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Research indicates that parental involvement improves outcomes for children whether

the topic is healthcare, mental health or education. The Statewide Parent Advocacy Network (SPAN) has been involved in various medical home initiatives which include parent partners – trained parents of children with special healthcare needs who serve as part of the medical home quality improvement team. SPAN educates and engages parents to be involved at all levels as partners in our medical home activities. This article includes lessons learned, best practices and suggested ways pediatricians can foster these partnerships to enhance outcomes for the children they care for and their families.

It is important to note that SPAN's medical home projects focus on the Maternal/Child Health Core Outcomes for Children and Youth with Special Health Care Needs which are:

1. Early/continuous screening to identify all needs
2. Access to a medical home to coordinate needed services
3. Adequate healthcare financing to cover needed services
4. Community based services
5. Family engagement and satisfaction with services
6. Transition to adult healthcare and other systems of care



Photo www.fmstudented.org

This work is conducted in collaboration with partners such as the New Jersey Chapter, American Academy of Pediatrics, the NJ Department of Health Title V program, and many other state, local, disability, medical/health, and community-based organizations.

An effective medical home is:

- family-centered
- continuous
- comprehensive
- coordinated
- compassionate
- culturally competent

Keeping the core outcomes and tenets of the medical home in mind, practices are able to collaborate with parent partners to improve outcomes¹ for children with special health care needs and their families.

Effective Parent Partners

What are the qualities that pediatricians should look for in partnering with parents in their practice?

Experience: Parents should have a child with a disability or special health care need(s) and some experience with navigating across systems such as health, mental health and education. Parents should be comfortable working as a team and speaking in a group setting.

Input: Parent partners should be able to share their story in a way that will have a positive impact on practice level changes. Their input is on behalf of all families, not just their own. Parent partners should recognize that this isn't a support group and if a parent is looking only to benefit their child, they aren't ready to be a parent partner. Pediatricians must value the input of their parent partners so parents feel their contributions are valuable.

Representation: Besides speaking on behalf of other families, parent partners should represent the diversity of the families in the practice. Cultural and linguistic competency on the part of the practices are essential for effective medical home implementation. Parent partners can also ensure that the practice has the necessary resources available and translated for their non-English speaking families.

Commitment: In addition to being committed to help other families, parent partners should ensure that they have adequate time to participate as a member of the medical home team. There may be times when a parent may not be able to participate if they are dealing with their child's own medical crisis so practices should identify more than one parent partner to allow for more flexibility and support more family participation as well as ensure broader representation of their patient base.

Training: Parent partners and practice staff can receive training from family organizations such as Family to Family Health Information Centers or Family Voices State Affiliates on the core outcomes to improve the effectiveness of their Medical Home. Additional training topics can include health advocacy, family support, and community resources. Providing compensation to parent partners for their time such as stipends, mileage and/or childcare reimbursement, etc., is greatly appreciated, and helps make them feel more respected. This will also enhance the opportunity for underserved and low-income families to participate.

Ongoing Communication: Parent partners and practices should discuss how often they will communicate throughout the process and the type of communication they will use. Team meetings should be scheduled to include parent partners, address concerns and improve quality of services that would lead to overall satisfaction of families in the practice. Ongoing open communication will lead to continuous improvement throughout the process.

These are some of the lessons learned to enhance pediatric/parent partnership during SPAN's Medical Home implementation projects.

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The benefits of partnering with parents in the medical home far outweigh any temporary disruption of the practice routine. The practice, their families, and most importantly the children and youth with special health care needs will benefit from these best practices for developing and building on pediatric/parent partnerships.

"Families are key to promoting medical homes at the practice, policy, and practical level and accomplishing our goal of a medical home for every child. Families are best able to communicate with other families about the benefits of a medical home and most effective in advocating for the needs of their children. They also have an important role to play in educating healthcare professionals around the changes in attitudes, behaviors, practices, and procedures that are needed to truly implement medical homes." In order to ensure that all families feel welcome and comfortable in medical homes, a diversity of families need to be involved in this effort." -Merle McPherson, MD-

"Our parent partner has offered to speak with other parents in our practice for support. It is extremely invaluable. We have a wide range of experience with our parent partners to refer other parents to." - A NJ medical home learning collaborative practice about the value of a parent partner "They wanted my feedback and perspective. It made me feel important that they reached out to me to assist them. After working with them it was great to see that the practice wanted to improve for all families." - NJ medical home parent partner

Resources

Family Voices National Center for Family/Professional Partnerships (list of state family groups)

<http://www.fv-ncfpp.org/>

<http://www.fv-ncfpp.org/activities/fcca/> (nationally validated Family Centered Care Assessment)

Medical Home - Information for Providers
http://www.spannj.org/cyshcn/core_outcome_2/Medical_Home_Provider_Brochure.pdf

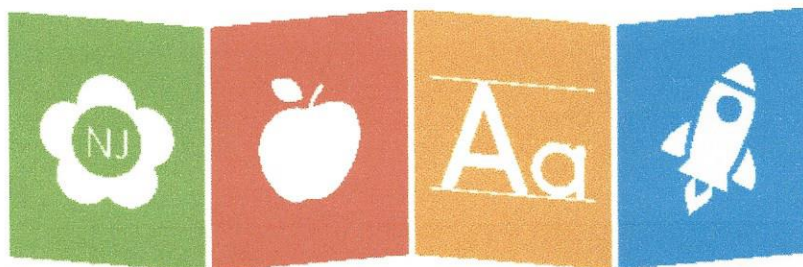
Medical Home - Information for Families
<http://www.thefamilymatterswebsite.org/PDF/MedicalHomeFAMILYBrochure.pdf>

National Center for Medical Home Implementation – Family Engagement in the Medical Home
<https://medicalhomeinfo.aap.org/about/Pages/May-2015.aspx>

Lauren Agoratus M.A. Counseling is the parent of a youth with multiple disabilities and is the NJ Coordinator of Family Voices, the national network that "works to keep families at the center of children's health care." She also serves as the Central/Southern Coordinator for the NJ Family-to-Family Health Information Center (F2FHIC). In NJ, Family Voices and F2FHIC are housed at the Statewide Parent Advocacy Network (SPAN), www.spanadvocacy.org. Malia Corde is SPAN's Parent to Parent Coordinator, and Improving Pregnancy and Birth Outcomes Program Manager, and Director of Medical Home Initiatives. Deepa Srinivasavaradan is CDC's Act Early Ambassador to NJ housed at SPAN and SPAN Family Resource Specialist.

¹Slides 19-31 www.signetwork.org/file_attachments/433/download

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