement, every conversation is actually intricately and carefully choreographed to achieve another task or goal.
- I feel better prepared to be a physician today – I feel that I know more of what it means when I say “he/she needs PT/OT and Speech.”
- I enjoyed speaking with the therapists and observing the therapies themselves.
- I did not know beforehand the difference between school therapies and hospital therapies.
- I enviously watch the therapists as they almost effortlessly discuss the cognitive and motor skills of the infants. It’s a type of training we have not received as residents.
- What really stood out to me was that the goals of therapy for a CSHCN are different than for kids without special health care needs. The therapists have to simply make therapy “more fun” for CSHCN.
- I thought it was glorified play at first –and in some ways it is. But every week there are new experiences and repeating older ones -all working towards achieving skills so he can adapt to and function within his environment.

Pediatric Extended Care

- This was a great experience. I had no idea CHW had such an outpatient facility.
- It was wonderful to see these kids (especially the trach-vent kids) running around and playing.
- I feel like we as residents are at times jaded by the progress of medicine. We see the trach-vent kids who are hospitalized, ill and non functional. We wonder what the point is when the child’s quality of life seems horrible. So it was nice to see happy, smiling, functional kids who clearly have a wonderful quality of life.
- Its good to see that there’s a place for CSHCN, especially with trachs, to go to be with other children and gain that social interaction with them, the volunteers and nurses.
- It’s also good to give the families the opportunity to do things during the day – work, or even just grocery shopping.
- We need more places like this!
- My preconceived notion, quite honestly, was that several children with varying needs and abilities would be “sitting around” as harried workers bustled about preventing (and dealing with) minor disasters. What I see instead is children smiling, learning, and socializing. They are receiving therapy. They are being cared for with the loving touch of nurses. They appear -in a word – happy. They are living. They are thriving!
- What a neat resource for families in this area!
- The workers clearly love their job.
- It was nice to see preschoolers with trachs acting like rambunctious, healthy kiddos.
- You walk in and the 1st thing to come to you is a 3-year-old ball of energy and all she wants to do is play. You do for a few minutes and it is only when you walk away that you realize she has a trach! It definitely

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Children's Hospital of Wisconsin, Medical College of Wisconsin & Special Needs Family Center

Pediatric Extended Care (continued)

did not interfere with her activities – she did not even know she was different than you or I. She seemed to feel comfortable and was clearly reminding us that she did not have limitations.

- If they're hiring an on site doc – I will apply

This was a visit to a day care facility for children with special health care needs. It is hidden away in a corner of the office building that I had never noticed before, though the playground slide does peep out at me when I walk up the Skywalk to work everyday. I think the reason I never turned my head towards the corner is the lack of voices – a normal accompaniment to swings and slides. This is the playground of silent children.

Most of the kids there are ex preemies of various (corrected gestational) ages! They have many of the complications of arriving into this world ahead of schedule. Most of the class has tracheotomies: a lifeline protruding from one's neck. A way to breathe when it would otherwise be impossible. The trade off is one's voice.

Once inside the silence was compensated for by the smiles! Big, happy, sunny smiles! Smiles that say "welcome to my world". Smiles that say "thank you for considering me worth saving even at 24 weeks. Thanks for not giving up on me in the NICU for all those months. I may not be your average 2 year old but that's just because I am special. I'm smiling because I too can feel happy...though they may not be things you know much about. For example I learned to sit up today."

To all those who ask whether it is worthwhile resuscitating a 24 weaker.... I say, "It is!"

Special Needs Family Center

- I can't believe the resources available to families of CSHCN. It's incredible!
- It's great that there's a center, which can bring it all together for families and direct them to where they need to be.
- Resources, aside, the emotional support provided must be invaluable to families and patients. I will definitely be referring families to the center.
- I will definitely refer families early on to the Family Resource Center. Hopefully they will (through the center) find support and ultimately strength to love and care for their child.
- I can't believe I've never been here before. I have been in this hospital almost every day for the last 2+ years and I feel like I just discovered a whole new world.
- What a wonderful resource. My first thought was of my own children – what if... what if...what if...what would I do? Information is powerful and as a parent I am glad to know that the Special Needs Family Center is available.
- As a health professional I see my role so often as an educator. Here is a wealth of information that I can share, that families can share with me. I am so glad to know of this place s that I can share it with patients and families.

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Special Needs Family Center (continued)

Here is another place I know nothing about!

Is that because I am fortunate enough not to require its services?

After all it is a place to help families of chronically ill kids. Or kids with complicated and uncommon diseases. Or kids with a grim diagnosis.

At reception I find families...mostly looking nervous. Generally unsmiling.

I really don't want to go further inside.

I meet the staff. Ordinary appearing people, to me anyway.

They meet parents, grandparents, talk.

Families see something on their faces, which they don't see on mine.

That something is an expression, a light in the eyes, lines on the face, maybe that say "I also know. I am one of you. A parent of a special child."

Let's talk about your problem. No it doesn't have to be related to your child.

It could also be about you. Or your spouse. Or other healthy kids.

Here is some information for you. A book. A video to give you a better picture.

You can also have hot chocolate when you read.

I can help you with insurance issues. And school issues.

Here is a picnic that you can go for.

Aaahh! It's nice to see you smiling again.

Come visit us again."

Did I really not know this place existed? I am humbled. A little ashamed.

But, I will be happy to come here again.

To help...and be helped.

Special Needs Program Intake Rounds

- It was surprising to hear how often some families were in contact with either their nurse or physician – often multiple times/day.
- What impressed me was the number of resources and agencies that the different providers at the meeting could come up with when they all discussed it together.
- What a dynamic team!
- It was nice to see how involved the nurses were in the entire process.

Sometimes laughter is the best medicine

Sometimes humor is therapeutic

Sometimes we care so much that, well, it hurts

Sometimes we love so much that it, well, it overflows.

Sometimes work is play and the other way around.

Sometimes we need to look back and take in the whole picture

Sometimes we need to cry.

Sometimes we need to laugh, to smile.

Sometimes we need to just be.

TEAM: Children and Youth with Special Health Care Needs Education Program

Children's Hospital of Wisconsin, Medical College of Wisconsin & Special Needs Family Center

Clinics (Rehab, Drooling, Seating and Equipment)

- We were unable to stop his seizures – however it was interesting to be a part of aiming to improve his ability to function.
- This was an extremely rewarding clinic this morning.
- It's amazing how without curing the problem we brought him back to a fully functional child!
- A great perspective – especially learning how Dr. K looks at how the primary injury or disease leads to secondary and tertiary functional impairments. This is important.
- We need to understand now only what the initial injury is but how this is going to affect function and quality of life.
- In the hospital we always concentrate on the primary issue. This reminds me that I need to think of the functional impact and consequences as well.
- The biggest impact during this activity was hearing about Dr. K's philosophy/approach to CSHCN and patients. His focus on function and how we can all address this for patients seems simple and yet so revolutionary, considering the current medical model.
- My goal is to always remember the functional consequences of illness/disability as I embark in my own practice.
- It was so nice to see coordination of care in action.
- What fun! This clinic more than any I've ever been to demonstrated the necessity of ancillary resources. Dr. K depends on all the members of the team, making decisions with everyone's input and expertise. What a great way to practice!
- Well we can't fix her heart. But she told us she has a lot of places to go and people to see so Dr. K suggested a scooter. Her only request was that it go "fast." We couldn't fix it but we sure could make it better –she will be able to keep up with the other kids on her scooter – her smile reminded me that though we can't always "fix" it we can make a difference by finding out what is important to the patient and family.
- Coordinated care always amazes me –I think because it makes me wonder why we don't have multidisciplinary care for every patient. It just makes perfect sense for the family to see everyone they need to see in one visit.
- Families clearly appreciate the coordination of care –which by the way seems to require a nurse to keep it all flowing smoothly.

Meeting with Community Pediatrician

- The economics are the sad reality of taking care of CSHCN. It's frustrating to think of the poor reimbursement PMDs are given for taking care of such complex kids.
- This was the most helpful thing thus far. I so appreciated discussing my questions and concerns with Dr. H.
- My time with Dr. H. helped me to think about the amount of time I would allot to CSHCN and how many I would have in my own practice.

Home Care Medical

- Home Care Medical is an incredible facility!
- I now see what goes into actually accomplishing our discharge plans.
- Home Care Medical and such facilities make a medical home possible.
- I never knew how MUCH is involved in delivering home care supplies.
- This place is incredible and it's such an eye opening experience to see what happens after we complete our end of the process.
- The planning that goes after we fax a script over, for example, is extensive, yet HCM finds a way to operate, to deliver and to devise a much needed service.
- Got to ride the scooters – GREAT!

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Home Care Medical (continued)

- Enormous – the word I use to describe this facility. I had no idea when I wrote a script for “home nebulizer” or “NG feeds” what went into the process.
- Enormous – also the word I use to describe the impact HCM can have on a child, family and care team.
- There is nothing better than being in one’s own home with one’s family. It is good to know that this can be achieved for children and families with special needs children who a few years ago would have been in the hospital long term or worse.
- What surprised me the most was how much more the home care company did than just providing equipment. There’s so much teaching and tailoring of equipment to the patient.
- Wow – what a cool facility.
- They took the time to answer my many specific questions.
- It is cool that the delivery guys are trained to trouble shoot faulty equipment and fix them on the side.
- It was really interesting to see the other side of things. What happens after we sign the discharge form and our patients magically get the equipment they need at home? Today we learned the answer.
- They taught me that I should find a good home medical equipment company in the area I am going, ask their advice, get their input early and advocate for my patients.

Family Home Visits

- At one point the mother said she felt like her child belonged more to the medical establishment than to her and her husband! When we take care of children I wonder how often parents think this. How often do they feel this way? How do we change this?
- I see in these parents surprise, shock, a seemingly unpreparedness, disbelief, wonder, questioning, doubt, some anger.
I see the effect on them: tiring, draining, relationship strain, and yet strength, resiliency, togetherness, bonding.
And these emerge: love, endurance, unconditional love, hope, pride, joy, happiness, strength, authenticity, honesty, integrity, human nature.
- What an incredible experience they share and thus what lessons they teach. It may be impossible to know what another person experiences but hearing a story, feeling a part of it, draws me closer.
- I see a small part of what goes into caring for a CSHCN on a daily, minute to minute basis. I am quite certain that residency – while challenging – is nothing compared to this. I will remember this when I visit with a family in my office. My eyes have been opened.
- I admire the family a lot for their organization and resourcefulness.
- We spoke of insurance, therapies, home modifications. We also spoke of the changes she has made in her life including quitting her job, moving and modifying the house.
- Throughout the visit I thought about whether or not I would have the strength and energy to do what this family has done.
- She said that what was hardest for her was knowing that her expectations for her babies would not be reached.
- The family was very well aware of her challenges and I was so impressed with how they were dealing with it.
- The parents got so much joy from every smile their daughter gave them.
- I never thought about that having home nursing took away their privacy and changed their home. I had looked at home nursing as a blessing or assistance for families. It comes with a price though.
- I was happy to hear that the father felt the words of a health care provider had empowered him and I wonder if the words I saw at some point in time to a family could have such a positive impact. I hope so.
- I am so impressed that families invite us into their homes and answer some very personal questions to better our education about CSHCN.
- The home visit was one of the best parts of the month.
- I was struck by how relatively “normal” their home was.

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Family Home Visit (Continued)

- Siblings – as one would expect there is some frustration about things they can't do given the CSHCN's needs.
- The mother said it's the little things she does and the small steps of progress she makes that brings them so much joy. They focus on what she can do and that she responds to them. They focus on these things rather than on what she cannot do.
- Having a child is a stress to a marriage but having a CSHCN seems like an extraordinary stress.
- I've always taken it for granted that I can speak. But the stories I have heard from families about how language delays contribute not only to behavior issues. Acting out which I'd been aware of but also profoundly affected their socialization with peers their own age.
- I thought about how tough it would be not to know the prognosis of your child and to watch your child grow weaker and weaker.
- What an impact a CSHCN can make on your life as well as your marriage!
- Its so wonderful how the family makes like as normal as possible for their CSHCN.
- It's so important to provide support to these families – not just for health care but through all the many transitions in their life.
- It is important as a physician to approach each child as a child and a human.
- The home visit helped me to appreciate the impact a child with special needs can make in a person's life that you won't see at the hospital or clinic.
- The time and commitment that parents of autistic children have to give to their child is much more than I had imagined.
- What a joy to see ____ (Child's name) in his home environment. He was so comfortable and happy – so different than how we residents see him in the hospital.
- The most interesting part of the conversation was about the difference between what they expected their life to be like and what it actually was like and how they really preserved the essence of what they expected by adapting things
- I got to see ____ (child's name) try out a test wheelchair that was brought to his house. What joy on his face – I could see that he could see all the possibilities of being able to “walk” to school and do things with the other neighborhood kids.
- It was so good to see and talk with a family outside of a clinic setting.
- I am in awe of how parents keep track of everything for their child.
- It was great to see the “healthy” siblings playing with the CSHCN – so much we read is about how stressful special needs can be on a family. It is – I see that. But I was also able to see how much joy this family still seems to have. I loved watching the bond between the siblings best of all!

Trach-Vent Clinic

- Spending time in the clinic was eye opening.
- The amount of equipment and supplies necessary for transporting a trach-vent child is tremendous.
- We take care of these kids in the acute setting and wonder why sometimes.... how nice to see them years later and oh so strong!

TEAM: Children and Youth with Special Health Care Needs Education Program

Children's Hospital of Wisconsin, Medical College of Wisconsin & Special Needs Family Center

Trach-Vent Clinic (continued)

The trach-vent clinic is a place where parent know far more than me. I have never inserted a trach. Or changed one. Or suctioned one. Therefore children with trachs are a little intimidating. And by extension, the parents are too.

Fortunately, I spent the morning with a young mom who was just about to adopt her beautiful baby foster son. He has had a trach since a month of age.

She travels with a care seat, which by itself it not too big a load. Added to that was a suction apparatus, emergency trach change kit, diapers, formula, pacifier, medical file. And a nurse.

He smiled. He knew how to play the audience. All attempts at playing with him were rewarded with grins. Chatting with mom and his nurse taught me more than an hour-long lecture about trachs.

And then we tried a speaking valve for the very first time. It is very much harder to breathe when one is not used to the valve.

He kept it on for 5 whole minutes. A record in the clinic!

Another first for him – he spoke.

Well he babbled, and cooed and then cried.

But his mom had never heard his voice before.

I was happy to be there to share it with her.