

What Residents Say About Team 2003-2004

A medical home is not a physical object such as a home or hospital, nor is it a place where there is medicine. Rather a medical home is a highly coordinated system involving both families and caretakers in providing children with special needs high level, cost effective care. It is an extensive organization that involves many individuals that are identified and needed to join in the care of a specific child. It helps identify the goals of families and the patient and those goals/ideas influence the level of care of a child. It is an overall team effort. *(PL3 Resident - Fall 2004)*

Overall Impression of the Rotation

- I think the time spent with the families is the memorable part about this rotation, the experience I will recollect next time I see a child with special needs and perhaps have a better appreciation for the type of lifestyle they lead.
- This rotation made me feel more comfortable in caring for these children.
- This rotation really emphasized living with CSHCN and how these families function in life outside of the hospital. This was an entirely different perspective than hospital experiences.

Trach-Vent Clinic – facilitated by Carole Wegner and families

- I could see the parent's relief to have someone to speak with who understands their lives. And more so someone who knows what they can do – are capable of.
- To my surprise, the families felt that their primary pediatrician was vital to the care of their child. Though the PMD may not have all the answers to questions that families may have, they were greatly appreciative that someone like their PMD was there to guide them to the right specialist as well as help organize the care of their child.
- Re: travel: The equipment is amazing! I can understand how a family would feel restricted in their ability to do anything spur of the moment.
-

Speech Language Therapy – facilitated by Katherine Frontier and family teacher

- The PMD's acknowledgement of therapist's letters, notes and evaluations is rare but important.
- It is important to find out the family's goals.
- It's always good to meet people who we use as resources in the hospital, and see exactly what they do.
- Ultimately the most important thing I got from the session is the realization that therapy doesn't just end in clinic but is a way of life at home. The extensive amount of work that a therapist does in clinic in an hour occurs 3-4 times a day at home, many times with less cooperation than what I witnessed today.

Pediatric Extended Care (PEC) - facilitated by Gina Cotrone and PEC staff

- I was reminded of the importance not only of advocating for pts when resources are needed but also of thinking responsibly about when certain services or levels of care may not be indicated.
- So often some of these children seem untouchable and fragile; as if you move them the wrong way and they'll break (especially when they are hospitalized). At PEC, these same kids are happy, running around and giving you attitude (like they should be at their age) it was refreshing.

Physical and Occupational Therapy – facilitated by Jackie Shay, Chris Casey, family teacher

- My 2 main take home points are TEAM and COMMUNICATION.
- Once again I am amazed at the level of dedication that the therapists have as well as the close bond they share with these children's families.

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 & Fitness, Cerebral Palsy, Wheelchair & Seating, Muscular Dystrophy, and Spina Bifida – facilitated by Dr. Fred Klingbeil and families

- The emphasis on function at home is something that I think most doctors do not consider when they give parents recommendations.
- I'm really starting to appreciate the need for a PMR physician and their role in the healthcare of CSHCN.
- The MD needs to look at the function of a child within a family and the function of a family within a community. It is crucial to maximize the mobility of a family rather than just one patient.
- Functionality is really what parents care about and want to talk about. I think as a resident, that is one aspect of a child's care we overlook daily.
- It seems so many things can get missed when one person is not coordinating cares.

Care Coordination Exercise - facilitated by Dr. John Gordon

- Good organizer, good listener, caring physician, and active advocate-these were many of the ideas that I was able to obtain from my meeting with Dr. G. today to help me prepare as a physician who may one day take care of children with special needs.
- The care coordination summary should highlight the goals and expectations of the family/patient so that this important aspect is not lost in the shuffle.
- The care coordination summaries for children with complex needs are a true asset to the family because it not only provides the various health care workers a snapshot of the child but it gives the family the confidence that their child's issues are being respected and addressed. I think it also helps avoid unnecessary costs for the family.

Special Needs Family Center - facilitated by Anne Juhlmann and SNFC Staff

- Families are a great support for each other both during initial discovery, diagnosis and in continued care.
- People who know resources are a substantial and invaluable resource for special needs children.
- My take home messages are:
 - Know the basics of my local, state, federal resources for families.
 - Know resource centers to refer families to when I need supplementation of my ideas.
- As a physician I can advocate for more resources

Special Needs Team Meeting –_facilitated by Special Needs Program staff

- It was nice to see the group approach to care for the patient with special needs. Everyone seemed to bring special experiences/expertise and it was obvious that this benefits the patient.
- Now I have an idea why I should involve case managers.

Palliative Care-Rehab Clinic - facilitated by Dr. Bruce Himmelstein, Dr. Fred Klingbeil and families

- Important to ask the family: Who is going to provide care when the parents need to leave, take a vacation, die?
- The multi specialty (multi-dimensional) approach seems very practical since the families can have fewer doctor appointments. The doctors can also communicate as a team with the families present.
- There were so many issues that Dr. H. had to prioritize with the family what the top three were that visit. I liked that approach so that the agenda did not seem overwhelming to the doctors or to the family.

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

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

Family Home Visit – facilitated by family teachers (1 family matched with 1 resident)

- Parents feel that the focus is often is on saving the child at all costs and not on saving the family.
- The visit finally opened my eyes to help me understand medical home – not a physical place but the concept and what it meant to the family, where we have fallen short creating a medical home for this family and where/how the medical community has assisted.
- Being a physician I tend to focus on the disabilities of the patients and forget to look at the capabilities. Sometimes it is hard to see the quality of life or what the future holds for them. This mom helped me understand that these parents still have hopes and dreams for their children to lead the best life that they can. Isn't that really the hope that all parents have for their children?
- In listening to this family I was inspired to be the physician they spoke so highly of and made a mental list of things I never wanted to become.
- After 2 hours I was exhausted – mainly mentally and emotionally. It is hard to imagine living with the daily routines this family had established. It is amazing what people are capable of doing when called to.
- The positive attitude of parents of special needs children is a true inspiration
- This was probably my best experience thus far to truly understand a family with special needs.

Home Care Provider – facilitated by the Staff of Home Care Medical in New Berlin, WI.

- Definitely striking is the amount of preparation (Both equipment and thought) that goes into even a single day at home for a single complex patient.
- I especially liked being able to see demos of the various pieces of equipment. Residents never really get instructed on instruments. You are just supposed to pick it up as you go.
- I got to see how medical orders that I feel are routine are major life changes for patients.
- I feel more comfortable about sending equipment home with patients.
- This brief tour was enlightening and made me realize as a physician that in addition to my interaction with a child in my clinic, there are many more people behind the scenes that help me in the care of a child with special needs; that the script I write for medical supplies/equipment isn't "magic" but takes a lot of hard work and dedication from others to complete those orders.