Building a medical home brick by brick
Practice enlists help of parents, state and national organizations to improve care for patients with special needs

by Timothy A. Geleske, M.D., FAAP

It's 10:30 a.m. and you're already running behind schedule. Two patients are waiting in exam rooms: One is a well-child appointment, the other a recheck. You figure you'll knock down the recheck, and move on to the well-child appointment.

In a medical home, a pediatric primary care provider works with the family/patient to ensure all of the patient's medical and non-medical needs are met. The provider can help the family/patient access and coordinate specialty care, educational services, out-of-home care, support and other community services. Primary care providers play a crucial role in managing the patient's chronic health condition, advising patient/families about testing and treatment options, and educating them about the condition.

With the medical home principles as our guide, our practice set out to improve our approach to children with special health care needs. We were fortunate to receive a lot of outside help. Illinois' Title V program helps practices evaluate and enhance their medical home activities through a quality improvement process. The Title V director gave our practice an in-service on the medical home and provided a facilitator to monitor our progress.

First, we completed the Medical Home Index (MHI), developed by the Center for Medical Home Improvement to measure a practice's organizational capacity, chronic condition management, care coordination, community outreach, data management and quality improvement. Another tool, the Medical Home Family Index, allows families to provide input on a practice's level of "medical homeness."

Under the direction of our Title V facilitator, we established a quality improvement team consisting of a physician, a nurse who serves as our care coordinator, a front office member and three parents of children with special needs.

We also became involved with the Medical Home Learning Collaborative, sponsored by the National Initiative for Children's Healthcare Quality with funding from the Maternal and Child Health Bureau (MCHB). Through this yearlong collaborative, we shared experiences and tools with other practices throughout the country involved in quality improvement processes. The collaborative provided a mechanism for modifying our practice through the Plan-Do-Study-Act cycle. This model allowed us to pilot small tests of change and study their success (or lack thereof) before fully implementing changes.

Identifying children with special needs
Our first initiative was to ensure that we allocated enough time to meet CYSHCN's needs.

Using the MCHB's definition of CYSHCN, we identified children whose diagnosis distinguished them as having special needs and assigned them a complexity score from one to three. When a family calls for an appointment, a notification appears on the computer that the child has special needs. This allows our front office staff to ask if there are any special considerations for that visit.

An identifier also alerts nurses and doctors when they review their schedule for the day that they will be seeing a patient with special needs, allowing them to prepare for the visit.

By creating a registry of CYSHCN, we are able to target specific groups for services, such as mailings on disease-specific information, flu vaccine reminders, and connecting families to support groups or community-based resources.

Managing chronic conditions
Our next initiative was to improve care coordination services.

Using several examples of care plans and drawing on their own experiences, our parents took the lead in designing a care plan that fit our specific needs. We started to develop care plans for patients with a complexity level of three. The care plans are presented in a binder along with information regarding the practice, the medical home, community-based resources and support groups. The binder provides families a template for organizing their own information. The care plan also is burned onto a CD. Funding for this project was provided through a subgrant procured by one of our parent partners through the Illinois Medical Home Project, which is funded through an MCHB grant.

Our practice is in its infancy as far as widespread dissemination of care plans, and we have not yet established a routine of periodic care coordination visits. Care coordination can be time-consuming and goes beyond the scope of the well-child visit. However, meeting regularly keeps everyone up-to-date and allows goals to be set for families and physicians.

As we try to expand the scope of our chronic condition management,
You quickly review the care plan before going into the room and are aware of the complex nature of the patient. Faxback forms from the pulmonologist also bring you up to speed on the treatment plan for his acute illness and the recommendation for a g-tube. You enter the room with a plan in mind.

After treating the acute illness and briefly addressing the chronic issues, you have your care coordinator write up a visit summary, delineating tasks and expectations for the next visit. You have the family schedule a recheck for the patient in a few days to reassess his acute illness as well as a visit with you and the care coordinator to update his care plan and address his long-term needs.

I can't say it always goes this smoothly in our practice. But little by little, we are making changes. There is greater awareness among our staff as to the challenges families face. We're providing better comprehensive, family-centered, coordinated care; the families are feeling more in control; and we are deriving greater professional satisfaction from delivering that care.

Dr. Gelecke is a member of the AAP National Center of Medical Home Initiatives' Project Advisory Committee.

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