

Autism:

Early Identification Defining a Medical Home Working with Families

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November 2015

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 - Chief Medical Consultant for Children's Special Health Care Services
- Member of the Governor's Autism Council
 - Co-chair of Early Childhood Committee

Bambi VanWoert

- Professional Background
 - Nearly 25 years experience in the dental and healthcare administration field including :
 - customer service, claims processing, IT analyst, project management and contract administration
- Parent Consultant, Family Center, CSHCS, MDHHS
- Parent of a Son with ASD
 - Provides primary case management for her son through the CMH; as well as Educational and Medical systems of care.
 - Over 130 hours of training seminars on ASD topics such as: functional behavior assessments, educational strategies and behavior modification

Disclosures:

- Jane Turner has no financial relationships related to this presentation to disclose; she does work on projects about autism at MSU and the Michigan Department of Health and Human Services (MDHHS).
- Bambi VanWoert has no financial relationships to disclose; she does work on projects about autism at Michigan Department of Health and Human Services (MDHHS).

Objectives:

- At the conclusion of this workshop, participants will be able to:
 - Describe early identification of ASD/DD by a primary care physician: how it is done and why it is important
 - Understand the concept of a Medical Home
 - Recognize effective parent-professional partnerships and know how to foster such relationships

Why early identification?

- Born 2004
 - Issues from birth- “colicky”
- 18 months (mid 2006)
 - Concern about hearing, wasn't responding
 - 3 hearing tests given, in office.
 - Not sleeping through the night
 - Refused to play with other children
- 24 months (Dec 2006)
 - Excessive behaviors, biting, aggression at daycare

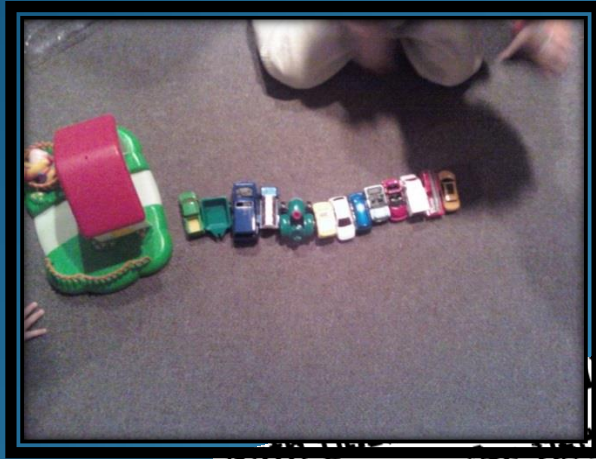


Why early identification?



- 36 months (Dec 2007)
 - Behaviors becoming significantly worse, aggression was a serious concern, refused to start potty training, still not sleeping more than 5 hours at a time, speech articulation still an issue

Why early identification?



very poor interactions with others) and marked impairment in the use of multiple means of communication (e.g., limited facial expression and little eye-to-eye gaze, sharing of enjoyments, interests, or achievements)

including an over sensitivity to light and sound.

head banging when he is stressed suggested a difficulty in

Why early identification?

Ben today:

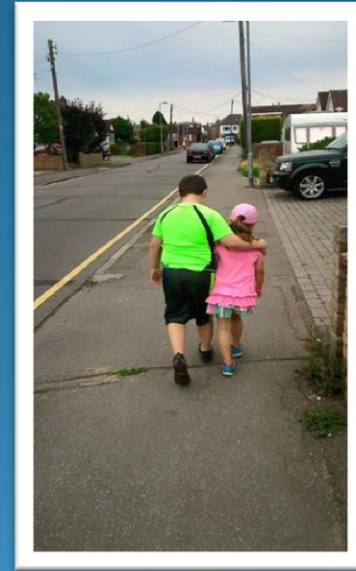
Age: 10

Interests: Minecraft, animals, My Little Pony
YouTube, Xbox, bike riding

Attends a program with the Intermediate School District, he can write his name, he can read at grade level, still struggles with math functions and more abstract curriculum.

Receives CMH in home supports, respite. Due to lack of services in our area, Ben's program and training protocol is handled by his mom through a self determination process. He receives services provided by the ISD such as: occupational therapy, social work, speech therapy and 1:1 educational supports.

Speech: Ben's last IEP showed progress; and Ben can now carry on a limited conversation with certain individuals, with more than 5 transitional phrases. He is learning about idioms, sarcasm and how to read facial communication indicators.



Early Intervention

- Research shows that early intervention treatment services can greatly improve a child's development.
- Scientific studies have demonstrated that early intensive behavioral intervention improves learning, communication and social skills in young children with Autism.
- While the outcomes of early intervention vary, ALL children benefit.

www.autismspeaks.org

Identify – Screening

- Screen – AAP (American Academy of Pediatrics)
Bright Futures:
 - M-CHAT or M-CHAT-R at 18 and 24 months
 - Available in multiple languages
 - ASQ (Ages and Stages Questionnaire) or PEDS (Parents Evaluation of Developmental Status) at 9, 18, and 30 (or 24 months)
- Older children if there is concern:
 - SCQ (Social Communication Questionnaire) for 4 years and older

Identify - Surveillance

- Recognize “red flags”
 - No babbling or gestures by 12 months
 - No single words by 16 months
 - No two word phrases by 24 months
 - Loss of language skills at any age
- Parent or other care giver is concerned
- Speech \neq Non Diagnosis
 - 60 % of children with ASD are verbal.

Children at increased risk of ASD

- Siblings of a child with ASD: 18.7%*
- Children with Fragile X Syndrome: 21%
- Children with Down Syndrome: 7-18%
- Children with Tuberous Sclerosis: 40%
- Premature infants
- Prenatal exposures (E.g.. Valproic Acid)

Doctor's Next Steps:

- “fails” the M-CHAT
 - More specific if follow up interview completed
 - Be aware of cultural differences
 - Language barriers
- Child exhibits “red flags”
- Parent has a concern
- Someone else has a concern (i.e. child care)

Doctor's Next Steps:

- Hearing evaluation
- Educational system – Early On or Early Childhood Special Education (typically housed within the Intermediate School District domain)
- Diagnostic evaluation
 - Medicaid/MiChild: Community Mental Health
 - Commercial insurance: it depends.....

Referral is needed to access treatment

- **Applied Behavior Therapy**
 - ABA = Applied Behavior Analysis
- Speech Therapy
- Occupational Therapy
- Peer Interaction
- Skill Development

What's new in services for families with commercial health insurance?

- Autism insurance reform – October 2012
 - Michigan based commercial insurance *must* cover services for autism.
 - Insurance company is reimbursed by the state
 - Birth through 18 years
 - Many, many companies are not subject to the mandate (i.e. self funded; out of state).
 - Each insurance company decides on the process for diagnosis.

Commercial insurance

- A GUIDE for FAMILIES – *see handout*
- FIRST STEPS:
 - Call the number on the insurance card.
 - Immediately ask to be connected to the behavioral health/mental health/substance abuse division of the company (these are the only individuals trained to respond to autism issues).
 - “My doctor told me my child may have autism and that our health insurance may cover services for children with autism. Can you give me information about what is covered for autism or connect me to someone who knows about your autism benefit?”

What's new in services for children covered by Medicaid or MiChild?

- Medicaid benefit launched April 2013
- Covers intensive therapy including Applied Behavior Analysis for children 18 to 72 months (until their 6th birthday)
- Evaluation, diagnosis and treatment provided by the Community Mental Health/PIHP system
- Children/youth 6 years and older can receive services from CMH; but not intensive ABA

Diagnostic evaluation: Medicaid/MiChild – up to 6 years age

- Refer to the Community Mental Health/PIHP in your region:
 - <http://www.michigan.gov/autism>
 - http://www.michigan.gov/autism/0,4848,7-294-63682_66069---,00.html for a map of counties with contact information for each county.
- Be sure to say AUTISM

Diagnostic evaluation

Medicaid/MiChild – 6 years and older

- Refer to the Community Mental Health/PIHP in your region:
 - <http://www.michigan.gov/autism>
 - http://www.michigan.gov/autism/0,4848,7-294-63682_66069---,00.html
 - Does not open the door to ABA
 - Be sure to say AUTISM
- Refer to local mental health provider on contract with the child's Medicaid Health Plan

Autism Program Updates

- MDHHS is working with Centers for Medicare and Medicaid Services (CMS) on behavioral health treatment service expansion for 2016 for children under 21 with ASD

Information Provided to the Medical Community:

- Early On and Early Childhood Special Education serve children with Developmental Disabilities including children with Autism
- Older children receive special education services in the classroom and/or in special programs
- *Medical diagnosis does **not** equal educational eligibility*

Education

vs

Medical

- Determine special education eligibility or ineligibility
- Determine educational impact
- Determine need for specially designed instruction
- Inform IEP and special education services

- Make Clinical/Medical/Behavioral Health Diagnosis
- Determine insurance or Medicaid Autism benefit eligibility
- Access non-educational agency services
- Dictate medical/clinical treatment

ABA = Applied Behavior Analysis

- Functionally assessing the relationship between a targeted behavior and the environment, with a goal of changing targeted, unwanted behavior.
 - Antecedent-what is happening prior to the ‘incident’
 - Behavior-can be wanted or unwanted behaviors
 - Consequence-what happens immediately after the behavior

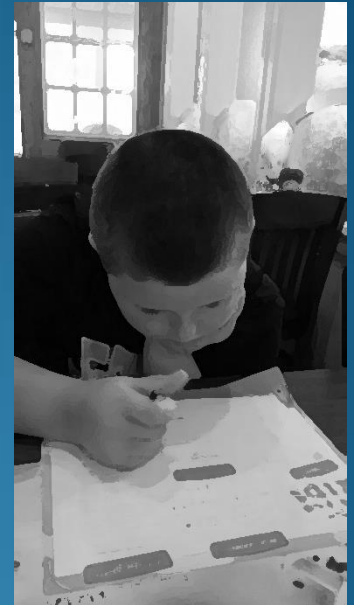
Behavior is communication

Basic ABA = Ben's example

Ben would become very aggressive after returning from his father's home

Functional Behavior Assessment:

- Antecedent – *leaving father's home to go to mother's*
- Behavior- *aggression during transition from father's home*
 - Some hypothetical conclusions that could be drawn: Ben likes his dad's house better, Ben does not want to go home and go to sleep. Etc.
 - Consequence was key to determining what outcome was driving the behavior
- Consequence – *dad would take Ben by himself back to his house, to calm him*



Other services/resources

- Speech and occupational therapy may be available to children who do not have an Autism specific benefit.
- Learn who provides these services in your area and who has developed expertise in Autism.
- Don't forget:
 - Community Service
 - Respite
 - Recreation

Summary:

- At this point, we hope you can describe how primary care providers can help in the early identification of ASD/DD and the basic concepts of ABA.
 - We have talked about why early identification is important,
 - How primary care can use screening and surveillance to identify children who should be evaluated for ASD/DD,
 - And what a primary care provider should do if they have concerns about ASD/DD in a young child.
 - Describe the basic concept of ABA

Medical Home

- Take a moment to think about what you would like your primary care provider to do for you.
- Tell us...

Medical home

- Now put on your professional hat, take a moment to think about what you would like your clients'/students' primary care providers to do for them and for you.
- Tell us...

There's no place like home



A Medical Home

Background



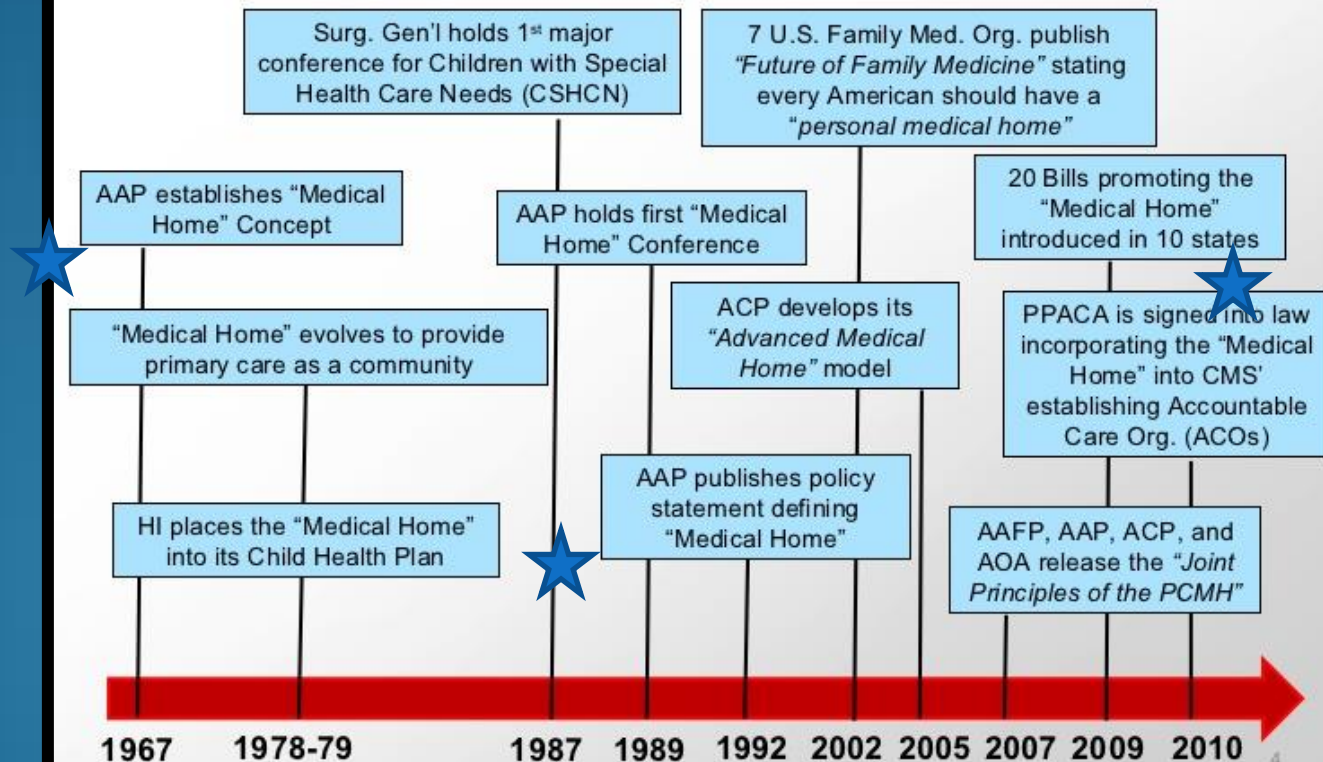
The **medical home** is a concept first introduced by the American Academy of Pediatrics (AAP) in 1967.

In its initial version, the AAP defined the **medical home** as the center of a child's **medical** records. At the time, the care of children with special health care needs was the primary focus of the **medical home** concept.

Since then, the medical home has evolved to reflect the changing needs and perspectives in health care.

History

PCMH Evolution Timeline



What is it ?

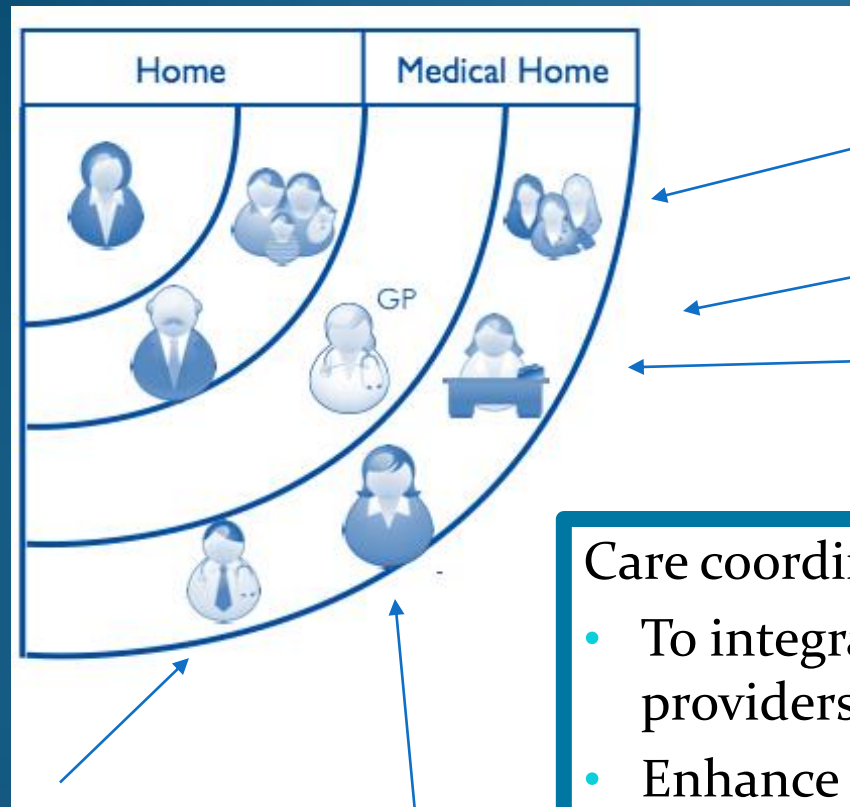


A family-centered medical home is **not** a building, house, hospital, or home healthcare service, but rather an approach to providing comprehensive primary care.

The American Academy of Pediatrics (AAP) defined Medical Home in a Policy Statement published in 1992. This policy statement contained an expanded and more comprehensive definition of the Medical Home model in hopes of clarifying multiple misinterpretations of this complex model.

The AAP further developed the medical home as a model of delivering primary care that is accessible, continuous, comprehensive, family-centered, coordinated, compassionate, and culturally effective to every child and adolescent.

What does Care Coordination have to do with it?



Therapists

Educational Services

Behavioral health

Care coordination is intended:

- To integrate care among multiple service providers
- Enhance the caregiving ability of the family
- Maximize the potential of the child.

Community
Based
Partners

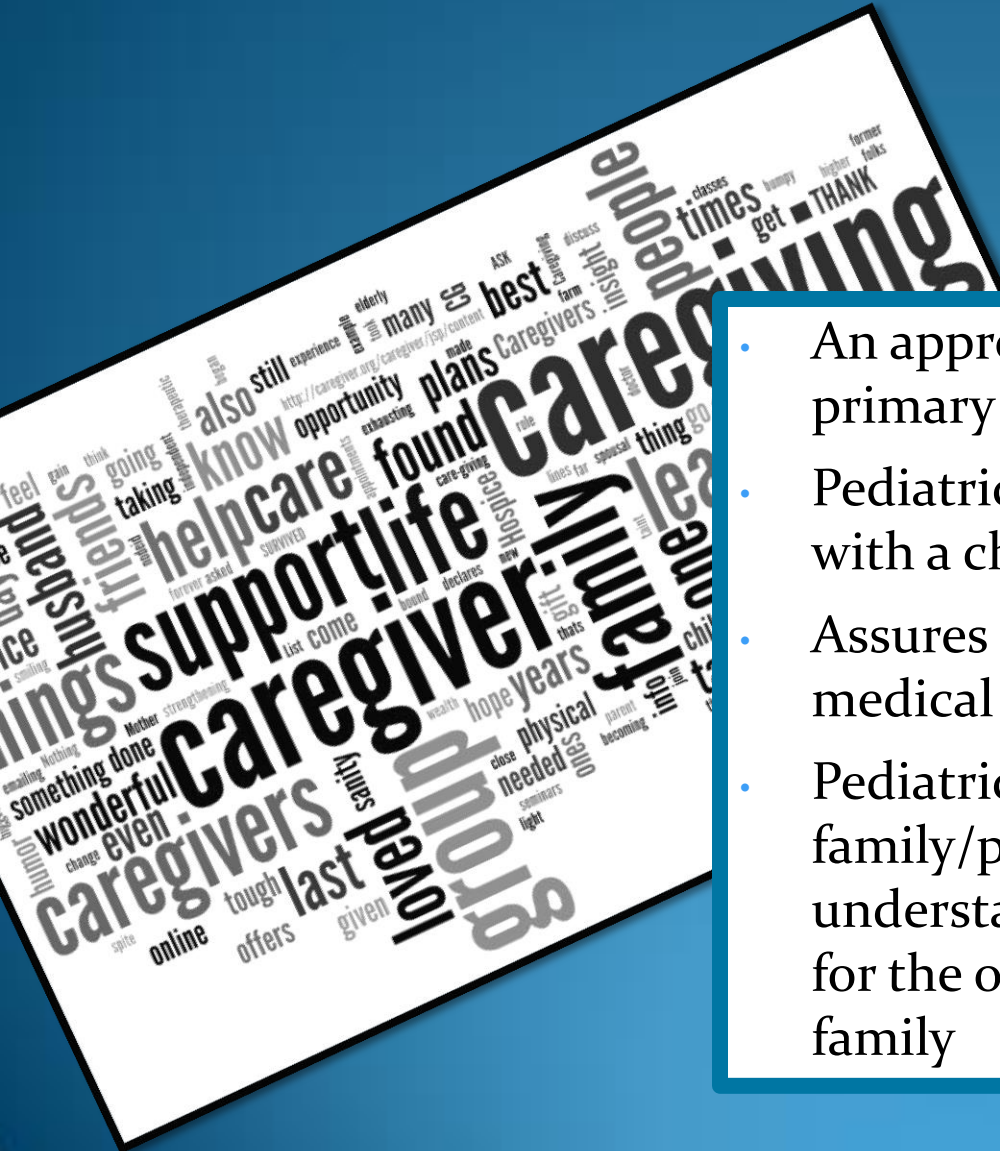
Specialists

Care Coordination



- Needs driven
- Team-based approach
- Families as partners
- Sharing information
- Integration of multiple providers
- Supports caregiver
- Higher patient satisfaction
- Results in best outcomes

Pediatric Medical Home



- An approach to providing comprehensive primary care
- Pediatric care team works in partnership with a child and a child's family
- Assures all of the medical and non-medical needs are met
- Pediatric care team can help the family/patient access, coordinate, and understand services that are important for the overall health of the child and family

Pediatric Medical Home



- Family-centered partnership
- Community-based system
- Sharing information
- Uninterrupted care
- Appropriate payment

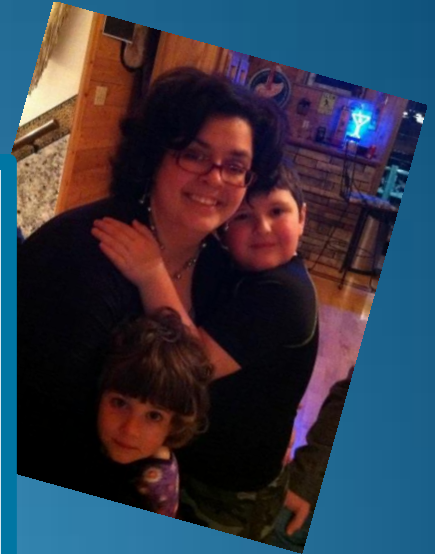
Characteristics of a Medical Home



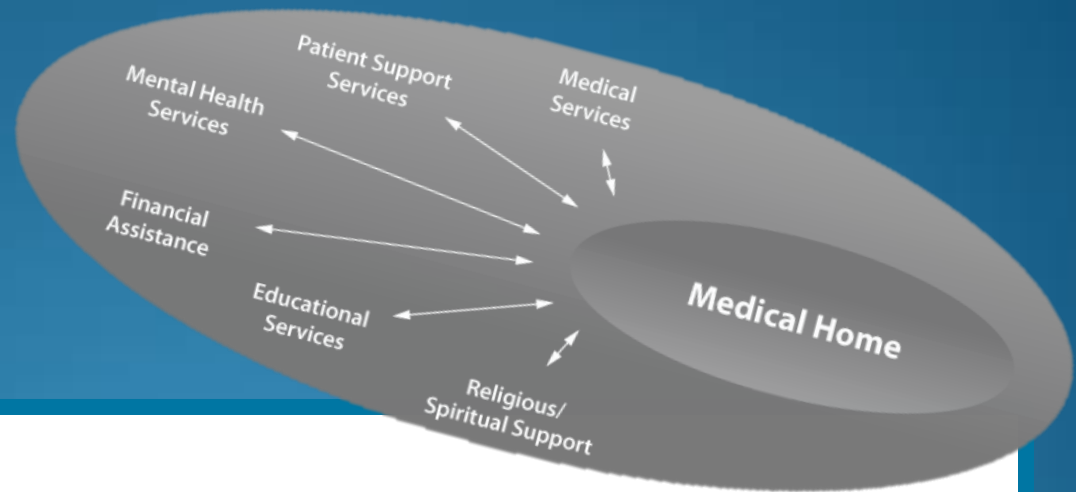
- Accessible
- Continuous
- Comprehensive
- Coordinated
- Compassionate
- Culturally Effective
- Family-Centered

Role of Family Members

- Constant in the life of the child
- Experts in the individual strengths and needs of the child
- Supervisors of those who coordinate the child's care
- Visionaries who see the big picture and long term goals



Benefits



- Doctors and office staff know your child and family
- Respectful family/professional partnership
- Family feels supported
- Connections to community-based resources
- Partnership promotes health and quality of life as your child grows and develops into adulthood
- Empowered to be an active participant at all levels of care



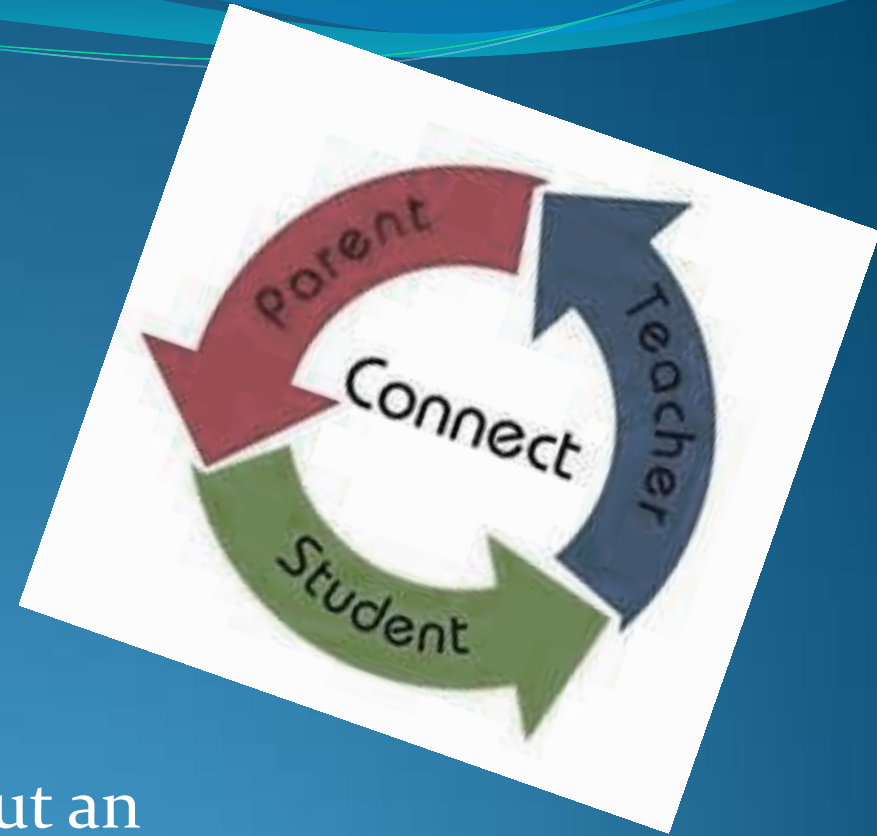
Resources

Medical Home Resources					
Agency	Phone Number	Local, State, National	Website	Link to Facebook Page	
Center for Medical Home Improvement (CMHI)		National	www.medicalhomeimprovement.org	Center for Medical Home Improvement	
Institute for Family Centered Care		National	www.familycenteredcare.org	Institute for Patient- and Family-Centered Care	
Medical Home Portal		National	www.medicalhomeportal.org	Medical Home Portal	
National Center for Medical Home Implementation (NCMHI)	847-434-7605	National	www.medicalhomeinfo.org	National Center for Medical Home Implementation	
National Center for Medical Home Implementation/Transition	800-433-9016	National	www.medicalhomeinfo.org/how/care_delivery/transitions.aspx		
National Initiative for Children's Healthcare Quality (NICHQ)		National	www.nichq.org	NICHQ - National Institute for Children's Health Quality	
Region 4 Midwest Genetics Collaborative		National	www.region4genetics.org	Region 4 Midwest Genetics Collaborative	

Summary

- At this point, we hope you can describe a family-centered medical home
- Advise families on what to expect from a family-centered medical home so every child with special health care needs will have access to high quality health care that is coordinated with developmental, educational, and behavioral health.

Family-Professional Partnerships



- Activity
- Take a moment to think about an ideal relationship between families and professionals
- Tell us...

Definition of an Effective Partnership

- Working toward a common goal
- Each member brings specific skill sets and values to the table
- Recognizing and respecting differences
- Active listening skills
- Mutual Respect and Trust

Working with Families:

- Remove barriers of communication
 - First name basis, everyone is on equal footing
 - Speak in plain language, remove acronyms from discussion
 - Understand hidden/unspoken dialogue
 - Fear, anger, uncertainty
 - Past experiences
 - Incorrect or inaccurate information

Maintaining the Partnership:

- Delicate Balance
 - Cooperation and compromise
 - Remaining open and honest
 - Be prepared for mistakes from all sides, admit them and move on
 - Maintaining a forward-thinking attitude
 - Don't get stuck in the mire

Summary

- At this point, we hope you can describe the elements of an effective family-professional partnership
- Give examples of how to remove barriers to communication

Questions/Discussion