Medical Home: One Family’s Story

Community of Practice on ASD/DD
February 10, 2010
Sheraton - Madison
Objectives

★ To hear a parent perspective on what a Medical Home can be
★ To hear how small changes can make the difference to families and providers in practice
Meet Adam

- Born at 35 weeks
- 4 lbs. 9 oz. 19”
- Cord wrapped 7x
  around neck/shoulder
- Poor muscle tone, floppy
- No suck, swallow or gag response
- Knew right away something was wrong

The beginning of our journey
This was a whole new world to navigate
It was scary
It was a swirl of new terms
We met people we hadn’t planned on knowing
We were sad that the child we had dreamed about was not in the cards
Connected with needed supports in the community i.e. local health department

Connected to Birth to 3, Katie Beckett, Family Support, Respite and CSHCN Program

Several initial diagnoses and finally got the “working” diagnosis of Opitz Trigonocephaly Syndrome when he was 18 mos.
How I got to this place

- Adam’s Birth to 3 provider saw the advocate in me
- I would need a more flexible job
- Wanted to help other families
- Disliked my current job
- Adam helped me find a new life path
Our Medical Home

When Adam was about 4 years old we asked his doctor “Who’s supposed to keep track of all of this?” Our pediatrician said “That’s my job.” We felt such relief. That was back in 1998.
How it worked for us

Dr. Kitty, as she liked to be called, was a wonderful advocate for all children.

- Helped us make the right decisions
- Allowed us as parents to
  - ask questions
  - ask for her feedback
  - opinions on care for Adam

Sadly, she passed away in February 2007.
Now what?

- My professional life came in handy
- Took a care plan developed by the WI Medical Home Transition Collaborative
- Talked to other colleagues for names of new physicians to consider
- Implemented what I learned
- Looked to the future
Medical Home Spread

★ Work with interested practices
★ Found a few Medical Home champions
★ Southwest Pediatrics in New Berlin
  ★ Developed an advisory committee
  ★ Partnered with local Library
★ Dedicated to slow but significant change
SW Peds is a Champion

- They made a commitment after the first learning collaborative
- Participated in a second learning collaborative related to transition
- Wrote for and received three grants to help them make the changes in their practice
- Got buy-in from the other three doctors
Champions for Inclusive Communities

Southwest Pediatrics was nominated as part of a Star Community

Features of the article:

- Parents making an impact
- Successful Community Partnering
- Navigating Insurance and Financing
- Early Identification screening trainer
- Hospital-based case managers
- Medical Home and Transition
- Model of Success
Every child deserves a Medical Home
Every person deserves a Medical Home
Together we can make it happen!
Where we are today

- We have met some awesome people
- Could not have done it without them
- Still grieve the loss of the “perfect” child but keep moving forward with hope
- Adam attends a great school, one that meets his needs

- Age: 15 ½
- Loves music, swimming, Special Olympics bowling and being at summer camp with the wind and sun on his face!!

Welcome to my life!
Questions?