

# Building Community-Based Medical Homes for Children

## Illinois Medical Home Annual Newsletter

FOURTH EDITION

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ILLINOIS CHAPTER OF THE AMERICAN ACADEMY OF PEDIATRICS

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### *What is a medical home? What does it mean for families?*

A medical home is not a building, house, or hospital, but rather an approach to providing comprehensive primary care. A medical home is defined as primary care that is accessible, continuous, comprehensive, family centered, coordinated, compassionate, and culturally effective.

In a medical home, a pediatric clinician works in partnership with the family/patient to assure that all of the medical and non-medical needs of the patient are met. Through this partnership, the pediatric clinician can help the family/patient access and coordinate specialty care, educational services, out-of-home care, family support, and other public and private community services that are important to the overall health of the child/youth and family.

*The Medical Home. Pediatrics. 2002; 110; 184-186.*

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## Acronyms

AAP-American Academy of Pediatrics  
CMHI-Center for Medical Home Improvement  
CYSHCN-Children and Youth with Special Health Care Needs  
ICAAP-Illinois Chapter, American Academy of Pediatrics  
IMHP-Illinois Medical Home Project  
MCHB-Maternal and Child Health Bureau  
NCQA-National Committee for Quality Assurance  
NICHQ-National Initiative for Children's Healthcare Quality  
QI-Quality Improvement

*Photos are courtesy of the Illinois Chapter of the American Academy of Pediatrics.*

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## Letter from the Editor: Medical Home Advancements in Illinois

By Kathy Sanabria, MBA, PMP

Newsletter Editor

ICAAP Senior Director, Medical Home Initiatives

In 2000 the federal government made “medical home” a priority in Healthy People 2010. At that time there was no organized effort to bring medical home initiatives to Illinois. In 2002, Charles Onufer, MD, FAAP, Director of the Division of Specialized Care for Children (DSCC), Illinois’ Title V Agency, began making presentations to primary care practices about medical home. Over two years he laid the groundwork...teaching about this concept. In 2004 the Illinois Chapter of the American Academy of Pediatrics (ICAAP) and DSCC submitted a grant application to the Maternal and Child Health Bureau (MCHB) to implement the *Illinois Medical Home Project (IMHP)*. The MCHB funded the IMHP to help 12 practices with medical home implementation. Practices learned how to use resources from the National Center for Medical Home Initiatives and the Center for Medical Home Improvement and pilot-tested a model of care developed through this project. The IMHP surpassed expectations and reached 19 practices during its five-year tenure. With this success, ICAAP and DSCC developed three new medical home initiatives.

The *Building Community-Based Medical Homes for Children (BCBMHC)* program currently works with seven practices across Illinois, including Federally Qualified Health Centers and public health clinics, to further implement the curriculum developed through the IMHP. Participating practices receive medical home quality improvement (QI) support and resources, including a QI team facilitator. In addition, they participate in a learning collaborative and attend two medical home training sessions. Three of the practices from the IMHP serve as mentor teams. The program has expanded so quickly that there is a list for practices to join the next cycle. The program is primarily supported through grants from the Michael Reese Health Trust and the Chicago Community Trust, with a small amount of funding from the MCHB.

**Happy Anniversary**  
*The Children’s Bureau was established in 1912. In 1935, the U.S. Congress enacted Title V of the Social Security Act, which authorized the Maternal and Child Health Services programs and provided a foundation and structure for assuring the health of American mothers and children. On behalf of Illinois providers and families...we wish the MCHB and its dedicated staff a very happy 75th anniversary!*

In 2008, ICAAP applied for and received a two-year grant from The Commonwealth Fund to implement the *Coordinating Care Between Early Intervention and the Primary Care Medical Home* project. The project aims to improve communication and care coordination among primary care practices (PCPs), Child and Family Connections (CFCs) staff, and families. ICAAP, Advocate Health Care’s Healthy Steps for Young Children program, and the Illinois Early Intervention Bureau developed and pilot-tested training curricula for PCPs and CFC staff. The training is being implemented across Illinois and is being shared with Part C Coordinators around the country.

In 2009 ICAAP and DSCC applied for and received a grant from the MCHB to implement the *Integrated Systems of Services for Illinois Children and Youth with Special Health Care Needs (CYSHCN)*. The Integrated Youth Services project will work to spread the medical home model and improve access to quality, comprehensive, coordinated, community-based services for CYSHCN and their families with a focus on helping to transition youth into adult service systems.

Over the past decade Illinois has built upon the dedication of many individuals to spread medical home implementation. Dr. Onufer retired as Director of the DSCC in 2008, but continues to be recognized as Illinois’ first Medical Home Champion. Many other DSCC staff members continue to make medical home implementation a priority, especially Gerri Clark, Donna Scherer, Rita Klemm, Robert Cook, and Darcy Contri. ICAAP thanks these individuals for developing an extraordinary partnership among the Illinois Title V DSCC agency, the AAP Illinois Chapter, the Illinois Department of Healthcare and Family Services, the Illinois Academy of Family Physicians, and others. These efforts have been enhanced by grant funds received from the MCHB, The Commonwealth Fund, the Chicago Community Trust, and the Michael Reese Health Trust. Thank you for helping to support our work and vision: to build medical homes for all. To learn more about Illinois medical home efforts, please read this newsletter and visit our Websites:

ICAAP:

<http://www.illinoisaaap.org/projects/medical-home/>

DSCC:

<http://www.uic.edu/hsc/dscc>

**Lucky**  
*Right now, with good access to our pediatrician and the hospital, I feel we are very lucky.*

– A Parent

# 1. The Family-Centered Medical Home in Pediatrics

By Richard Antonelli, MD, MS, FAAP; and Renee M. Turchi, MD, MPH, FAAP

Excerpts of this article are from Antonelli, R. and Turchi, R. M. (2009). *The family-centered medical home in pediatrics. Pediatric Annals*, 38(9), 472-474.

“A core element of the medical home model is its family-centeredness. This is often provided through the family-professional partnership, empowering families and patients to self-manage their care and to advocate for their needs. This notion has a long tradition in pediatrics, but is just catching on more broadly in national discussions of health system re-design. In order to include families as partners, we must value and embrace their diversity and look at health and medical care from a strength-based perspective instead of the historical view of a deficit based approach. Goode, Haywood, Wells, and Rhee present a powerful framework for designing systems of care that is integrally culturally competent and family-centered.

How do we transform systems that are missing key elements? In order to close the “quality chasm,” it is essential to create systems for delivering care coordination services. But what is care coordination, and how does it differ from case management? What about the roles of families, nurses, social workers, physicians, and others in providing care coordination? McAllister, Presler, Turchi, and Antonelli make the case that a family centered, multidisciplinary approach to care coordination is critical. They present a framework, which includes competencies, functions, and outcomes for care coordination. In order for the medical home to be high performing, it requires links to community-based organizations that support the needs of families, children, and youth. The work does not have to be done by primary care providers alone, but by teams of which they are a part, and over which they have accountability in the medical home. The framework for care coordination must develop, nurture, and continuously improve the functionality of those relationships within the healthcare setting as well as across the broader community. In short, care coordination must develop organically from the community, building on assets and supporting needs broadly. The roles of federal, state, and community partners become apparent when the necessary linkages and expected outcomes are defined.

As we build the system of care, the medical home must serve as a hub for communications about the patient and family. Stille eloquently informs the discussion by demonstrating methods and tools that can be used to improve how information is transferred among families, primary care, and subspecialty providers.

Transforming the way “consultations” are managed will be a critical driver of re-design. Utilizing care plans to delineate roles and responsibilities for families, PCPs, and subspecialists will introduce measurable accountability to the system. Developing mechanisms that define frameworks for different models of consultation will be essential.

What about youth transitioning from pediatrics to adult systems of care? Transition is a process. It is not an event. The percent of youth with special healthcare needs who receive structured services preparing them for transition to adult systems of care continues to rise with advances in medicine, but also persists as the lowest performing measure with respect to children with special healthcare needs in Healthy People 2010. There are many reasons for this, but it is urgent that this population and their caregivers be properly prepared for the process of transition. White and Hackett make the compelling case and offer tools and strategies for enabling this as a core component of the medical home.

While we continue to encourage the implementation of the medical home model with the current workforce of practitioners, it is essential to fuel this fire in our learners and trainees. Incorporating medical home concepts into training programs for residents and medical students ensures its sustained success, similar to the way that other standard practices such as developmental screening or immunizations are taught. Narayan describes the landscape for this educational platform and the current role of pediatricians actively working to build on existing residency competencies to ensure the future of the family-centered medical home for children and youth.

Business leaders often cite: “No margin, no mission!”<sup>6</sup> How can we transform healthcare, optimizing value for all stakeholders, if the appropriate resources are not committed to the work? Wegner and Antonelli make the case that although there is no single, universally endorsed model for financing the medical home, we do know that the current scheme is untenable. They provide an overview of potential policy directions and offer some practical tips for the primary care pediatric provider. It is encouraging that policy and political discussions are all addressing the need for payment reform, with movement away from volume-based financing and toward paradigms, which reward outcomes and support accountability.

Pediatricians have always advocated first and foremost for the wellbeing of children and families. The national conversation on health system transformation has now firmly placed the family-centered medical home model

as a critical element of the value proposition. Although the evidence is mounting that high performing medical homes can play a key role in enhancing patient-centered outcomes, there is much more to be done. Robert Frost reminds us of next steps for health system transformation:”

*“The woods are lovely, dark and deep,  
But I have promises to keep,  
And miles to go before I sleep,  
And miles to go before I sleep.”*

## 2. Tools and Resources Available from the National Center for Medical Home Implementation

By Heather Stob and Angela Tobin, American Academy of Pediatrics

The National Center for Medical Home Implementation is a cooperative agreement between the Maternal and Child Health Bureau (MCHB) and the American Academy of Pediatrics (AAP). The National Center provides medical home resources, technical assistance, and support to physicians, families, and other medical and non-medical providers who care for children. Recently, the National Center has unveiled several new resources that we would like to encourage you to use in helping us to ensure that every child has a medical home. These resources include:



### National Center for Medical Home Implementation Web site

The National Center for Medical Home Implementation has launched a new and improved Web site (<http://www.medicalhomeinfo.org>)! The new site features a plethora of resources and information designed to help you learn more about family-centered medical home and how practices, families, communities and states are working on implementation. Informational destinations on the Web site include: the Medical Homes@Work e-Newsletter; How to Implement Tools/Resources; Training Resources; State Pages highlights information on state pediatric medical home initiatives, key contacts, partners, and related grant activities and initiatives; the Quick Links section containing links to valuable resources and information including the *Building Your Medical Home* toolkit, upcoming conferences, emerging issues and marketing materials; the For Families section that presents links to

tools and resources aimed at assisting families including the Building Your Care Notebook, Family-to-Family Health Information Centers, tips for partnering with your physician, and Title V; and National Initiatives including information on the many national medical home initiatives, including multi-payor demonstration projects and state grant initiatives that are rapidly increasing across the country.

For additional information about the Web site or the National Center for Medical Home Implementation, please contact Heather Stob at [hstob@aap.org](mailto:hstob@aap.org) or 800/433-9016, ext 4902.

### Measuring Medical Homes: Tools to Evaluate the Pediatric Patient- and Family-Centered Medical Home

The purpose of this monograph is to present various tools available and in use to identify, recognize, and evaluate a practice as a pediatric medical home. Because no one tool is recognized as the de facto tool to assess pediatric practices, a review of the relative merits of existing tools will help inform purchasers, payers, providers, and patients in evaluating pediatric practices. Many of the multistakeholder and single-payer medical home demonstration projects focus on adult populations and adult outcomes. An understanding of tools to assess pediatric practices may assist such pilots in incorporating and evaluating pediatric practices in both practice transformation and payment reform.

The development of this monograph was funded by the American Academy of Pediatrics’s National Center for Medical Home Implementation through a cooperative agreement (U43MC09134) with the US Department of Health and Human Services, Health Resources and Services Administration,



Suzi Montasir, MPH, presents on the National Center for Medical Home Implementation administered by the American Academy of Pediatrics and funded by the Maternal and Child Health Bureau.

Maternal and Child Health Bureau. The monograph is free for anyone to view and can be accessed at <http://www.medicalhomeinfo.org/downloads/pdfs/MonographFINAL3.29.10.pdf>

For more information, contact Angela Tobin at [atobin@aap.org](mailto:atobin@aap.org) or 800/433-9016, ext 7621.

### **Building Your Medical Home Toolkit**

The AAP/MCHB *Building Your Medical Home* toolkit supports the primary care practitioner's development and improvement of a pediatric medical home. This toolkit also helps to prepare a pediatric office to apply for, and potentially meet, the National Committee for Quality Assurance (NCQA) Physician Practice Connections® Patient Centered Medical Home™ (PPC®-PCMH™) Recognition Program requirements. One key element of the toolkit is a crosswalk that the AAP created between each of the toolkit building blocks and the NCQA PPC®-PCMH™ Recognition Program 'must pass' elements. Patient care associated with the medical home improves outcomes, such as health status, timeliness of care, family centeredness and family functioning. The NCQA PPC®-PCMH™ standards provide a way to qualify and quantify care in the medical home. In some practices, scoring at NCQA higher levels has resulted in enhanced payment to the practice. The *Building Your Medical Home* toolkit is free for anyone to use and can be accessed at <http://www.pediatricmedhome.org>.

For more information on the toolkit, contact the National Center for Medical Home Implementation at [medicalhometoolkit@aap.org](mailto:medicalhometoolkit@aap.org) or 800/433-9016, ext 4311.

### **Medical Home Data Portal**

Brought to you by the Child & Adolescent Health Measurement Initiative (CAHMI), the National Center for Medical Home Implementation and the AAP, the *Medical Home Data Portal*

( <http://www.medicalhomedata.org/> ) presents state-by-state summaries and state comparisons on how children are meeting the overall criteria for having a medical home.

As Title V programs engage in policy-level discussions regarding the healthcare of children, this portal can provide state performance data on medical home for all children, including those with special needs. Data for these summaries and comparisons are taken from the National Survey of Children's Health and the National Survey of Children with Special Health Care Needs, which are sponsored by the federal Maternal and Child

Health Bureau and conducted by the National Center for Health Statistics. The medical home measure used for this data set includes an assessment of whether children and youth have a personal doctor or nurse, have a usual source of care, receive care that is family-centered, receive care that is culturally sensitive, obtain needed specialty care referrals, and receive needed help coordinating care across multiple providers and types of services.

This user-friendly resource has the capability to interactively search and compare measures by important subgroups of children—such as age, sex, race/ethnicity, insurance type and household income. Further, states can be compared to one another or against the nation on the percentage of children who receive ongoing, comprehensive and coordinated care within a medical home.

For more information, contact Angela Tobin at [atobin@aap.org](mailto:atobin@aap.org) or 800/433-9016, ext 7621.

## **3. Web-Based Resources on Medical Home**

### **National Resources:**

1. The **American Academy of Pediatrics** (AAP) National Center for Medical Home Implementation has developed a helpful new resource, the Building Your Medical Home Toolkit. The toolkit is designed to help practices that are implementing the medical home model for the first time as well as established medical homes that are interested in quality improvement. The toolkit is organized into six building blocks and includes downloadable forms and resources. It can also help practices prepare for application to the National Committee for Quality Assurance Physician Practice Connections® Patient Centered Medical Home (PPC-PCMH™) recognition program. The toolkit is available at <http://www.pediatricmedhome.org/>.

2. The **Utah Medical Home Portal** is a comprehensive website that offers medical home resources for both families and professionals. The site is easy to navigate and provides extensive information and tools to help improve care for CYSHCN. Visit the portal at <http://www.medicalhomeportal.org>.

3. The **National Center for Cultural Competence** provides information, tools, and resources to help providers deliver culturally and linguistically competent care to diverse patient populations. To access the site, go to <http://www11.georgetown.edu/research/gucchd/nccc/>.

4. The **Center for Medical Home Improvement** maintains an online knowledge and resource center with

### **Experts**

*We have a wonderful pediatrician who considers us experts on our child and who works with us.*

– A Parent

numerous references on medical home transformation, evidence, measurement, coordinated care, and more. Find more information at <http://www.medicalhomeimprovement.org/>.

5. The **National Committee for Quality Assurance** is a private, not-for-profit organization that works to improve health care quality. Their Physician Practice Connections® Patient-Centered Medical Home (PPC®-PCMH™) program provides Recognition to primary care practices that function as patient-centered medical homes. For details about this program, visit <http://www.ncqa.org/>.

6. **Family Voices** works to ensure that all CYSHCN receive family-centered care by providing families with information and tools, building partnerships between professionals and families, and engaging in advocacy for policy change. To learn more about family-centered care, access their website at <http://www.familyvoices.org/>.

### Illinois Resources:

1. The **Illinois Chapter of the American Academy of Pediatrics** (ICAAP) has re-designed its website to provide more tools and resources in a user-friendly format. Learn more about ICAAP's educational programs and access materials to help build your medical home by visiting <http://www.illinoisAAP.org>.

2. The **Division of Specialized Care for Children** (DSCC), the Illinois Title V agency for CYSHCN, has been working to promote medical homes in Illinois since 2002. DSCC has developed Medical Home Primers for both physicians and families, along with various tools for building medical homes and improving health care transition. These materials can be accessed at <http://www.uic.edu/hsc/dsc/>.

3. The **Region IV Genetics Collaborative** has developed a number of resources and informational materials for children with inherited disorders, including a helpful guide for families entitled Partnering with your Doctor: The Medical Home Approach. Visit <http://region4genetics.org/> for more information.

4. The **Family to Family Health Information and Education Center** serves families of children and youth with special health care needs by providing information and referral services, health-related trainings, specialized training for parent leaders and organizations, and linkages to local, regional, statewide, and national partners. Visit their website at <http://www.thearcofil.org/familytofamily/index.asp>.

5. The **Arc of Illinois** provides extensive informational materials and trainings for individuals with disabilities

and their families. Members of the Arc receive daily emails with breaking news related to people with disabilities. Learn more at <http://www.thearcofil.org/>.

6. The **Illinois Academy of Family Physicians** offers conferences, resources, and tools to help build your medical home, including links to the American Academy of Family Physicians TransforMed program. Go to <http://www.iafp.com/> for more information.

## Web-Based Resources on Transition

1. The **Adolescent Health Transition Project** has compiled helpful tools and links to improve health care transition, including checklists, timelines, medical summaries, and more. Resources for providers and for teens are available. For more information, visit <http://depts.washington.edu/healthtr/>

2. The **Health Care Transitions Initiative** of the University of Florida provides links to guides and videos to help teens prepare for transition. You can also sign up for the Transition Digest, a monthly e-newsletter about health care transition. <http://hctransitions.ichp.ufl.edu/>

3. The **Waisman Resource Center** has developed guidebooks, training curricula, workbooks, stories, and a Spanish radio novella, all designed to improve health care transition. These materials can be obtained at <http://www.waisman.wisc.edu/wrc/pub.html>

4. **Healthy and Ready to Work** (HRTW) provides information on federal and state systems of services for CYSHCN, guides and toolkits to promote youth involvement, and numerous tools for providers, including transition planning brochures, screening and assessment tools, checklists, care plans, and patient education materials. HRTW also holds free monthly calls on various aspects of transition. Visit <http://www.hrtw.org/> to learn more.

## 4. Illinois Health Connect Update

By Margaret Kirkegaard, MD, MPH,  
Illinois Health Connect Medical  
Director

Numerous studies have shown that patients who have a medical home have better health outcomes and lower healthcare costs. In 2006, the Illinois Department of Healthcare and Family Services (HFS) moved to a primary care case management model called Illinois Health Connect (IHC) to ensure that HFS clients have a medical home.

**Respect**  
*All of our child's doctors  
have played an important  
role as part of our  
"medical team." We all  
have the utmost respect  
for each other.*

— A Parent

IHC is administered by Automated Health Systems and has created a primary care provider (PCP) network of over 5,600 primary care physicians, clinics and other providers who have agreed to create a medical home for their clients. Currently the IHC PCP network has a capacity for 5.3 million clients and approximately 1.8 million clients are enrolled. Clients living in some counties, including Cook County and the Metro East Counties have the option of selecting a Medicaid Managed Care Organization (MCO) for their medical home and approximately 200,000 patients are enrolled with an MCO.

Illinois Health Connect not only supports the participating PCPs in providing high-quality care but also outreaches to clients to educate them about the importance of using their medical homes. IHC provides numerous quality tools to participating providers including a monthly “panel roster” that lists the name and demographic information of each client who is linked to that medical home along with a summary of the patient’s most recent clinical information such as dates of last preventive care services, including mammography or well-child visits. IHC also provides electronic access to a database of claims that allows clinicians to determine what care has been provided to patients in the past two years, including prescription and immunization data. IHC hosts monthly webinars for providers on both clinical topics like pain management and operational topics like billing issues. Working with clients, IHC sends out a semi-annual patient education letter addressing such topics as appropriate ED utilization, smoking cessation and what to expect during a school-entry exam. IHC also assists clients with making well-child appointments with their medical home and helps clients locate specialty providers and ancillary medical services.

Providers who participate in Illinois Health Connect receive an enhanced fee schedule and a monthly care management fee for each patient who is linked to that provider regardless of whether or not the patient receives services during that month. In addition to the enhanced fee schedule and the care management fees, IHC has created a Bonus Payment Program for High Performance targeting 5 common clinical measures for quality improvement. These measures are: mammography rates, immunization rates, controller medication use in asthma, objective developmental screening rates and obtaining a yearly HbA1C measure in patients with diabetes. In 2009, over \$2.8 million was distributed to nearly 4,500 providers for care provided in 2008 that exceeded the quality standards. The 2009 and 2010 Bonus Payment Programs will target the same measures.

Approximately 260,000 IHC patients with chronic diseases and high utilization are eligible for additional disease management services through a program called Your Healthcare Plus (administered by McKesson Health Solutions). Nearly 100,000 of these patients are children and adults with persistent asthma which is a significant health problem in Illinois. Your Healthcare Plus provides additional care coordination ranging from face-to-face visits to phone support. For more information about Your Healthcare Plus, please review their website at <http://www.yourhealthcareplusdr.com> or contact McKesson Health Solutions at 1-800-973-6792.

Through securing a “best fit” medical home, IHC improves continuity of care, access to preventive services and coordination of chronic disease care for the client. IHC has reduced both inpatient hospitalizations and emergency room visits and estimates suggest a significant savings in FY 2008. In the 2009 Provider Satisfaction Survey, 91% of respondents (N=875) indicated that IHC was beneficial to their patients and 84% of respondents found the administration of the program to be satisfactory. In the 2009 Client Survey, both rural and urban clients who had been enrolled in IHC for longer than 6 months were interviewed via phone. In both groups, more than 95% of respondents were satisfied or highly satisfied with both the IHC program and their medical home. IHC is beginning to track population-based clinical metrics such as rates of immunizations and mammography. Some rates, such as the rate of developmental screenings, are beginning to show improvement.

For more information, check out the IHC website at <http://www.illinoishealthconnect.com> or contact the Illinois Health Connect Medical Director, Dr. Margaret Kirkegaard at [mkirkegaard@automated-health.com](mailto:mkirkegaard@automated-health.com).

## **5. Strengthening Service Delivery for Illinois Children at Risk**

*By Juanona Brewster, MDiv MTS MJ, Director, Early Childhood Development, ICAAP*

The Illinois Department of Healthcare and Family Services (HFS) in partnership with the Illinois Chapter, American Academy of Pediatrics (ICAAP) is pleased to announce receipt of a grant from the Assuring Better Child Health and Development (ABCD) three-year learning collaborative offered by The Commonwealth Fund and National Academy for State Health Policy (NASHP) for the *Illinois Healthy Beginnings II: Coordinating Medical*

*Knowledge  
Nice, friendly,  
knowledgeable office  
and providers ease  
unnecessary stress  
when having a child  
with special needs.*

*– A Parent*

**Homes and Community Resources** initiative. HFS will serve as the grantee and lead agency, with ICAAP administering the project.

HFS is the single state agency responsible for administration of Title XIX (Medicaid), Title XXI, (Children's Health Insurance Program Reauthorization Act of 2009 {CHIP}), and State-only funded coverage for children who do not qualify for either Title, all under the umbrella of the **All Kids** program. **All Kids** makes healthcare a reality for families across the state whose children would otherwise be without health insurance. Through **All Kids**, comprehensive health insurance is available to every uninsured child, either at no cost or at affordable rates. HFS provides healthcare coverage for over 51% of the state's births. **All Kids** provides enriched benefit coverage, modeled on the Early and Periodic Screening, Diagnosis and Treatment (EPSDT) mandate for all covered children regardless of funding source.

In Illinois, medical homes are a reality for HFS beneficiaries – there are more than 3,600 primary care providers (PCPs) enrolled to offer a medical home for young children. The next step includes strengthening the medical home by implementing strategies to assure the content of care is consistent with clinical and best practice guidelines; primary care providers have the tools they need to perform quality care and address the needs of the families they serve; referral resources are coordinated and known by the provider community; and communication/feedback is “provider friendly,” meaningful and useful, and ongoing. Illinois is well positioned to participate in ABCD III – **Illinois Healthy Beginnings II**, which will be designed to strengthen our delivery system through strategies that promise to assure appropriate referrals and coordinated care for young children. We will test those strategies, and from lessons learned, we will implement best practices statewide.

During the grant period (November 2009-October 2012), the Illinois Healthy Beginnings II Project will identify the best, sustainable practices for ensuring effective referrals and care coordination across screening, treatment and prevention programs, and will ensure that all children (including those at risk) are linked to the services that best fit their unique needs. Under the leadership of the IDHFS and pediatric providers, Illinois will build on its strong, diverse systems that provide comprehensive developmental screening, prevention and treatment through many providers, including medical homes, early care and education systems (home visiting, preschool), and community health providers (WIC, Family Case Management). Goal one of the project

ensures that Illinois children receive well-coordinated, comprehensive care, in which providers interacting with the family are aware of one another, appropriately access a variety of services, and collaborate to ensure the best possible outcomes are achieved. Goal two will be to support children who may be at-risk of a developmental delay or disability but who do not meet Early Intervention or Special Education eligibility guidelines.

Three subcommittees, with representation from nearly 30 partnering groups/programs, will address the project's goals: **Referral Resource Integration, Service Data Integration, and Support to Families at Risk**. Over a three-year period, each subcommittee will undertake a needs assessment to identify barriers and opportunities, develop community-level pilots involving PCPs and community agencies, and incorporate lessons learned into final policy revisions and programs, which will be spread throughout the state. Evaluation will focus on developing assessment tools, conducting provider focus groups and phone interviews, documenting policy support, and assessing the effectiveness of the pilots and statewide trainings. Illinois Healthy Beginnings II is committed to developing models which are sustainable and will be replicated by programs in other states.

If you are interested in participating as part of one of the above mentioned subcommittees or if you have any questions or comments about this project, please do not hesitate to contact Juanona Brewster, MDiv, MTS, MJ, Director of Early Childhood Development for Illinois AAP at [jbrewster@illinoisAAP.com](mailto:jbrewster@illinoisAAP.com) or 312/733-1026 ext 203.

## **6. ICAAP Programs Move Beyond Core Medical Home Concepts**

*By Scott G. Allen, MS, ICAAP Executive Director*

Illinois primary care providers (PCPs) provide excellent care in high quality medical homes. As pediatricians, we recognized long ago – well before many of our counterparts in other specialties – the need to coordinate care, to listen to and learn from parents and caregivers, and to be comprehensive in considering the needs of our patients. But are you as prepared to coordinate the care of a young child with developmental delay as you are a pregnant teen? Can you access community resources to meet the needs of your overweight adolescents as effectively as you can for your technology dependent patients? Are you as current with the guidelines for management of asthma as you are with clinical recommendations regarding the various threats to a premature infant's health? While the principles of quality, comprehensive, and coordinated care may remain the same, meeting the needs of each and

every patient requires that you are not only up to speed on all the pediatric clinical guidelines but also know how to work with diverse systems and resources external to the practice.

That's why all of ICAAP's programs help build stronger medical homes. ICAAP's goal is to develop programs that help pediatricians, family physicians, and their staff understand and implement current clinical recommendations; appreciate the unique needs of their patients and families; and identify and effectively access resources such as specialty care, community programs, and social services. We also recognize that barriers to comprehensive, coordinated care exist and often vary depending on the issue. Through our programs, we identify those barriers and then work with insurers, community and state agencies, and even legislators to address them.

ICAAP is currently developing new and exciting programs to meet these needs. For instance:

In 2009, ICAAP initiated the "Promoting Health" obesity project, supported by the Otho S. A. Sprague Memorial Institute, which seeks to help practices identify and refer to community resources for physical activity and nutrition. We know from the literature and our own needs assessment that such resources are not well known or consistently available; that referrals to them lack the support and feedback of a more traditional referral for, say, specialty medical care; and that patients face unique barriers in trying to access such resources including cost, travel limitations, scarcity of programs, and even discrimination. ICAAP is hard at work cataloguing resources that practices might tap into and assessing them for quality and accessibility, and then working with a few pilot practices to make those referrals as effective as possible. We are also developing educational modules on nutrition, comorbidities, behavior management, and more.

Under the leadership of ICAAP's Committee on Fetus and Newborn, a series of educational modules designed to help PCPs care for premature and low birthweight babies is in development. This "Care of the NICU Graduate" project will address the specific issues faced by these newborns, particularly in terms of respiratory health, infectious disease, nutrition and development. What are the most recent clinical guidelines for these patients? How do you screen and refer for delays?

**Independence**  
*So far we have been lucky in getting all medical care needed; doctors, therapists and support staff are all working on a common goal of helping our child to be independent with more mobility.*

– A Parent

Who are the specialists you need to coordinate with in order to support these families? Our program will give practices a head start on all these issues, and concurrently we will work with hospitals, Medicaid and other insurers, and others to raise awareness of the challenges these babies face and how we can all work together to improve their care.

ICAAP and the Illinois Academy of Family Physicians recently received support from the Michael Reese Health Trust to develop interventions for practices to better serve families impacted by military deployment. Thousands of National Guard veterans are returning home to Illinois and face unique issues such as post-traumatic stress disorder (PTSD) and traumatic brain injury. Children with deployed parents exhibit more behavioral problems than other children, and family experiences change due to PTSD. Since the returning veterans are National Guard, the resources available to them are different than those for U.S. military veterans and many will be served by the traditional Illinois primary care system. Illinois' primary care physicians are the front lines of our health care system and need to be made aware of these unique issues and given skills and resources to address them.

With each of the programs noted above, we hope to eventually spread the education and resources throughout Illinois and turn the findings from our pilots into policy initiatives that help remove barriers and provide incentives such as reimbursement. This will help all Illinois pediatricians to be effective medical homes for their overweight and obese patients, premature babies, and families impacted by military deployment. And of course, these are just a few of the most recent programs ICAAP has initiated. We continue to work with many providers on childhood and adolescent immunizations, oral health and fluoride varnish application, early childhood developmental and postpartum depression screening, and more.

Recently, Illinois was successful in its application for a Children's Health Insurance Program Reauthorization Act (CHIPRA) Quality Demonstration Grant. Through this five-year project, ICAAP, the Illinois Department of Healthcare and Family Services (IDHFS) and others will work to implement new child health quality measures within the Medicaid population. The programs we develop will further help implement elements of the medical home. We will work with IDHFS to identify measures in need of improvement and then develop education and incentives to encourage providers to participate – such as integration into the current "bonus" program or alignment with the American Board of Pediatrics new certification requirements.

We will build on our successful primary care case management program, Illinois Health Connect, to strengthen referrals and to provide data back to PCPs for quality improvement to improve patient care. We will consider policy changes to better support care coordination and make more effective use of state resources.

Practices embarking on the journey to become a true medical home face formidable challenges. Both the practice systems and staff need to be reoriented to ensure that care is family centered and input from parents and patients helps shape care; to ensure that community resources are well understood and used effectively; and to provide comprehensive care that addresses all of the patient's needs. With the help of the ICAAP's medical home projects and ICAAP's staff and volunteers, many practices are well on their way. But once the philosophy is understood, staff have committed to improvement, and key tools like patient registries and referral logs are in place, the work is just getting started! Each patient and family offers unique challenges, and often, quality improvement needs to shift from the level of the practice systems to the individual patient or clinical service area. And ICAAP is here to help!

## **7. New Project Aims to Improve Health Care Transition for Youth with Special Health Care Needs**

*By Laura DeStigter, MPH, ICAAP Manager*

The transition to adult life has become an important area of focus as a growing number of youth with disabilities and chronic health conditions survive into adulthood. Nationally, more than 500,000 Youth with Special Health Care Needs (YSHCN) reach adulthood each year (Reiss and Gibson, 2002). This encouraging trend is a testament to improvements in health care and other services as well as evolving attitudes towards individuals with disabilities. Unfortunately, adolescents and young adults still face many barriers to a successful transition to adulthood. The transition to adult health care, in particular, is a critical but often challenging aspect of the transition process for YSHCN.

The Society of Adolescent Medicine has formally defined health care transition as “the purposeful and planned movement of adolescents and young adults with chronic conditions from child-centered to adult-centered care” (Society for Adolescent Medicine, 2003). It is a process that takes place over time, not a simple transfer of care. As adolescents undergo the process of health care transition, they encounter many difficulties.

Youth are faced with the increased responsibilities and independence required of adulthood along with physical changes in their bodies and a variety of social pressures. Youth with special needs often face a change or loss of insurance and reduced access to the services and supports that they and their families have relied on throughout childhood. Youth and families are often fearful of leaving their pediatric provider and uncertain about the competence of their new physician (Burdo-Hartman and Patel, 2008; McManus et al., 2008; Reiss and Gibson, 2002). YSHCN often lack knowledge about their condition and have not developed the skills to interact with the health care system, leaving them unprepared to accept responsibility for their own care and causing frustration for both the patient and the new provider (Kennedy and Sawyer, 2008). Some YSHCN are simply unable to find an adult-oriented physician in their local area who is willing to accept them as a patient (Burdo-Hartman and Patel, 2008; McManus et al., 2008; Reiss and Gibson, 2002).

Physicians also face challenges when caring for youth in transition. According to a 2008 survey of fellows of the American Academy of Pediatrics, pediatricians report having difficulty identifying adult-oriented providers to whom they can refer their adolescent patients, with 41 percent of pediatricians reporting this is a major barrier to the provision of transition services. Obtaining reimbursement for transition services such as creating written transition plans is challenging, with 38 percent of pediatricians identifying this as a major barrier. Pediatricians also struggle with terminating relationships with patients that they have been treating for years. In addition, pediatric providers lack familiarity with the complex adult service system and insurance options for young adults with disabilities and therefore have difficulty informing their patients of the options available to them (McManus et al., 2008). As a result of these barriers, many pediatricians do not provide transition support to their patients (see Table 1). Only 47 percent of pediatricians reported providing assistance with referrals to adult providers for all or most of their adolescent patients with special needs, only 27 percent assisted all or most of YSHCN in creating a portable medical summary, and only 19 percent assisted in identifying insurance options after age 18 (McManus et al., 2008).

**451,776 OR 13.9%  
OF ALL CHILDREN  
IN ILLINOIS HAVE  
SPECIAL HEALTH  
CARE NEEDS.**

*(2005/06 SLAITS survey)*

**Table 1: AAP Periodic Survey of Fellows #71, 2008: Transition Services Offered in Pediatric Practices to Adolescents with Special Needs**

Transition Services	For all or most	For some
Assistance with referral to family or internal medicine physician	47%	33%
Assistance with referral to adult specialists	45%	32%
Discussion of consent and confidentiality issues prior to age 18	33%	27%
Assistance with medical documentation for program eligibility	32%	34%
Assistance in creating a portable medical summary	27%	26%
Education and consultative support to family or internal medicine physicians	23%	30%
Assistance with identifying insurance options after age 18	19%	22%
Assistance in creating an individualized health care transition plan	12%	26%
Provision of packet or handouts to adolescent/parents	11%	14%

(Data from McManus et al., 2008)

These findings are echoed by the 2005-2006 National Survey of Children with Special Health Care Needs, which surveyed parents and guardians of YSHCN aged 12-17 about their receipt of transition services (see Table 2). The survey found that 55 percent of parents/guardians reported that they did not receive the services needed to transition to adulthood, and only 42 percent discussed the shift to an adult provider with their health care provider (Lotstein et al., 2009).

**Table 2: Proportion of YSHCN Aged 12 to 17 Years Meeting the Transition Planning Core Outcome and Related Components: United States, 2005–2006**

Transition Planning and Its Components	CSHCN
Core outcome: Received transition planning services	41.2%
Doctor or other health care provider discussed shift to adult provider	41.9%
Doctor or other health care provider discussed adult health care needs	62.4%
Anyone discussed health insurance	34.1%
CSHCN usually/always encouraged to take responsibility	78%

(Data from Lotstein et al., 2009)

## 44,997 ILLINOIS CHILDREN ARE SSI RECIPIENTS

(12/07 figures per Clark Pickett, Social Security Administration, [www.ssa.gov](http://www.ssa.gov))

On the receiving end, adult-oriented providers report obstacles such as lack of training in childhood-onset disabilities and chronic conditions, difficulty facing disability and end of life issues for young patients, lack of appropriate reimbursement for the time required to provide quality care for YSHCN, lack of familiarity with the social services that are available to support YSHCN, and difficulty obtaining and sorting through past medical records (Peter et al., 2009; Reiss and Gibson, 2002). Adult-oriented providers are also less accustomed to working with patients who are not independent and are not used to involving parents and family members (Peter et al., 2009; Reiss and Gibson, 2002). These challenges have made some providers feel uneasy about accepting young adults with special health care needs into their practice.

The data show that these transition difficulties are having a concrete impact on the health of young adults with special health care needs. As a group, young adults with disabilities report poorer health status, higher user of emergency care, and are more likely to go without needed care in comparison with their peers (Blomquist, Graham, and Thomas, 2007). In addition, many young adults continue to receive care at pediatric practices and hospitals, which are not equipped to meet the needs of adult patients. In response, numerous medical associations, including the American Academy of Pediatrics (AAP), American Academy of Family Physicians (AAFP), and American College of Physicians (ACP) have called for improvements in transitional care for YSHCN (American Academy of Pediatrics, American Academy of Family Physicians, and American College of Physicians-American Society of Internal Medicine, 2002). Ensuring that youth receive successful transition services is one of the Maternal and Child Health Bureau's six core outcomes listed in the Healthy People 2010 and Healthy People 2020 goals.

In order to address this need and support physicians in improving health care transition for YSHCN, The Illinois Chapter of the American Academy of Pediatrics (ICAAP) and the Division of Specialized Care for Children (DSCC) applied for and received a 3-year grant from the Health Resources and Services Administration, Maternal and Child Health Bureau. The medical advisor for this project is Miriam A. Kalichman, MD, FAAP, a neurodevelopmental pediatrician who is Associate Medical Director of DSCC. The principal investigator and project director is Kathy Sanabria, MBA, PMP. This project, titled "Integrated Systems of Services for Illinois Children and Youth with Special Health Care Needs," aims to provide training and support to assist YSHCN to transition successfully into the adult health care system and maximize their potential in adulthood.

Over the past year, project staff have conducted a literature review, compiled resource materials, and undertaken needs assessments and interviews with physicians in order to evaluate knowledge gaps and training needs. ICAAP has established partnerships with four pilot sites: Access Community Health Centers, a Federally Qualified Health Center with 50 locations in the Chicago area; Children's Memorial Hospital's Uptown Clinic in Chicago; Pediatric Health Partners, a pediatric practice in Chicago Ridge; and North Arlington Pediatrics, a pediatric practice in Arlington Heights.

In the upcoming year, ICAAP and DSCC will work to develop transition training programs and resource materials along three tracks: (1) training curriculum and resources to assist pediatricians, family physicians, and their staff in transitioning YSHCN to adult health care; (2) training curriculum and resources to assist adult-oriented health care providers in delivering coordinated, ongoing, comprehensive care for youth and young adults with special health care needs; and (3) resources to assess transition readiness and prepare youth and families for transition to adult care. These trainings will include topics such as planning for and coordinating health care transition, using portable medical summaries, developing model care plans and problem lists, increasing accessibility, working with families, utilizing state and community resources, and building self-management skills in adolescents with special health care needs.

These trainings will be developed in collaboration with experts in the field and will be tested at the pilot sites prior to widespread dissemination. Rachel Caskey, MD, University of Illinois Chicago; Rita Rossi-Foulkes, MD, University of Chicago; Sue Mukherjee, MD, Rehabilitation Institute of Chicago; and Teresa Nam, MD, Rush University Medical Center, along with the pilot site partners, will assist with the development of trainings in tracks one and two. Track three will be developed under the leadership of Dr. Parag Shah and the Chronic Illness Transition Team at Children's Memorial Hospital and will focus on interventions that help improve adolescents' health care skills and knowledge. In addition, project staff will work with DSCC's Transition Workgroup to incorporate the Transition Milestones toolkit along with high-quality materials from other organizations. These materials will help primary care providers and care coordinators assess and improve youth readiness for transition. Youth and families will be involved in reviewing these training materials, which will be packaged so that primary care physicians can easily use them in their practice.

The three training tracks will be offered as in-office presentations as well as by webinar. Trainings and webinars will be offered for CME credit and will be accompanied by a comprehensive resource binder. Other project offerings will include a day-long training session for Internal Medicine, Family Physicians, and Med/Peds physicians to be held in late 2010; trainings on health care transition at the Illinois Statewide Transitions Conference to be held October 2010 in Effingham, IL; and Grand Rounds and Residency program presentations. Dr. Miriam Kalichman is also available to provide free consultation services and conduct joint patient visits with providers who request training in how to conduct physical exams and assessments of medically complex patients or those with developmental disabilities.

Finally, one of the greatest unmet needs for transition-age youth is the identification of adult-oriented primary care providers willing to accept youth with special needs, particularly those insured through Medicaid, into their practices. In response to this reality, project staff are redesigning and enhancing ICAAP's special needs provider database to include information about providers who are willing to accept children, youth and young adults with special needs into their practices.

For more information about this project, please contact Laura DeStigter, Manager of Medical Home Initiatives, at 312/733-1026 ext 210 or at [ldestigter@illinoisap.com](mailto:ldestigter@illinoisap.com).

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## **8. Integrated Services Committee Works to Improve Transition Services for Illinois Youth with Special Health Care Needs**

By *Laura DeStigter, MPH, ICAAP Manager*

The Illinois Chapter, American Academy of Pediatrics (ICAAP) and the Division of Specialized Care for Children (DSCC) have convened a new Integrated Services Committee (ISC) as part of the Integrated Systems of Services for Illinois Children and Youth with Special Health Care Needs (CYSHCN) and their Families project, which is funded by a 3-year grant from the Maternal and Child Health Bureau (MCHB). The ISC is charged with addressing the performance measures for community-based systems of service for CYSHCN as set forth by Healthy People 2010 and the Title V Program. The ISC will work toward all of these performance measures, but will primarily focus on three of them: 1) families partner in decision making and are satisfied with the services they receive; 2) community-based service systems are organized so families can use them easily; and 3) youth with special health care needs receive the services necessary to transition to adult life, including adult health care, work, and independence.

To achieve these outcomes, the ISC will work to accomplish the following goals:

- Identify services, resources, and projects in the area of transition from around the state
- Coordinate and integrate the efforts of state and community-based agencies in the area of transition in order to maximize impact and reduce duplication of efforts
- Identify successful strategies and promising approaches to improving access to services for youth in transition that can serve as a model for initiatives across the state
- Increase the responsiveness of services and programs to meet the needs of families
- Increase families' access to accurate information about transition-related services
- Simplify and streamline the process for accessing services
- Increase the number of youth who receive comprehensive transition planning assistance that includes consideration of health care issues that impact successful transition

Major projects of the ISC include conducting a needs assessment to examine state capacity for achieving a community-based service system for CYSHCN and developing a statewide universal screening and referral tool along with informational resources for families and professionals.

ICAAP and DSCC appreciate the commitment that members of the ISC have shown to working to improve services for CYSHCN. If you are interested in joining this Committee, please contact Laura DeStigter at [ldestigter@illinoisaaap.com](mailto:ldestigter@illinoisaaap.com).

## **9. Are You Interested in Improving Health Care Transition for Youth with Special Health Care Needs?**

By *Miriam Kalichman, MD, Associate Medical Director, University of Illinois at Chicago Division of Specialized Care for Children, Children's Habilitation Clinic*

For many pediatricians, transitioning an "aging out" patient who has chronic illness or disabilities to a family physician or internist is challenging. There are many barriers that make health care transition difficult. Adolescent patients are often unprepared to accept responsibility for their own care; parents may be fearful of changing doctors; pediatricians frequently have difficulty identifying an internist or family practitioner willing to accept the patient; and the bond between the pediatrician and the family can make it difficult to terminate care. On the receiving end, family physicians and internists have identified concerns which limit their willingness to accept young adults with special health care needs. These barriers include lack of familiarity with specific conditions, especially developmental disabilities; discomfort with the involvement of the parents; a perceived habit of dependence on the pediatrician by the family; and lack of a medical summary or formal referral from the pediatrician. In addition, since many young adults with special health care needs are uninsured or publicly insured, reimbursement is a challenge.

As noted in a previous article, the Illinois Chapter of the American Academy of Pediatrics (ICAAP) and the Division of Specialized Care for Children (DSCC) have received a grant from the Health Resources and Services Administration (HRSA), Maternal and Child Health Bureau (MCHB), to improve the health care transition for young adults, pediatricians, and physicians who care for adults.

A major goal of the grant is to identify and assist physicians who are willing to care for young adults with

childhood onset chronic illness and/or disabilities. We are seeking family practices, med-peds practices, internal medicine practices, and FQHCs that are interested in building their skills in caring for these patients. We will provide individualized teaching and technical assistance based on the needs of each practice. This may take the form of implementing “medical home” procedures, developing model care plans and problem lists about specific conditions, or developing community resource directories. We also will provide office-based clinical consultations about specific patients in order to familiarize physicians with key pathophysiologic findings and to help them learn to examine non-verbal patients.

We will also work with pediatricians and family physicians to help them prepare teens to become more independent in managing their own health. We will assist practices in evaluating and strengthening their efforts to build self-management skills in adolescents with special health care needs. We will also work with them to prepare and maintain a medical summary for transition-age youth that is accessible to the family, patient, and other health care providers.

We welcome your advice and encourage you to participate in this project. We are particularly interested in strategies or situations that you have found to be successful for helping young adults transition to adult care. If you would like to participate in the project, please contact Laura DeStigter, Project Manager, at 312/733-1026 ext 210 or at [ldestigter@illinoisAAP.com](mailto:ldestigter@illinoisAAP.com).

## 10. ICAAP Volunteer Recognized

ICAAP is pleased to acknowledge Miriam A. Kalichman, MD as a Chapter volunteer. Dr. Kalichman is

Associate Professor of Clinical Pediatrics at the University of Illinois College of Medicine and Associate Medical Director, Division of Specialized Care for Children, University of Illinois Chicago. She received her undergraduate degree at the University of Chicago and her Medical Degree at the University of Michigan. She is board certified in Pediatrics and Neurodevelopmental Disabilities. Her practice focuses exclusively on children with disabilities, including post-trauma rehabilitation and the evaluation and management of medically complex and multiply impaired children.

Dr. Kalichman volunteers on ICAAP’s Committee on



The ICAAP Executive Committee selected Miriam Kalichman, MD, as the April 2010 pediatrician of the month. Dr. Kalichman is Associate Professor of Clinical Pediatrics at the University of Illinois College of Medicine and Associate Medical Director, Division of Specialized Care for Children, University of Illinois Chicago. Miriam also serves as the lead pediatrician for implementing the Integrated Systems of Services for Illinois Children and Youth with Special Health Care Needs state implementation grant.

Children with Disabilities and serves as the medical advisor for the Integrated Systems of Services for Children and Youth with Special Health Care Needs project. Dr. Kalichman has provided her leadership and expertise to the Integrated Services project by creating resource materials and developing presentations and trainings on transitioning youth with special health care needs to adult health care and service systems. She has helped to promote the project and recruit participants, and she has made herself available to provide individualized teaching, technical assistance, and clinical consultations for primary care practices on caring for medically complex patients. In addition, she serves on the Project Advisory Committee and Integrated Services Committee. ICAAP thanks Dr. Kalichman for all of her hard work to make the Integrated Services project a success and to improve health care for children, youth, and young adults with special health care needs!

## 11. Building Community-Based Medical Homes Program

By Jodie Barger, MSW, LSW, ICAAP Manager, Medical Homes Initiatives and Kathy Sanabria, MBA, PMP, ICAAP Senior Director

The Illinois Chapter of the American Academy of Pediatrics (ICAAP) kicked off the Building Community-Based Medical Homes for Children (BCBMHC) program in October 2009. The AAP and Healthy People 2010 goals emphasize that Medical Home is the best practice for medical care, especially for Children and Youth with Special Health Care Needs (CYSHCN). A Medical Home provides care that is accessible, continuous, comprehensive, family-centered, coordinated, compassionate, and culturally effective. The BCBMHC program builds upon the success and lessons learned from the Illinois Medical Home Project (IMHP) and provides free medical home quality improvement (QI) support and resources, including a QI facilitator, to participating practices. These pediatric and family physician practices/clinics work to provide high quality preventative care, acute

care, and chronic condition management in a planned, coordinated, and family-centered manner. With the BCBMHC program, practices...

- create effective medical home QI teams
- participate in a Learning Collaborative with other practices
- learn from mentor teams who have been through the process
- receive coaching on how to include families in QI efforts
- increase accessibility and cultural competency
- learn how to implement effective care coordination
- learn how to provide planned, pro-active care, including development of written/electronic care plans
- become a Division of Specialized Care for Children medical home provider and benefit from increased reimbursement
- learn about the National Committee for Quality Assurance's Medical Home Recognition program and how to apply

Currently there are seven practices/clinics and three mentor sites participating in ICAAP's program. The program is made possible by grants from the Michael Reese Health Trust, the Chicago Community Trust, and the Maternal and Child Health Bureau. Below is a list of participating sites.

Building Community-Based Medical Homes for Children Sites		
Participating Practices/Clinics	Lead Physician	Location
Pediatric Ambulatory Care Clinic and NICU Follow Up Clinic, Fantus Clinic, Stroger Hospital	Judy Neafsey, MD	Chicago
Wheaton Pediatrics, Ltd.	Ruben Rucoba, MD	Wheaton
Order of Saint Francis (OSF) Medical Group Washington Pediatrics	Shelly Shallat, MD	Washington
OSF Medical Group, Knoxville Avenue Pediatrics	John Galbreath, MD	Knoxville
Family and Community Medicine Carbondale and West Frankfort Clinics	Quincy O. Scott, DO	Carbondale/ West Frankfort
Mentor Practices	Lead Physician	City
Children's Health Center	Sara N. Parvinian, MD	Gurnee
North Arlington Pediatrics	Tim Geleske, MD Laurie Vlcek, RN	Arlington Heights
LaRabida Children's Hospital, Premier Kids Program	Edith Chernoff, MD Pam Northrop, MSW	Chicago

Participants receive many layers of support during their 18-month tenure with the BCBMHC program, including surveying practice staff and families to gather baseline and follow up data. These include the Medical Home Index (MHI), a staff self-assessment survey developed by the Center for Medical Home Improvement, and the Medical Home Family Index (MHFI), a survey of families of children with special needs. The individual practice results on the MHI and MHFI are cross tabulated by an evaluation consultant to help teams identify practice strengths and areas for improvement. These data help the teams identify QI goals and objectives and measure systems change and outcomes over time.

If your practice is interested in joining the next program cycle with new practices/clinics in 2011 (pending continuation of funding), please contact Jodie Barger (jbargeron@illinoisap.com) or Kathy Sanabria (ksanabria@illinoisap.com) or 312/733-1026.

## 12. Building Community-Based Medical Homes for Children Learning Session A Huge Success!

By Jodie Barger, MSW, LSW, Manager for Medical Home Initiatives, ICAAP

On Saturday, April 10, 2010 eight practices came together for a Medical Home Learning Session through the Building Community-Based Medical Homes for Children Program (BCMHC). The BCMHC aims to improve quality of care by building a practice that is accessible, continuous, comprehensive, family centered, coordinated, compassionate, and culturally effective. These diverse Quality Improvement (QI) teams represented practices statewide, from Carbondale, West Frankfort, Peoria area, the collar counties, and Chicago. Some teams are in private practice while others are nested within larger hospital systems or public health clinics. Two sites, La Rabida Premiere Kids and North Arlington Pediatrics, served as mentor teams. They provided their expertise on implementing the medical home model. Participants were well poised to learn from each other.

The session focused on providing teams with specialized education, resources, training, and facilitation to support practices as they build community-based medical homes.

Pediatricians, family physicians, nurses, parent partners, social workers, front desk staff, and a care coordinator may all serve on a QI team. The parent partner and the care coordinator anchor QI teams. QI teams meet at least once a month to determine and imple-

ment the best steps to improve their care to special needs patients. Many teams or subgroups meet more often.

Dr. Jane Taylor, a nationally recognized Improvement Advisor and Learning Designer, presented on the Plan-Do-Study-Act cycle of practice improvement. QI teams designed their own Plan-Do-Study-Act cycles and AIM statements with an emphasis on small, measurable, incremental change. Teams also received tools for strengthening linkages between their practices and community resources. One way to accomplish this is to invite regional DSCC care coordinators to attend QI meetings. They can be a wealth of information regarding local resources. The session also provided information on the National Committee for Quality Assurance's Medical Home Recognition program and the AAP National Center for Medical Home Implementation. The ARC of Illinois and the Family to Family Health Information and Education Center provided information on state resources for families.

Many of the day's lessons came from the QI mentor teams. Participants heard from parent partners, care coordinators, and staff during a panel session. They reinforced the twin messages of persistence and small increments of change. Mentors provided a realistic



Dr. Tim Geleske, Laurie Vlcek, and Barb Tobias from North Arlington Pediatrics' Medical Home mentor team talk about their experiences in building their practice brick-by-brick to become a medical home.

**23,418 CHILDREN  
ARE SERVED BY  
THE DIVISION OF  
SPECIALIZED CARE  
FOR CHILDREN IN  
ALL PROGRAMS**

(Illinois MCH Block Grant  
Application/Annual Report, 2007)

perspective on the barriers and rewards of medical home implementation. Parent partners' perspectives particularly resonated with participants. The rewards that they described, both as parents of special needs children and as members of the QI Team, left new teams inspired and ready to put their new tools to use.

This session was videotaped and is posted to ICAAP's Website. Please visit the Website to view the presentations and benefit from the training. You can view presentations at <http://illinoisAAP.org/2010/04/april-2010-illinois-medical-home-learning-session-videos/>.

The BCMHCP is made possible by grants from the Michael Reese Health Trust, the Chicago Community Trust, and the Maternal and Child Health Bureau. The second learning session is planned for September 25,



Barb Tobias and Trish Pazdioch speak about the importance of the family-professional partnership.



Dr. Judy Neafsey, lead pediatrician for Stroger's (Fantus) Ambulatory Pediatric Care Clinic in Chicago, helps her QI team hammer out an AIM statement.

2010 in Joliet, IL. For more information about the Learning Session, please contact Jodie Barger on at [jbarger on@illinois aap.com](mailto:jbarger on@illinois aap.com).

### **13. Voices of Experience: An Interview with the La Rabida Medical Home Quality Improvement Team**

*Interviewer: Donna Scherer, RN, MPH, Division of Specialized Care for Children*

#### **Team Members:**

**Pam Northrop, MSW, LSW**

**Jane Konstant, RN**

**Sheri Hurdle, Parent Partner**

**Dorothy Owens, Grandparent Partner**

*Can you start by telling us a little bit about your program?*

**Pam:** La Rabida's Premier Kids Program is a Medical Home for children birth to five years of age with special health care needs. Our Quality Improvement (QI) team was officially established in November of 2006.

*How did you feel when you were first getting started with your QI team?*

**Pam:** I remember we started three-and-a-half years ago and I listened to the resourcefulness, creativity, and commitment of the established QI teams, thinking with anxiety in my gut, 'how will La Rabida Premier Kids ever be able to have such a QUALITY Quality Improvement Team? How will we get parents to actively participate, how will we get staff to make a commitment to the team? How will we find team members who will do the work to promote the change cycle? We began the process slowly by engaging all members of our QI Team and making a concerted effort to involve families. My best advice is to make sure you have your family members on board at the outset of your QI activity... the parents and family members will help ground your team.

*How do you structure your QI team?*

**Pam:** On our QI team we have Dr. Edith Chernoff, who is the medical director, another pediatrician, a nurse care coordinator, a family advocate, a program volunteer, a care coordinator from the Division of Specialized Care for Children, and myself, the medical home program manager. We have two parents and one grandparent on the team. Two of them have been with us from the beginning, and one joined us after two years, which was great for the team as it put new energy and ideas into what we are doing. We meet monthly for 90 minute meetings over the lunch hour. Regularly scheduled meetings help to keep us on track for change.



*Dorothy Owens, Sheri Hurdle, and Pam Northrop from La Rabida talk about their experiences in helping the Premier Kids Program transform itself into a true medical home.*

The Illinois Medical Home Project and ICAAP provided us with a facilitator, Donna Scherer, RN, MPH who helps to keep team members on target and ensure that everyone is actively participating in the decision-making process. We are so fortunate to have her experience working with other teams so that we did not feel like we were starting from scratch. Donna comes to us as a staff member from the Division of Specialized Care for Children (DSCC) and has been a great resource. Donna and the regional DSCC office care coordinator help us identify and access needed community resources for families.

*How do you involve parents on your QI team?*

**Pam:** The overall goal of the team was to create a parent-professional partnership to improve the program for the families. Parent partners regularly attend each monthly meeting. These parents have made a commitment to these meetings and follow through with the work to promote the change cycle. We can really count on these parents!!

*In your opinion, what was the most successful activity or strategy that your team implemented?*

**Pam:** After doing our baseline assessments, we discovered that an important need was to develop a care plan that would help both staff and families coordinate a child's care. This care plan is a summary of the child from birth to current status.

**Jane:** The care plans include not only the medical information but also nursing, therapy, equipment, and more. Originally we had the care plans in binders, but they were large and cumbersome and could not be easily carried in a purse. After much discussion with the parent partners, the team decided to try placing these care plans on a flash drive to enable families to easily

carry the information with them and to allow all providers easy access to the care plans. We did a Plan-Do-Study-Act cycle to test this. We piloted the use of the flash drive with parent partners, and based on their feedback and the feedback of other community health-care providers we decided to make these available to all families.

Having the care plan on the flash drive has a number of benefits. The information is easily and accurately conveyed, it is password protected, outside providers can add information to it, and it helps to improve communication between providers. In addition, if someone other than the primary caregiver has to bring the child to the doctor, they can easily bring the flash drive so that they have all of the necessary information to give to the provider.

**Dorothy:** Originally we would carry a binder to all doctor's appointments and emergency room visits. The binders are bulky and cumbersome regardless of how organized you are. There was always something missing or you would have to thumb through hundreds of pieces of paper, which was very frustrating. Having the flash drive provides immediate access to pertinent information, medications and doses, especially during ER visits when families are more concerned with comforting their child.

**Sheri:** I find the flash drive helpful because it limits my repeating myself constantly, especially in an emergency when I want my focus to be on my son. My child receives medical care from a variety of specialists as well as therapists. It is difficult to remember the abundance of information given during those visits. If the provider enters the information into the flash drive, the information is relayed to the other providers accurately, which ensures that my child's medical care is less likely to be compromised. Another benefit for me is that if the doctor tells me something that I don't quite understand, I can look at the care plan and pull the information up and research it as necessary.

*Did you encounter any challenges while implementing the care plans? If so, how did you overcome them?*

**Jane:** As with any initiative there are challenges. It is very time consuming to create the care plans (over two hours per plan), and we have found that it cannot usually be done during clinic. One way we have addressed this is to have a care plan day each quarter for parents to come and work on care plans. Another issue we confronted is how to allow outside providers access to the care plan without them changing the information. To address this, we created an empty folder on the flash drives where consultants and other providers can add

information. We are always looking for ways to improve the process.

*Do you feel that participating in this team has been valuable for you and for the practice?*

**Pam:** The Quality Improvement Team has turned out to be more than I ever imagined it could be. The team as I see it has only advantages and no downsides. Most importantly, it helps us to make sure that decisions are made with parent input and priorities.

## 14. New Early Intervention Training Curricula Available

*By Kathy Sanabria, MBA, ICAAP Senior Director, Medical Home Initiatives and Jodie Barger, MSW, ICAAP Manager*

The "Coordinating Care Between Early Intervention and the Primary Care Medical Home" project is launching a new training curricula. The curricula aims to improve communication among primary care providers (PCPs), Child and Family Connections (CFCs) staff, and families. Based on surveys conducted through the project, it was learned some families need help accessing Early Intervention (EI) services in a timely manner and face challenges finding community-based resources to promote child development. To address these issues, ICAAP developed and pilot-tested training curricula for both PCPs and CFC staff in a project funded by The Commonwealth Fund (2008 to 2010) in collaboration with Advocate Health Care's Healthy Steps for Young Children Program and the Illinois Early Intervention Bureau.

The curricula encompasses trainings for PCPs and CFC staff and includes a resource binder. The training was pilot-tested with CFCs 2 (Waukegan), 12 (South Suburban Cook), 14 (Peoria), and 19 (Decatur). Simultaneously, local medical home primary care practices within those CFC service areas tested their curriculum. Through the training, PCPs learn how to streamline the referral to EI using a standardized form, help patients during the referral process, and more easily access community services and resources. Physicians involved with the pilot requested that an Individual Family Service Plan (IFSP) summary page be developed and sent to physicians as follow up for referrals made to EI. As a result, an IFSP Summary Form is being pilot-tested. CFC staff gained knowledge about pediatricians' patient loads, challenges in conducting in-office developmental screenings, and how to assist pediatricians during the EI referral process. The CFC curriculum will be offered through the EI Training Program during regional training conferences and via the Web. The Illinois EI Bureau approved the training in

March 2010 with a few suggested changes, which have been incorporated.

ICAAP uses a trainer to deliver the primary care program in the office as a one-hour in-service, with CME. The training is also being developed as a Webinar for office staff to complete online in one or more sessions and should be available fall 2010. ICAAP is promoting the curricula across the state. We will also promote it to Part C state coordinators nationwide. If you are interested in implementing the EI Coordinating Care training with your practice, please contact Jodie Barger on. [jbarger@illinoisaaap.com](mailto:jbarger@illinoisaaap.com) or 312/733-1026.

## 15. Recognition Opportunity for Medical Home Practices

### The National Committee for Quality Assurance (NCQA) Physician Practice Connections® Patient-Centered Medical Home (PPC®-PCMH™) Recognition Program

By Laura Frankel DeStigter, MPH

Practices that have implemented the medical home model may be interested in applying for Recognition through the National Committee for Quality Assurance (NCQA) Physician Practice Connections® Patient-Centered Medical Home (PPC®-PCMH™) program. This program, which was initiated in 2008, provides Recognition to primary care practices that function as patient-centered medical homes. Although Illinois has been a leader in providing medical home care, as of January 1, 2010, no practices in Illinois had received this Recognition.

The purpose of the NCQA's PPC®-PCMH™ Recognition program is to provide a rigorous evaluation process for determining whether a practice is operating as a medical home and to promote practices that pass this evaluation. In order to develop the program, the NCQA worked with the American Academy of Pediatrics, the American Academy of Family Physicians, the American College of Physicians, and the American Osteopathic Association. The program is aligned with the joint standards on medical home established by these organizations, and all practices must attest to these principles as part of their application.

Receiving PPC®-PCMH™ Recognition has several benefits. Engaging in the application process can help practices to evaluate and strengthen their medical home. The NCQA broadly publicizes physicians who have achieved Recognition, and achieving Recognition may help attract new patients and promote patient retention. In some states, several health insurance compa-

nies have provided higher payments or reimbursements to practices that achieve Recognition. If you are considering applying for Recognition, talk to the insurance companies you work with to find out if this might be a possibility. Practices should be aware that the application requires detailed, comprehensive information and may take three to six months to complete. There is a fee to apply.

Practices seeking PPC®-PCMH™ Recognition complete a web-based survey tool and provide supporting documentation demonstrating their achievements. The NCQA evaluates practices on nine standards, emphasizing the systematic use of patient-centered, coordinated care management processes. Each standard has 2 or more elements, and there are 10 "must pass" elements. Three levels of recognition are possible. Recognition lasts 3 years and applies to the practice as a whole, not to individual physicians.

The NCQA is a private, not-for-profit organization that works to improve health care quality. The NCQA develops quality standards and performance measures for a broad range of health care entities, and has Recognized over 15,000 physicians nationally across all of its programs, which include Diabetes, Heart/Stroke, and Back Pain Recognition programs, as well Physician Practice Connections (a previous version of PPC®-PCMH™) and PPC®-PCMH™.

More information is available at <http://www.ncqa.org/tabid/631/Default.aspx>. If you would like advice and guidance from ICAAP staff on applying for Recognition, please contact Laura DeStigter by email at [ldestigter@illinoisaaap.com](mailto:ldestigter@illinoisaaap.com) or by phone at 312-733-1026, ext 210.

## 16. Illinois Provider Directory for Children and Youth with Special Health Care Needs

Children, youth, and young adults with chronic medical conditions and disabilities often have a difficult time identifying health care providers. This is a particular challenge for individuals insured through Medicaid. In response to this reality, ICAAP is working to improve and expand the Illinois Provider Directory for Individuals with Special Health Care Needs. This online directory includes primary care providers, specialists, dentists, mental health providers, occupational and physical therapists, and other providers who are

**Feel Like Family**  
*Having a child with special needs is hard but having doctors that know about special needs children/adults makes the family feel so much better knowing they really understand.*

— A Parent

committed to providing high-quality care to individuals with special health care needs. The directory is searchable by location, provider type, and other criteria, and is available as a free resource for families who are looking for a provider as well as for professionals in need of referral resources. Providers who would like to be listed in the directory can sign up online and create their own profile. To search for a provider or sign up for the directory, please visit <http://www.illinoisproviderdirectory.com>.

**326,539 CHILDREN HAD INDIVIDUALIZED EDUCATIONAL PLANS DURING 2006-7.**

**18,467 CHILDREN HAD INDIVIDUALIZED FAMILY SERVICE PLANS 2006-8.**

**1,912 CHILDREN ENROLLED IN HOME AND COMMUNITY-BASED 1915(C) MEDICAID WAIVERS.**

**637 WERE MEDICALLY FRAGILE/TECHNOLOGY DEPENDENT.**

**1,100 WERE DEVELOPMENTALLY DISABLED**

**175 WERE IN RESIDENTIAL SETTINGS**

#### **Services**

*I did not realize the wide variety of services available to families with special health care needs until I became a parent of a special needs child.*

*– A Parent*

**SAVE THE DATE**  
**October 24-26, 2010**



Sixth Annual  
**Illinois Statewide Transition Conference**

Thelma Keller Convention Center  
1202 North Keller Drive  
P.O. Box 747  
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<http://www.illinoistransitionconference.org>

**Watch for Registration Information, coming soon!**

## **PATIENT-CENTERED MEDICAL HOME RECOGNITION PROGRAM**

Practices that have implemented the medical home model may wish to apply for recognition through the National Committee for Quality Assurance (NCQA) Physician Practice Connections® Patient-Centered Medical Home (PPC®-PCMH™) program. This program, which was initiated in 2008, provides recognition to primary care practices that function as patient-centered medical homes. The program is aligned with joint standards established by the American Academy of Pediatrics, the American Academy of Family Physicians, the American College of Physicians, and the American Osteopathic Association and emphasizes the systematic use of patient-centered, coordinated care management processes.

Practices seeking PPC®-PCMH™ recognition complete a web-based survey and provide supporting documentation. Three levels of recognition are possible. The NCQA broadly publicizes physicians who have achieved recognition, and in some cases, practices earning PPC®-PCMH™ recognition may qualify for higher payments. More information and guidance on applying for recognition is available at <http://www.ncqa.org/tabid/631/Default.aspx>.

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# Membership in the directory is free!

All you need is an e-mail address.

To become a member go to the Provider Directory Web site and click on the "Provider Login" button. The online application is quick and easy to complete. Also you can login to the directory and update your listing anytime.

Finding doctors and health care providers for children just got easier with the free Web-based Illinois Provider Directory for Children with Special Health Care Needs. The Provider Directory was created by ICAAP and DSCC to help families and providers utilize the Internet to easily locate specialists serving Illinois children by geography, specialty area, or services needed.

Follow these links to use the searchable statewide Provider Directory:

<http://www.illinoisproviderdirectory.com>

→ Find a Pediatrician

→ Provider Directory for Children with Disabilities

## Questions?

Contact Laura DeStigter, MPH for more information:  
312-733-1026, ext 210  
[ldestigter@illinoisaaap.com](mailto:ldestigter@illinoisaaap.com)

PLEASE FEEL FREE TO COPY AND SHARE THIS NEWSLETTER WITH OTHERS. THE NEWSLETTER ALSO APPEARS IN PDF FORMAT AND CAN BE DOWNLOADED AT [HTTP://WWW.ILLINOISAAAP.ORG/PROJECTS/MEDICAL-HOME/](http://www.illinoisaaap.org/projects/medical-home/)

## Efforts

But then, when I get a note home from school saying what a great day my son had, I realize all our efforts with doctor appointments are doing something.

— A Parent

This Newsletter is supported through grants from the U.S. Department of Health and Human Services, Health Resources and Services Administration, Maternal and Child Health Bureau, D70MC12840.

Building Community-Based Medical Homes for Children  
<http://www.illinoisaaap.org/projects/medical-home/>

# Illinois Provider Directory

for individuals with special health care needs

[www.illinoisproviderdirectory.com](http://www.illinoisproviderdirectory.com)

## Find a Provider

The Illinois Provider Directory lists health care providers who are interested in providing care to children, youth, and adults with special health care needs and disabilities. Search the directory for a provider in your area. Listings include primary care physicians, specialists, therapists, and more.



Questions? Contact ICAAP at  
312-733-1026 or  
[info@illinoisAAP.org](mailto:info@illinoisAAP.org)

## Be Listed as a Provider

Are you interested in accepting patients with special health care needs or disabilities? Visit the website listed above to register for the Directory. You can manage your listing and change your information at any time.

Help make it  
easier for  
patients to  
find you!



American Academy of Pediatrics

DEDICATED TO THE HEALTH OF ALL CHILDREN™

Illinois Chapter



[www.illinoisAAP.org](http://www.illinoisAAP.org)

# Get started on improving your office. Sign up today!

ICAAP offers several office- and hospital-based educational programs focused on universal topics and emerging issues in pediatrics. The majority of these programs provide FREE CME credit to participating physicians and some also provide nursing contact hours. They are presented in your office to your entire practice staff and focus on systems change, staff roles, how to identify local resources, and other practical issues. All programs are presented by trained faculty (physicians and/or nursing professionals) using a peer-to-peer educational model.

Please check all programs that interest you:

- Building Community-Based Medical Homes for Children Program**
- Coordinating Care Between Early Intervention and the Medical Home**
- Reaching Our Goals: Immunization Provider Education**
- I-CARE: Immunization Registry Training**
- The Truth Behind the Ads**
- Early Hearing Detection and Intervention**
- Hepatitis B Vaccine—the Importance of the Birth Dose**
- Bright Smiles from Birth: An Oral Health Education Program**
- Tobacco Use Prevention and Cessation: Strategies for Primary Care Providers**
- Enhancing Developmentally Oriented Primary Care (EDOPC)**
  - Developmental Screening and Referral**
  - Early Autism Detection and Referral**
  - Perinatal/Maternal Depression Screening**
  - Social/Emotional Screening and Referral**
  - Domestic Violence Screening**

Name	
Degree	
ICAAP Member	<input type="checkbox"/> yes <input type="checkbox"/> no
Institution/Practice	
Office Manager/Support Staff Contact	
Address	
Suite/Apt.	
City, State, Zip	
Office Phone Number	Home Phone Number
Fax Number	
E-mail	

These programs would not be possible without the support of the following groups:

Chicago Community Trust  
Chicago Department of Public Health  
Division of Specialized Care for Children  
GlaxoSmithKline  
Illinois Children's Healthcare Foundation  
Illinois Department of Healthcare and Family Services  
Illinois Department of Public Health  
Michael Reese Health Trust  
The Autism Program  
The Aetna Foundation  
The W. Clement & Jesse V. Stone Foundation  
U.S. Department of Health and Human Services, Health Resources and Services Administration, Maternal and Child Health Bureau

For more information on a specific program, please visit <http://illinoisaaap.org> or call the chapter at 312-733-1026.

**To register, cut this page off and fax to:  
312-733-1791**

or mail to the ICAAP office at the address on the Table of Contents page. An ICAAP staff member will contact you to enroll your practice into the desired program.