

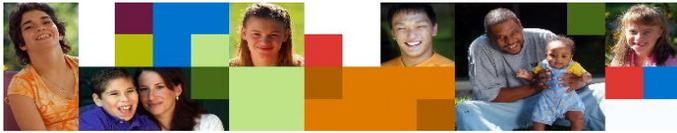
The Critical Role of Patients and Families in Implementing the Medical Home Approach

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Environment
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A Medical Home **System** Supporting

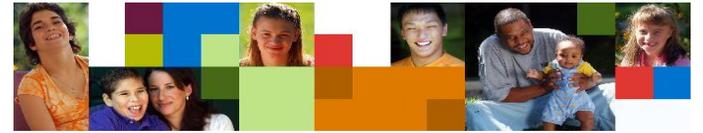
Individual Health Care Practices to
Provide a Medical Home **Approach**





Objectives

- • *Understand the family perspective within the Medical Home concept*
- • *Understand how cultural competence intersects with the Medical Home concept*
- • *Explore the difference between family involvement, family advocacy and family leadership*
- • *Understand the progression of family leadership*



Colorado's Medical Home Initiative

The Colorado Medical Home Initiative is a statewide effort to build systems of quality health care for all children while increasing the capacity of providers to deliver care to kids in our state.



Colorado's Medical Home Definition per Legislation

“ An appropriately qualified medical specialty, developmental, therapeutic, or mental health care practice that verifiably ensures continuous, accessible, and comprehensive access to and coordination of community-based medical care, mental health care, oral health care and related services for a child. ***..If a child's medical home is not a primary medical care provider, the child MUST have a primary medical care provider to ensure that a child's primary medical care needs are appropriately addressed.***”

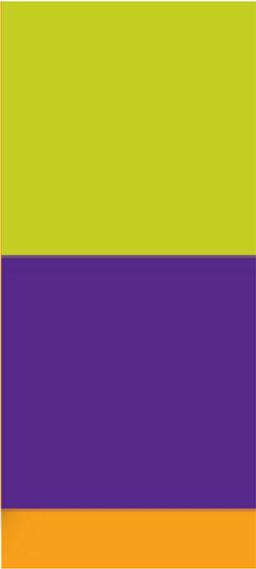


Guiding Principles

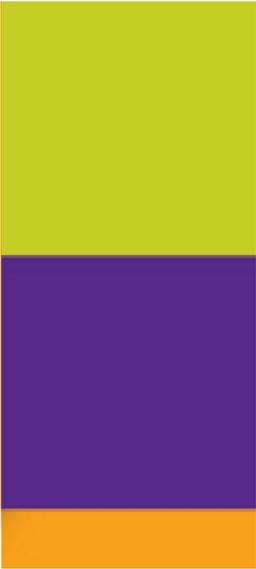
Title V is a facilitator in shifting the paradigm of health care delivery in response to changes in the traditional PCP model:

- The concept of the health care ***team***
- Increasing educational opportunities for families to assure authentic partnerships
- Medical, Mental and Oral health providers are equal partners

Core Medical Home Components

- 
- **Accessible** – support of primary and specialty care capacity, insurance eligibility, advocacy
 - **Family Centered** – support of families as advocates, participants in *community* planning
 - **Continuous** – linking community resources, support of medical information transfer
 - **Comprehensive** – linking medical, mental health and dental providers to ensure global thinking about the total child and family

Core Medical Home Components



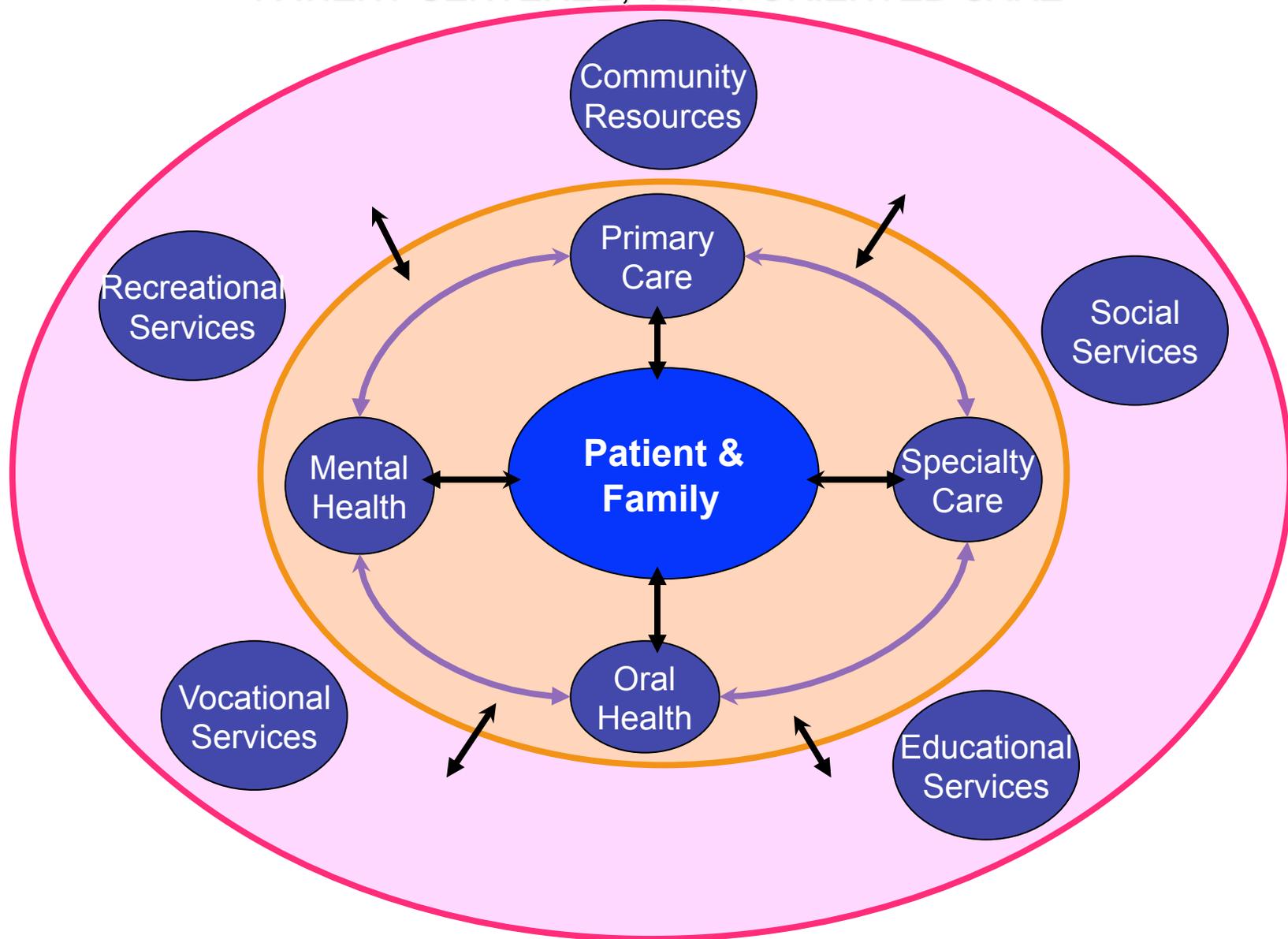
- **Coordinated** – working with medical components (inpatient and outpatient), educational and community resources to ensure efficiency

- **Compassionate** – community resources include provision for respite care, linking to faith communities, and behavioral/mental health

- **Culturally Responsive** – culturally sensitive partners are recognized and linked to families

MEDICAL HOME APPROACH

PATIENT-CENTERED, TEAM-ORIENTED CARE



Health services are core while needed family supports are readily available.

Who's in charge... all of us



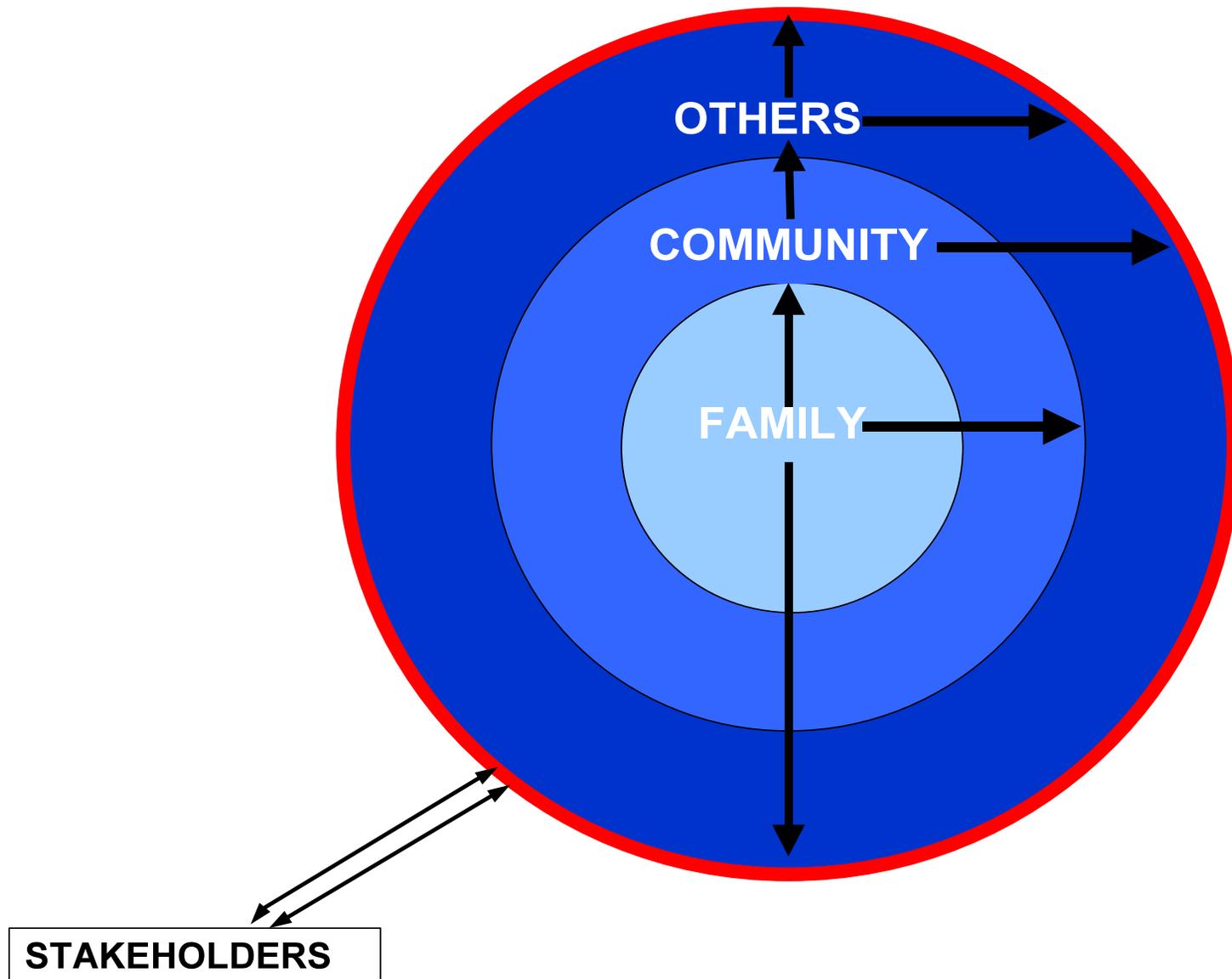
- Reality check – patient/families are the primary care coordinators
- Partnerships are critical
- Partnerships decrease duplication of services
- Systems approach to leadership development



Value of Consumer Input

- Able to identify gaps as well as solutions
- Core concept of wellness are shared
- Positive movement in health care reform
- Demonstrated in other areas of business sector, i.e. product marketing
- Historically, health care industry elicits minimal consumer input

PROGRESSION OF FAMILY LEADERSHIP





Families as Partners

- Embracing families as a resource not simply as a consumer of services
- Integrating the core concept that CYSHCN are not asking to be “fixed”
- Understanding the difference between family representatives and family leaders
- Invest in family leadership development and utilization thereof
- Respect the process of leadership development

Examples of Integrating Family Leaders into Medical Home efforts

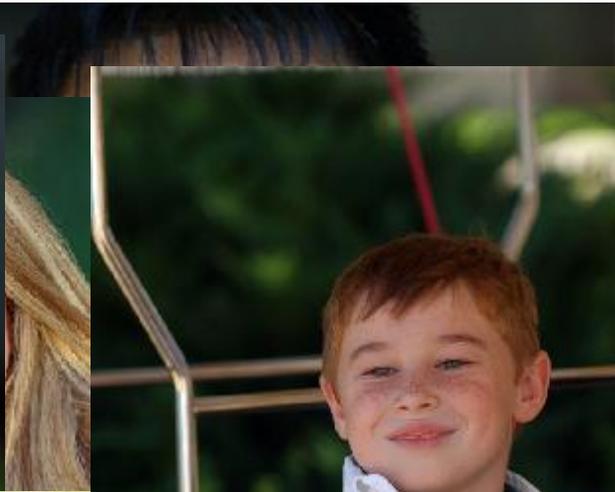


- Understanding families are a valuable resource and human capital
- Supporting emerging family leaders to attend national and state conferences
- Equitable compensation
- Systems approach to leadership development

Recommendations for future directions

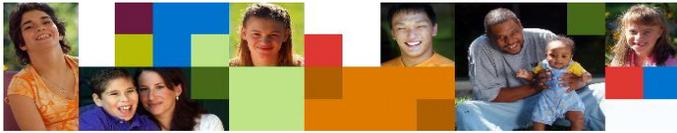


- Support strategies to credential consumer leaders
- Develop a Patient Advisory mechanism
- Support emerging consumer leaders to attend national and state conferences
- Equitable compensation
- Share impact of successful consumer involvement



Helpful Resources/References

- American Academy of Pediatrics, National Center of Medical Home Initiatives for Children with Special Needs
www.medicalhomeinfo.org
- Center for Medical Home Improvement,
www.medicalhomeimprovement.org
- National Initiative for Children's Health Quality,
www.NICHQ.org
- American Academy of Family Physicians,
www.futurefamilymed.org
- American College of Physicians,
www.acponline.org/advocacy/?hp
- Health Care Program for Children with Special Needs
www.hcpcolorado.org
- Colorado Children's Health Access Project
www.cchap.org



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ColoradoMedicalHome.com

ColoradoFamilyLeadership.com

Journeys in Family Centered Care

Benefits, Barriers, and Big Successes

A presentation by the
PA Medical Home Initiative

Renee Turchi, MD, MPH



American Academy
of Pediatrics
DEDICATED TO THE HEALTH OF ALL CHILDREN®
Pennsylvania Chapter



DEPARTMENT OF
HEALTH

U.S. Department of Health and Human Services
HRSA
Health Resources and Services Administration
Maternal and Child Health Bureau



What is Patient/Family Centered Care?

- Dignity & Respect
- Information Sharing
- Participation
- Collaboration

Institute for Family Centered Care, 2008



Family Centered Care

- Core element of Medical Home
- “..assures health and well being of children and their families through respectful family professional partnership. It honors the strengths, cultures, traditions, and expertise that everyone brings to the table”
 - Bishop, Wall, Arango, 2002-04.



EPIC IC
Educating Practices
in Community
Integrated
Care



How do practices participate?

- EPIC IC practices:
 - Participate in monthly teleconferences
 - Attend bi-yearly quality improvement conferences
 - Are provided education on:
 - identification of CYSHCN
 - Parent Partner recruitment
 - utilization of Parent Partners
 - coding strategies
 - time management
 - “hot topics”-transition to adulthood, cultural competency

Parent Partners



Why Parent Partners?



How to Choose a Parent Partner

- Parents who:
 - have experienced various systems of care
 - have a desire to help other parents navigate the systems of care
 - child is not newly diagnosed
 - have good communication skills – especially listening



Different Priorities

Parents	Physicians	Rank of Service
9	1	Respite Care
21	2	Day Care
3	3	Parent Support Groups
10	4	Help with Behavior Problems
2	5	Financial information or help
20	6	After-school child care
15	7	Assistance with physical household changes
6	8	Vocational counseling
5	9	Psychological services
22	10	Homemaker services
4	13	Recreational opportunities
1	14	Information about community resources

-Liptak et al. *Pediatrics*, 1989.

Engaging Parent Partners

Focus Groups

- Invite 10-12 parents
- Provide food, parking, child care reimbursement
- Medical home concept and role of FCC
- Expectations
- Discuss positive aspects of practice
- Discuss areas for growth.
- Examples include scheduling, referral processing, telephone call backs, on-call protocols, office visits

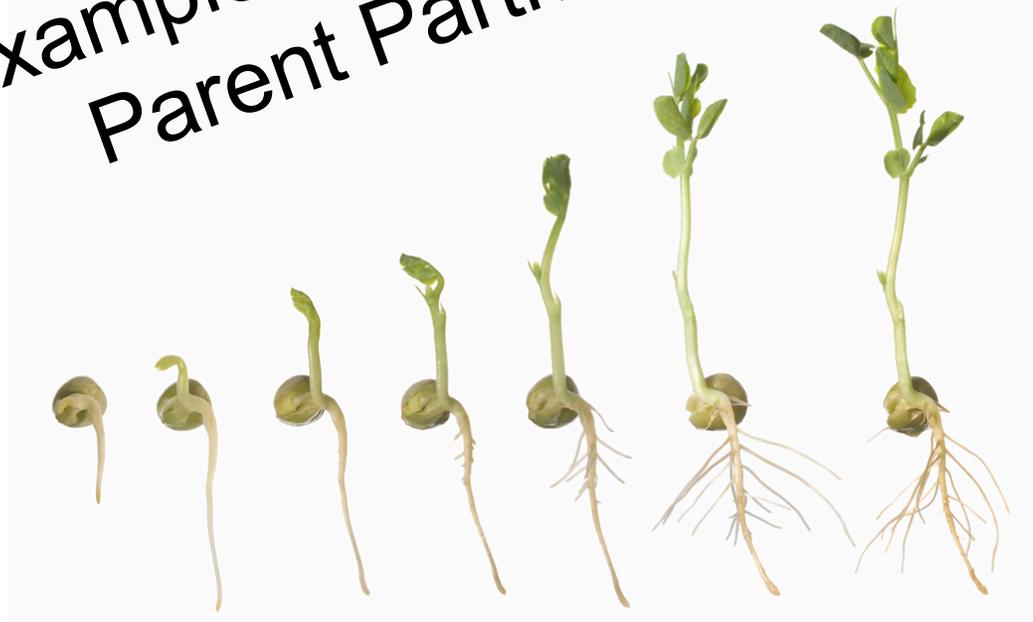


Maintaining and Sustaining Parent Involvement

- Avoid tokenism
- At least 2-3 parents per practice
- Varying age and diagnosis of CYSHCN
- Contract
- Invite to staff meetings
- Family Faculty
- Family Advisory Council



Examples of Impact of Parent Partners



Examples of Positive Feedback

- Care plan components
- How to use care plans
- Bulletin Boards
- Parent catalyst for quality Improvement



Data Collection with Families and Results



EPIC IC Family Survey

- Areas measured on the survey:
 - Components of the Medical Home
 - Accessibility
 - Parental satisfaction/trust
 - Health care utilization
 - Unmet medical needs
 - Demographic information

www.pamedicalhome.org



Pennsylvania
Medical Home Initiative



EPIC IC

Educating Practices in
Community-Integrated Care

A Medical Home is not a building,
a house, or a hospital...

...it is an approach to health care
that emphasizes the partnership between
pediatric clinicians and families,
providing care for children and
youth with special health care needs
(CYSHCN) that is:

- accessible
- continuous
- comprehensive
- family-centered
- coordinated
- compassionate, and
- culturally-effective



Parents & Caregivers
START HERE



Medical Practices
START HERE

American Academy
of Pediatrics
DEDICATED TO THE HEALTH OF ALL CHILDREN™
Pennsylvania Chapter

Especially for Parents

- “Especially for Parents” is a Web 2.0 application, designed to increase in value as the size of the community and activity level increases.
- Launched in September 2008
- The website operates under the premise that parents are experts and have valuable insights and information to share. Knowledge and offer support.
- Members are able to start a discussion, share tips, tricks and shortcuts, offer support to others, write a blog, create a group for parents with similar interests or situations, create a virtual meeting spot for a local community group, promote events and invite friends to join the web community



- Anyone can use the social networking site, including parents outside of Pennsylvania!
 - Visit us by going to www.pamedicalhome.org and clicking on the parents button

The *Especially for Parents* social networking site, hosted by the EPIC IC Pennsylvania Medical Home Initiative, was launched in September of 2008.

As of December, the site had over 100 members representing parents of children with special needs, health care professionals, government employees, and nonprofit employees.

Any community member can contribute content on *Especially for Parents*.

Members can:

- Ask questions in the forums
 - Answer questions
- Ask for or provide emotional support
 - Post a link to a web page (such as when sharing a favorite resource)
- Promote a community event or find out about community events
 - Search for other community members with similar interests (such as autism or transition)
- Browse articles and resources posted on the site by the PA MHI
 - Write their own blog
- Subscribe via RSS feeds in order to easily follow discussions of interest on the forum

Social Networking and the EPIC IC Pennsylvania Medical Home Initiative

Especially for Parents
A network for parents of children and youth with special needs
Hosted by the PA Medical Home Initiative

[Main](#) | [My Page](#) | [Members](#) | [Forum](#) | [Groups](#) | [Events](#) | [Blogs](#)

Members
This community for parents of Children and Youth with Special Health Care Needs grows out of Pennsylvania, but everyone is welcome!
[View All](#)

Friday Afternoon Blog
[Healthy Lifestyles for Kids: Part 1](#)
[Helping siblings cope](#)
[Autism Insurance Act](#)

Handy Links
[PA MHI home](#)
[About PA MHI](#)
[Resources](#)
[Forums Home Page](#)

How to use this site
[Changing your user name](#)
[Posting a picture](#)
[Forums vs. Groups](#)
[Promote/manage an event](#)
[Take the plunge!](#)

Articles
[An Estate Plan Built for Special Needs](#)
Wall Street Journal, Oct. 2008

Forum
Autism
A forum for parents whose children have been diagnosed with an autistic spectrum disorder
2 discussions
Current Events
Post a link to a current event related to children and youth with special health care needs. Tell us what you think about it!
2 discussions
Education
Post your tips or ask questions about IEP's, special education, wraparound services
1 discussions
En Español
0 discussions
Family & home life
2 discussions
Great Resources
Please share a great community resource for CYSHCN that you want more people to know about.

Welcome to PA Medical Home Initiative for Parents
[Sign Up](#)
or [Sign In](#)

Tech tip of the week
Did you know that if you "**friend**" someone, you can send them private messages?

Blog Posts
[Healthy Lifestyles for Kids: Part 1](#)
Posted by [Debbie](#) on December 16, 2008 at 1:42pm
[View All](#)

Events
[PEAL Conference on Inclusion](#)
[March 17, 2009](#) at 8am to [March 18, 2009](#) at 5pm – [Cranberry Township PA](#)

"Especially for Parents" is a Web 2.0 application, designed to increase in value as the amount of users and activity level increase. The website operates under the premise that parents are experts and have valuable insights and information to share. The largest challenges in this project are the differing levels of technical proficiency among users, the lack of internet access among some parents, the idea that the internet is a passive medium, and the large amount of time it takes to produce content and update the website..

Contact information

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