

# Bring your patients with special needs home ...to your Medical Home!

Children and youth with special health care needs (CYSHCN) – and their families – face multiple challenges each and every day.

As a Medical Home, your practice can significantly reduce those challenges and provide crucial support to make a true difference in the lives of these families.

Here's what participating health care professionals are saying about the EPIC IC Pennsylvania Medical Home Initiative:

## *“Since implementing the Medical Home Initiative at our practice, we have:*

- Improved patient care and support for families
- Improved our management of complex patients in need of multiple specialty referrals, medical equipment, therapists, education and transportation
- Involved parents in practice improvement
- Built a file of state and local resources used to connect families with appropriate community services
- Gained some funding to support a dedicated care coordinator
- Contributed to an active and enthusiastic Community of Practice, sharing ideas and information through networking at conferences, conference calls, and personal linkages
- Enjoyed free EPIC IC conferences with CME and CEU credits
- Reaped the rewards of our initial investment of time and effort- reducing stress and hassles while improving quality of care
- Learned to see our practice as a system in which we can intervene, causing positive changes
- Been invited to speak about our practice's makeover at national conferences
- Benefited from the commitment and support of the EPIC IC staff.”

EPIC IC will help you every step along the way!



## Pennsylvania Medical Home Initiative

Educating Practices In Community Integrated Care

Learn how by contacting:  
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(484) 446-3039 or 1-800-414-7391  
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Visit us on the web at: [www.pamedicalhome.org](http://www.pamedicalhome.org)

# Interview: Renee Turchi,

## **When were you first introduced to the concept of “Medical Home”?**

At the end of my residency, I attended the very first EPIC IC PA Medical Home conference. At the conference, I realized all the good things my practice did consistent with Medical Home principles, but I also saw that we had a long way to go.

## **Did the idea of Medical Home seem abstract at first? When/how did the idea become “real” to you?**

I didn't truly “get” medical home until I returned from my fellowship and started working at St. Christopher's Hospital for Children in Philadelphia, PA. I had the good fortune to join up with a wonderful pediatrician who had already been working with the EPIC Medical Home Initiative for about a year. There was also an amazing nurse who acted as our practice's designated care coordinator. In six months, that nurse taught me more about care coordination than I had learned in all my education and experience up to that point. Medical Home became real for me when I saw what we could do for our patients through effective care coordination and family centered care. It really took a lot of time and exposure before I internalized the tenets of Medical Home enough to externalize them in the way I practice medicine.

## **Are all primary care practices “medical homes”?**

I would say that practices providing comprehensive, coordinated, patient

and family-centered care are medical homes. But the question is: are you the best medical home you can be? When a health care practitioner makes a commitment to medicine, they also commit to continuing to grow as medicine grows. Just as physicians need to maintain their certification by getting Continuing Medical Education credits, medical practices need to keep learning and improving as a whole. A medical practice should constantly examine the quality of care provided and should ask consumers (meaning patients and their families) how to improve. Medical Home is a continuum of learning and practice.

## **Why does the Medical Home Initiative advocate the involvement of parents in quality improvement?**

It's imperative that patients, parents, caregivers, and families have a say in the care that they receive, because if their needs are not being met, then truly effective care is not being provided.

## **How does Medical Home benefit staff members at medical practices?**

The most dramatic benefit at my practice was that the staff's satisfaction at work increased while stress levels decreased. Also, the benefits extend beyond health care practitioners, because the front desk staff and office managers are integral to the implementation and sustainability of

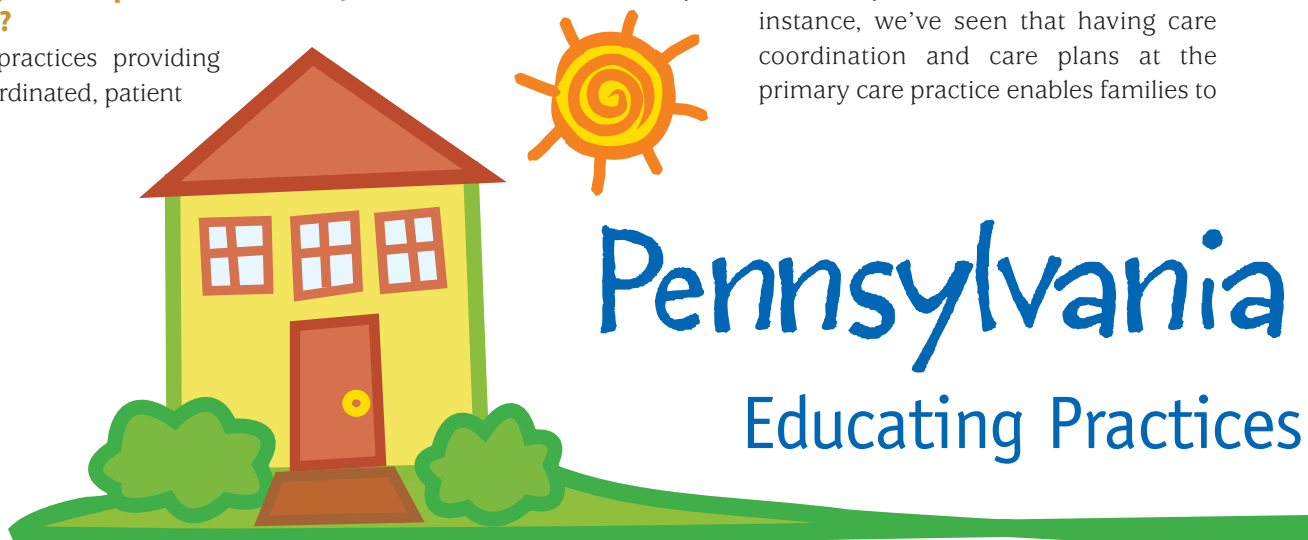
a medical home. The entire office gets to reap the rewards of helping patients and their families thrive.

## **How do you expect Medical Home to benefit payers, society, and communities now and in the future?**

At EPIC IC, we are currently looking at Medical Home in terms of negotiating with payers and demonstrating involvement with medical home improves the bottom line by increasing efficiency and allowing practices to see more patients, while improving quality of life, decreasing school absences and facilitating appropriate utilization of emergency department visits and hospital admissions.

I believe that payers are going to benefit from having healthier enrollees. Medical Home really builds on the concept of preventive medicine and chronic condition management. A child may have a chronic condition, but if we're maximizing that child's potential by being proactive and preventing long term complications, hospitalizations, or institutionalization then the impact of that child's condition on payers, the family, society and the child will be lessened.

If every child with special health care needs had a medical home, the impact on society could be enormous. For instance, we've seen that having care coordination and care plans at the primary care practice enables families to



Pennsylvania  
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# MD, MPH

trust others to do the things that they are often forced to do on their own. As a result, parents and caregivers are able to thrive in the workplace, miss fewer work days, experience less stress, and focus on nurturing their family relationships.

## **Do you have any closing thoughts?**

The benefits of having a medical home do not just apply to children with special health care needs. Every person (child and adult) deserves a medical home!

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*Renee Turchi, MD, MPH spends her time directing the EPIC IC Pennsylvania Medical Home Initiative, acting as a faculty member and teacher at Drexel University School of Public Health, and directing The Center for Children with Special Health Care Needs at St. Christopher's Hospital for Children in Philadelphia PA.*

*As Medical Director of the EPIC IC Pennsylvania Medical Home Initiative, Dr. Turchi works on garnering funding, recruiting practices, implementing the medical home program at participating practices, conference planning, data collection and data analysis. Dr. Turchi visits as many pediatric practices as possible and attends federal and state meetings in order to bring information and resources from National Medical Home Initiatives back to Pennsylvania.*

**In 2007-2008, the PA Medical Home Initiative created a nine article series for Exceptional Parent Magazine with the help of experts and advocates from all over the country. In this series, we look at a Medical Home through the lens of one family's experience.**

## **Dear Reader,**

This story was printed in EParent magazine in chapter form over nine issues. It was written to illustrate the medical home model of care. A medical home is described by the American Academy of Pediatrics as “a model of delivering primary care that is accessible, continuous, comprehensive, family-centered, coordinated, compassionate, and culturally effective.”

In the story, we meet a fictional couple, Amita and Samir, and their daughter Anjali. Anjali was born 11 weeks prematurely. She has some health complications from her early birth. In the early chapters, Anjali's parents learn how to care for their daughter with special needs. Amita and Samir discover ways to partner with Anjali's caregivers, to link with community resources, and to advocate for their daughter. As readers, we accompany Anjali from childhood to young adulthood. Along the way, we see how valuable the medical home model is for this family. We see Anjali grow from being the recipient of care arranged by others to becoming her own health care decision maker.

Each chapter was written as a collaborative effort with medical home experts from around the country. Sidebars provide relevant information on resources, websites, and organizations throughout the story. We hope that you enjoy spending time with Anjali and her family and learning about the value of Medical Home.

## **Sarah Macdonald, MD**

Pediatric Advisor, EPIC IC Medical Home Initiative

# Medical Home Initiative

## In Community Integrated Care



## PART ONE

# One Family's Journey: Medical Home and the network of supports it offers children and youth with special health care needs

Over the next year, *EP* will present a case study about the American Academy of Pediatrics' Medical Home Initiative. A "Medical Home" is not a building. It is an approach to providing healthcare services to children with special healthcare needs.

We will spend the next year visiting with Amita and Samir and their daughter, Anjali, a fictitious family. We will learn about Medical Home through their experiences.

By Sarah MacDonald, MD; Molly Gatto; Deb Walker; Renee Turchi, MD, MPH

### Meet Our Fictitious Medical Home Family

- Amita is Hindi for Infinite, Immeasurable
- Samir is Hindi for a Companion in evening talk
- Anjali is Hindi for Offering

**A**fter work Amita met Samir at a local café for a light dinner. While the young couple ate, they finished writing their "for-the-nursery" list.

Amita was pregnant with their first child. Except for a little morning sickness in the first trimester, Amita had felt great during her pregnancy. Now she had made it to her third trimester—only 11 weeks until they would meet the newest member of their family!

After dinner, Amita and Samir headed over to the nearest baby-goods store. The happy couple strolled the aisles for over an hour. Would their little one really need all of these plastic, multi-colored, battery-powered gadgets? Feeling overwhelmed by the number of choices, Amita and Samir decided to purchase a baby monitor, a beautiful crib blanket, a stroller, a car seat, nursing pads, and a package of diapers (size 1).

Amita woke from a sound sleep at 1:30 a.m., feeling a sharp pain in her belly and wetness on her sheets. Her water had broken. Alarmed, Amita shook Samir's shoulder until his eyes opened—the baby wasn't due for

weeks. What was happening? Samir called 9-1-1 and stayed with Amita, holding her hand until the ambulance arrived.

The ambulance reached the house only 14 minutes later, but it felt like an hour to Samir. Amita was having contractions. Samir called their obstetrician and let her know that Amita was in labor. The doctor said she would meet them at the hospital.

At the hospital, Amita was rushed to the Labor and Delivery floor where the nurse administered intravenous medication to try to stop the contractions. Samir stayed downstairs filling out admission paperwork. Amita felt nauseous, weak, scared, and alone. By 2:15 a.m., Amita was dilated 8 centimeters with contractions every three minutes. Their baby would be born tonight.

Baby Anjali entered the world at 2:38 a.m. As soon as Anjali was delivered from the womb, she was handed to the neonatologist who was on-call, Dr. Robinson, before Amita and Samir had a chance to see her. Anjali was not breathing.

Dr. Robinson was able to resuscitate Anjali, and the baby was settled into a Neonatal Intensive Care Unit (NICU) before Amita or Samir could hold her. In the NICU, Amita and Samir finally got to see their baby girl. Anjali had thick black hair and a cleft in her chin like her father. The baby weighed only two pounds, 6 ounces. She was on a ventilator, and her little bed was surrounded by flashing, beeping, colorful monitors—monitors so much more sophisticated than the one Amita and Samir had purchased just a few hours earlier at the baby-goods store.

Anjali's nurse that first day was Doris. Doris had worked in the NICU for over 10 years and had become



## The American Academy of Pediatrics describes the following core elements of Medical Home:

- > Family-centered
- > Comprehensive
- > Continuous
- > Coordinated
- > Compassionate
- > Community-based
- > Culturally-competent
- > Accessible
- > Environment of trust and mutual responsibility

adept at helping new parents cope with the stress of their baby's health problems. She knew that the NICU could be an intimidating place. Doris did everything she could to make Amita and Samir feel included in Anjali's care.

As Doris worked with Dr. Robinson to stabilize Anjali, she explained the tubes, fluids, lights, and sounds. She reassured Amita and Samir that Anjali was in a wonderful NICU with great doctors and staff. Anjali stabilized after a few hours, and Doris hugged the new parents and sent them back to Amita's room with a Polaroid picture of their baby girl, suggesting they get some rest. Most importantly, Doris provided words of encouragement: "Your daughter is stable now; she is sleeping. We will work as a team to be sure Anjali gets the best care possible. Did you notice how she tried to open her eyes when she heard your voices?"

When Anjali was 10 days old, Amita and Samir held Anjali's baby naming ceremony, or Namakarana. They had talked with Doris about the observance, an important Hindu ritual to welcome a baby into the world. Amita and Samir were happy to be able to hold the ceremony in the NICU, though it would not be completely traditional. They would not be able to massage Anjali with oil or lay her on a betel leaf, and her grandparents wouldn't be at her side.

The ceremony was beautiful regardless of the unusual circumstances. Anjali's parents each said a special prayer, then Samir whispered Anjali's name into her right ear, and Amita tied a black string around the incubette (instead of around Anjali's waist) to ward off evil spirits.

Anjali spent five long weeks in the NICU. This time was extremely difficult for Amita and Samir, as they learned the many terms that described their daughter's condition and made decisions they felt would be in Anjali's best interest. However, Doris and the other NICU staff assured them that Anjali was doing well. The baby was gaining weight with nasogastric tube (NG) feeds. She had been taken off the ventilator, although she did receive oxygen through a canula in her nose.

Amita and Samir were joyful and frightened when they learned that Anjali's discharge planning meeting would be held that week. The NICU staff said she was ready to go home, but Amita and Samir were not sure they were ready. Anjali wasn't the healthy, full-term baby they had been expecting. What if something happened at home? Who would help them? How would they

know they were doing the best job of caring for their daughter? Amita had only bathed Anjali once and that was with assistance; both parents had fed her through the NG tube a few times; they had learned about prematurity, apnea, and sepsis; and they had completed the CPR class. They both loved her so much, more than they had ever imagined a person could love another—but was this enough? Was it enough to keep her safe and healthy?

Doris did her best to prepare Amita and Samir for the discharge planning meeting. She explained that they would get a copy of Anjali's medical history, her diagnoses, tests, important lab results, and medications. Doris also encouraged them to ask any questions and praised them for how well they had adjusted to being the parents of a premature baby with special needs.

Doris also explained about a Medical Home. When Amita first heard the words, she began to cry; she thought that Doris was saying that Anjali would have to live in a special home for sick children. Doris patted Amita's hand and explained that a Medical Home isn't a place, but rather a comprehensive approach to medical care for children with special healthcare needs. She mentioned that there was a pediatrician in the community who was involved with a Medical Home program and recommended that Amita and Samir schedule a visit with her before Anjali went home.

That afternoon, Samir and Amita sat next to each other in the conference room where Anjali's discharge planning meeting would be held. Samir had brought a notebook and sat with his pen posed, ready to take notes. By 2:15, the conference room was crowded. Dr. Robinson and Doris were there along with a social worker, a member of the hospital business office, two medical students, one pediatric resident, a lactation consultant, a respiratory therapist, and the discharge coordinator. Samir and Amita felt intimidated at first, but Doris had prepared them for the meeting, and they also felt reassured that everyone involved in Anjali's care was there. They were ready to be parents in their own home with Anjali secure in her new crib, tucked in under the beautiful baby blanket they had bought five weeks before.

Next month, we will visit with Amita, Samir, and Anjali as they adjust to life together at home. We will learn more about Medical Home, including parent support networks,

early intervention, and care coordination.

For more information on Medical Home, please visit the National Center of Medical Home Initiatives for Children with Special Needs at [www.medicalhomeinfo.org](http://www.medicalhomeinfo.org). For a list of references that accompany this article, please make request to [jhollingsworth@eparent.com](mailto:jhollingsworth@eparent.com). •

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Joint Statement from the American Academy of Family Physicians, American Academy of Pediatrics, American College of Physicians, and American College of Osteopathic Medicine identifies the following core principles of the Medical Home:

- > Personal Physician where each patient has a personal physician that knows them well and provides comprehensive care
- > Physician Directed Medical Practice with a core team caring for the patient and their family
- > Whole person orientation through caring for the patient across all life stages
- > Care is coordinated across multiple aspects of the health care system
- > Quality and safety are incorporated in to all aspects of the medical home
- > Enhanced access to care through scheduling, convenience, hours, communication
- > Payment reflects time and effort afforded by healthcare providers.



In this nine installment Medical Home series, *EP* will present a case study about the American Academy of Pediatrics' Medical Home Initiative.

A “Medical Home” is not a building. It is an approach to providing healthcare services to children with special healthcare needs.

This article presents Part 2 in the series as readers learn more about Amita and Samir and their daughter, Anjali, a fictional family. *EP* readers will learn about Medical Home through their experiences.

# One Family's Journey: Medical Home and the network of supports it offers children and youth with special health care needs: Care Coordination

By Monica Kondrad, RN, BSN; Bonnie Zehr, MD; Christine Hanna, MD; Vicki Rote; Sweetie Jain, MD

Amita and Samir attended the discharge planning meeting for Anjali. Samir wanted to make sure he wrote everything down that the doctors had to say. Amita had so many questions. They wanted to be prepared to care for Anjali at home. After introductions were made, Dr. Robinson explained that Anjali was stable enough to go home at the end of the week. She reviewed her medical conditions:

- Apnea of prematurity
- Lung disease
- Poor weight gain
- Retinopathy of prematurity
- Failed hearing screen

Dr. Robinson explained these conditions would improve as Anjali grows. Amita asked if she should continue pumping her breast milk for the baby's feedings. Dr. Robinson encouraged her to continue to use pumped breast milk. The discharge planner explained that the feeding pump and oxygen would be delivered the day before discharge to Amita and Samir's home by an equipment company. A nursing visit was set up for the day of discharge. The nurse will come to the home and teach Samir and Amita how to operate the feeding pump, pulse oximeter monitor, and oxygen. Doris, the primary nurse, explained how discharge teaching would be completed in the hospital. She encouraged Samir and Amita to set up the first appointment with the pediatrician in the community who was involved with Medical Home. As Samir took pages of notes, the rest of the team answered questions about Anjali's condition. How long would she need oxygen? When could she just be fed by bottle? What should be done if the monitor alarms?

Anjali's discharge date was set for Friday. With tears in their eyes, Amita and Samir thanked everyone for taking good care of Anjali.

Both Amita and Samir were excited and nervous about Anjali's first day home from the hospital. They spent the evening before preparing for Anjali's arrival. The crib was draped with a pink and white lace crib blanket with a matching diaper stacker hooked to the end. A colorful mobile was attached, ready to provide soothing music and visual stimulation for the baby. The baby monitor purchased by Amita and Samir was perched on the dressing table next to a stack of neatly folded t-shirts and bibs. There was a picture of the Hindu God, Ganesha, hanging on the wall next to the crib. Ganesha is believed to be the Lord of all beginnings, and Hindus pray to Him before starting anything special.

The nursery also contained items that Amita and Samir had never anticipated needing. The corner of the nursery was occupied by an oxygen concentrator, a large box that was noisy when switched on. A green portable oxygen tank had been placed in a carrier for Anjali's use on her first car ride home from the hospital. A feeding pump on a tray containing feeding tubes, a roll of tape, syringes, and nasal canulas sat next to the crib. A pulse oximeter rested on the dressing table.

Questions and doubts filled Amita's mind, while her eyes filled with tears. Would she know what to do when one of the machines sounded its alarm? Would she be able to keep up with the schedule of formula preparation, medicines, and the monitoring of all the machines along with bathing, dressing, and diapering? She wanted so much just to be Anjali's mom – rocking

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her, singing to her, loving her.

Samir took a final glance around the nursery. The feeding pump was plugged in and charging, just as they were instructed by the technician from the equipment company. He had filled the sterile jar with distilled water and attached it to the concentrator; the nasal canula was connected to the concentrator. Yes—everything was in place ready for Anjali's homecoming.

Samir secured the infant car seat in the back seat of the family's vehicle in a rear facing position. The trip to the hospital would take nearly an hour since they lived in a small, rural town. Thoughts of an emergency situation with Anjali raced through his mind. What if they needed to rush her to the hospital? They lived so far away. He placed the portable oxygen next to the car seat. Amita and Samir began the journey to the hospital as they did every day. However, today was different, it was a special day. They were bringing their baby girl home for the first time. Both Amita and Samir chanted a short prayer or 'Mantra' as they started on their very important journey to the hospital to take Anjali home.

When Amita and Samir arrived at the hospital, they were met by the charge nurse who reviewed the discharge instructions, which included Anjali's feeding schedule, formula preparation, administration of medications and feeds through the nasogastric tube, oxygen administration, and oxygen saturation monitoring. The neonatologist reviewed concerns to notify their pediatrician about and listed follow up appointments that needed to be made with the pediatrician, cardiologist, pulmonologist, gastroenterologist, ophthalmologist and audiologist as well as neonatal follow up.

Samir expressed his concern about the travel distance from their home to the hospital in the event of an emergency. As a precaution, the charge nurse advised Amita and Samir to dial 911 if they were uncomfortable transporting Anjali by car. Doris gave the family the number for community early intervention services and stated a referral was made for Anjali. She reminded them to contact Anjali's pediatrician's office soon after they arrive home. They had specifically chosen a pediatrician who incorporates the Medical Home concept for children with special healthcare needs into the medical practice.

Amita remembered that Doris had described the medical home as a place that would provide comprehensive medical care for Anjali along with providing access to community resources, parent support groups, home care services, and patient education. Amita resolved to call the practice for an appointment as soon as Anjali was settled at home.

The discharge planner explained to Amita and Samir that a nurse would arrive later that afternoon to assist and teach the family all they would need to know to provide care for Anjali. She gave them with the phone numbers for the durable medical equipment company and the pediatrician's office. The respiratory therapist assisted Samir as he opened the oxygen valve to the home portable tank while Amita placed Anjali on the oxygen.

Samir secured the baby in the car seat and Amita was buckled up next to her. As they drove home, Amita could not help crying tears of joy and anticipation. As they entered the house, Amita placed a red vermillion dot on Anjali's forehead and blew a conchshell to welcome Anjali to her home.

At home, they gently placed Anjali in her crib and attached her to the oxygen concentrator. They placed her on the pulse oximeter; good—the reading was 98 percent. Soon it would be time to prepare the formula, try to feed Anjali by bottle first and then set up the medications and nasogastric tube feeding. The visiting nurse would come soon to help with all of these tasks. Samir left Amita to watch Anjali as he ran out to get Anjali's medicines at the local pharmacy.

The phone rang, and it was Amita's parents in India. They wanted to know if Anjali had arrived home safely so that they could start celebrating at their home with prayers and festivities.

Amita reviewed the multitude of tasks she needed to accomplish. What should she do first? Put the supplies away? Prepare the formula? Schedule the follow appointments? Maybe she should study the discharge instructions.

Amita decided to call the pediatrician's office to set up Anjali's first appointment. She was surprised when the receptionist asked her if her child had special healthcare needs. Amita summarized Anjali's special needs, and the receptionist immediately scheduled an appointment for Thursday



**A Pooja Thali is a tray for Pooja or prayers. It has a small idol of Ganesha on it. Usually pooja thalis or trays have vermillion on them and the red powder is used in every special ceremony as a sacred powder, often applied to the forehead of the Gods' idols or to the foreheads of people.**

with additional time allotted. Then the receptionist transferred Amita to the practice's care coordinator.

Amita was thrilled that the care coordinator was available to discuss all of her concerns. The care coordinator gave Amita some helpful hints to ease Anjali's transition from hospital to home:

- 1) A phone number for the practice was given to Amita. She could call the same number after hours and on weekends. After hours, the pediatrician answers questions and concerns.

- 2) The care coordinator assisted Amita in creating a schedule of feedings and medications. She and Amita spoke at length about timing the medicines before Anjali's feedings. The schedule took the family's daily life into consideration. Amita was welcome to call if the schedule didn't work out or for questions about Anjali and her care.

- 3) The care coordinator answered questions about proper storage and pumping of breast milk and how to mix the breast milk with the formula, if needed.

- 4) They talked about how best to organize supplies.

- 5) The care coordinator reviewed services available through early intervention and explained a call would be made to ensure that the referral was already in place from the NICU.

Amita smiled with relief after she hung up the phone. She felt less alone and knew she could contact the office with any concerns. The care coordinator had offered such practical suggestions. Perhaps she and Samir would now have the time to be loving parents to Anjali while providing essential oxygen, medications, feedings, and treatments.

Samir came home with the medications and the visiting nurse arrived as well.

Together, they learned about all of the equipment and procedures necessary to care for Anjali. The nurse helped Amita and Samir fine-tune their schedule and answered questions about the nursery appointment.

On the day of Anjali's appointment with her pediatrician, Amita and Samir worked together to prepare Anjali for the hour-long trip. Samir had Anjali's feeding schedule for the trip and attempted to anticipate her other medical needs. When they arrived at the office, Amita carried the baby in her car seat and Samir carried the portable oxygen and diaper bag with medicines, instructions, and supplies.

The waiting room was bright and friendly. The registration staff gave Amita and Samir a friendly greeting. Amita began to browse through the many handouts describing early intervention and parent network groups that were scattered through the office, but she and Samir were called back to the exam room before she could read anything. Amita put the most interesting looking brochures in her purse to examine later.

Amita was happy to put a face to the kind voice of the care coordinator she had talked to on the phone the day before. Amita and Samir had even more questions for the care coordinator than before, but she patiently answered more questions about administration of feedings, medications, and other procedures.

The care coordinator learned that the current feeding and medication schedule was overwhelming for Samir and Amita. The parents explained a different way to space the medicines and feedings. Together they came up with a realistic schedule that seemed less intense. The care coordinator printed this, scheduled for the pediatrician to review, and also handed copies to Samir and Amita.

Then the care coordinator went into detail about early intervention and how therapists would come to their home and would work with the whole family to assist Anjali's physical development. She explained how to apply for medical assistance for Anjali. When Samir mentioned they only had one feeding tube left, the care coordinator called the equipment company and asked the pediatrician to complete prescriptions for supplies. She then gave Amita and Samir information about a parent support network. She explained that the parent support network enables parents of children with similar diagnoses and situations to communicate

with each other and share information. Parents support one another through difficult times and have a unique perspective that empowers other parents to gain access to other services.

After Amita and Samir had finished working with the care coordinator, the pediatrician, Dr. Werner, came in to examine Anjali for the first time. Dr. Werner reviewed the care coordinator's assessment of Anjali and performed a history and physical. She listened to Samir and Amita's concerns and addressed the priorities they had for Anjali. She recommended follow up with pulmonologist with a goal of weaning Anjali off her oxygen, a follow up with a gastroenterologist, a visit with a nutritionist to promote oral feeding and optimize nutrition, and a neonatal follow up when Anjali reached her third month.

The care coordinator immediately contacted the referral coordinator to request the necessary referrals for the specialist visits and scheduled all the appointments. Together, Dr. Werner, the care coordinator, and the new parents created a care plan with goals and interventions for Anjali. One copy of the care plan was provided for Amita and Samir; the other care plan was placed in Anjali's chart.

On the long ride home, Amita and Samir felt less overwhelmed and more in control. They talked about contacting the parent network. Amita hoped that they would be linked to parents who had had similar experiences and who could understand their fears as parents of a medically fragile child. As Anjali's parents, Amita and Samir were an important part of the medical team caring for their child, but they were not alone.

In next month's article, Amita and Samir will be learning about parent partners at their pediatrician's office.

For more information on Medical Home, please visit the National Center of Medical Home Initiatives for Children with Special Needs at [www.medicalhomeinfo.org](http://www.medicalhomeinfo.org). For a list of references that accompany this article, please make request to [jhollingsworth@eparent.com](mailto:jhollingsworth@eparent.com). •

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## Medical Home Glossary

**Care Coordination:** The process of linking the CYHSCN/family with pediatrician, specialist, community agencies, mental health services, home nursing and equipment companies, insurance providers, school and parent programs to optimize access to resources in the care of the child.

**Durable Medical Equipment:** Equipment that is medically necessary and ordered by a physician.

**Home Care Services:** Home nursing or home health aid services that provide direct patient care and monitoring as ordered by the physician.

**Care Plan:** A document describing the medications, treatments, referrals to specialists, referrals to community resources and goals for the child with special health care needs. The care plan is written by the parents, physician, care coordinator and social worker. A copy of the care plan is given to the family and kept in the chart.

**Early Intervention:** A county funded program that provides home based services to promote growth and development.

**Parent Support Organizations:** Organizations that link parents and family members of children with special health care needs with parents of similar conditions/circumstances to promote mutual support, networking and sharing of resources.



## PART THREE

# One Family's Journey: Medical Home and the network of supports it offers children and youth with special health care needs: Parent Partners

By Sabra Townsend, BSIE, Gina Pola-Money, Molly Gatto

In this nine installment Medical Home series, *EP* will present a case study about the American Academy of Pediatrics' Medical Home Initiative. A "Medical Home" is not a building. It is an approach to providing healthcare services to children with special healthcare needs.

This article presents Part 3 in the series as readers learn more about Amita and Samir and their daughter, Anjali, a fictional family. *EP* readers will learn about Medical Home through their experiences.

**B**aby Anjali was a new patient on the practice's panel. The care coordinator added her name to the list of patients for discussion at the pediatrician's weekly case conference meetings.

Prior to the meeting, the care coordinator notified one of the parent partners in the practice about a new premature baby to be discussed at the case conference. The parent partner, a mother to a now eight-year-old son, knew what it was like when her son spent two weeks in the Neonatal Intensive Care Unit (NICU) after being born prematurely. She shared her concerns with the care coordinator about Anjali and her family to facilitate discussion at the meeting. Anjali's condition was complex and the parent partner knew from her own experience the practice could help this family cope with the many people coming into their home and any feelings of frustration. Moreover, she recalled how unprepared she and her husband felt when they took their son home from the NICU eight years earlier.

The parent partner remembered speaking to another parent with a premature infant eight years ago and the invaluable support she provided.

The case conference got started after the pediatrician finished seeing the last patient. The care coordinator discussed some of

the parent partner's suggestions for things to discuss when Amita and Samir took Anjali in for her weight check the following week. They agreed the questions provided some wonderful thoughts to include in their discussion with the family at the visit.

Baby Anjali, Amita, and Samir arrived on time to the pediatrician's office the following Wednesday. While they were nervous about driving to the office, they were even more nervous to see if Anjali was gaining weight. The nurse took them back to the exam room where they carefully undressed Anjali and placed her on the scale. Terrific! Their little Anjali had gained 8 ounces since her discharge from the hospital last week!

The pediatrician and care coordinator met them in the exam room to go over Anjali's growth and talk about the family's first week at home. Amita and Samir began to express their concerns about their baby and how to cope when Samir returned to work. Amita mentioned she made appointments for seven different specialists Anjali needed to see in the next few weeks but was worried how she would manage Anjali by herself in the car. Amita told the care coordinator that her mother was coming from India to help her with Anjali but would not be arriving for another two weeks.

The care coordinator felt Amita was a caring and competent mother but knew she was concerned about all of her responsibilities. She spoke to Amita and Samir about talking to another parent from the practice who had a premature infant. This parent was working with the

## PARENT PARTNERS

### Selecting Parent Partners

- All practice team members need to understand and embrace the idea of having parents of a child/youth with special health care needs (CYSHCN) as equal partners.
- Discuss the parental traits, qualities, and characteristics that would compliment the practice team.
- Discuss potential parent partners and determine if they would be a good match for the practice team.
- Working on a team where all members are equally valued and respected may be a new adventure for all involved. Think about parents who have sought you out for help but who also have shared their ideas and resources. Which parents have taught you the most about raising and caring for a CYSHCN? Teams develop as trust grows among team members; remember this may take time.

### Parent qualities

- Has a child or youth with special health care needs
- Can look beyond their own issues and concerns and consider ideas from the perspectives of other families with CYSHCN.
- A sense of humor
- Good listener and effective communicator.
- Representative of diversity in the community
- Accessed a wide variety of services, resources, supports and providers (specialists, therapists)
- Have knowledge of statewide and local family and disability organizations
- Understand that this is not a support group and have energy, enthusiasm to participate
- Commit the time necessary for meetings, assignments and follow up. Teams embracing partnerships will find a time to meet that accommodates everyone's schedule.

### Engaging and Maintaining Parent Partners

- Invite parent of CYSHCN to a participate in a focus group or resource night
- Respect the parent as a professional
- Provide small stipend for team meeting attendance
- Reimburse or child care, mileage and tolls
- Rotate meeting days and times
- Offer the option to call into the meetings
- Partner the parent with another parent partner
- Excerpted from Parent Partners, Creative Forces on Medical Home Improvement Teams, A Guide for Parent and Practice "Partners" Working to Build Medical Homes for Children with Special Health Care Needs, p. 9-10, Center for Medical Home Improvement, 2003
- [http://www.medicalhomeimprovement.org/assets/pdf/CMHI\\_PP\\_Guide.pdf](http://www.medicalhomeimprovement.org/assets/pdf/CMHI_PP_Guide.pdf)

practice to support parents like Amita and Samir by both talking to them about their own experiences but also linking them to community resources. The care coordinator mentioned the role of this parent was called a "parent partner." Engaging and working with parent partners was one aspect of the practice's participation in the medical home program. She went on to explain all the benefits of having a parent

partner in the practice. Parent partners expanded their knowledge and skills about families' needs and priorities. Some parent partners helped the practice develop folders to give to parents about the scope of services provided by parent partners as well as phone numbers for services Anjali may eventually need.

Amita and Samir were very excited about talking to another parent who had been

through what they are experiencing now. They agreed to provide their phone number to the care coordinator so the parent partner could contact them. They left the office wondering how soon she would call!

On the way home from the doctor's office, Amita read to Samir from the folder as he drove. She relayed the history of how the medical home initiative got started and how parent partners are a critical piece in the practice's approach to family centered care. She continued to read to Samir how many states were working on medical home programs. They all were using parent partners but in various ways. Some practices had parent partners as part of their staff providing support to the families visiting the practice with their children who have special health care needs; others had groups of volunteer parents working on things like resource nights, parent networking, information bulleting boards and care binders. "I wonder what a care binder is?" Amita said. "We can add that to our list of questions for the parent partner when she calls!"

As Amita and Samir sat down to dinner, the phone rang. To their surprise, the voice on the other end of the phone introduced herself as the parent partner for their pediatric office. She asked if it was a good time to talk and Amita told her they just started eating dinner and following dinner they had to feed Anjali. Could they possibly talk after that? "Absolutely!" replied the parent partner.

At 9:00 PM, the phone rang again, and this time Amita and Samir knew who was calling. They each picked up a phone so they could both hear what the parent partner was saying. First, she told them more information about the medical home initiative and the value of parent partners. Furthermore, she stated practices with parent partners are striving hard to provide family centered care. She felt empowered to share her experiences and expertise with: other parents of children and youth with special health care needs, pediatricians, care coordinator, and office staff because she has "walked the walk." The parent partner also said she feels like an equal team

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member in the practice. All members of the practice listen to her suggestions and ask for help with families with children with new diagnoses. Amita and Samir learned she is one of several parent partners in the practice and that she too had a child who was born prematurely. Her son was now in second grade, but she remembers how alone she felt when they first took him home from the hospital. Amita and Samir began to tell her about their own fears for their daughter and how they would manage to care for her properly. They knew they had wonderful support at the pediatric office but still had concerns.

Next Amita and Samir asked if there were other parents at the practice with children like Anjali – maybe even one who practiced Hindu. They thought talking with another Indian family who shared similar traditions might assist them – especially when Amita's mother arrived. Amita told the parent partner that in India, grandmothers play a vital role in the care of children, and they wanted her to understand everything that was happening to Baby Anjali. The parent partner said there was, in fact, another family from India she they could talk to and she would be happy to facilitate a conversation.

Finally, Samir asked the question Amita brought up in the car. He asked what a care plan binder is and how it is used. The parent partner explained this was an idea developed from their parent partner group at the practice. The care plan binder was given to families with children and youth with special health care needs. The care plan binder contained information about the child's medical history, schedules of upcoming appointments with specialist contact information, letters of medical necessity, copies of prescriptions, and medication and feeding instructions. She told Amita and Samir the binders are completed with the family, incorporating their input. At Anjali's next appointment in the pediatric office, they would schedule a time to meet with the care coordinator, parent partner and pediatrician to begin Anjali's care plan binder. Amita asked if her mother could come to the care plan binder meeting and was told other family mem-

bers are always encouraged to attend. She told them to start picking out some of their favorite pictures of Anjali to be included in the binder. Amita and Samir thought this was a wonderful idea and would help keep them organized.

The following week, Amita was sorting through the many, many pictures they had taken of Anjali, trying to decide which to take to the care plan binder appointment, when she heard the mail drop through the mail slot onto the floor. She put the pictures aside and went to get the mail. On top of the pile was what looked like an invitation. She opened it and was surprised to see she and Samir were being invited to a resource night being held at the pediatrician's office next month. The invitation listed some of the groups who would be present. Amita was very excited and called Samir at work to inform him about this exciting news.

Next month Amita and Samir attend the resource night with Amita's mother and Baby Anjali. They learn about many resources right in their own community!

For more information on Medical Home, please visit the National Center of Medical Home Initiatives for Children with Special Needs at [www.medicalhome-info.org](http://www.medicalhome-info.org). For a list of references that accompany this article, please make request to [jhollingsworth@eparent.com](mailto:jhollingsworth@eparent.com). •

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Gina Pola-Money is the parent of five children two of which have passed away one at age 5 and the other at age 17 from a rare dystrophy. She is the Family Involvement Coordinator for the Utah Bureau of Children with Special Health Care Needs which includes the Utah Collaborative Medical Home Project and the Director of Utah Family Voices Health Information Center.

Molly Gatto, is Associate Program Director of the Pennsylvania Medical Home Program (EPIC IC) at the PA Chapter of the American Academy of Pediatrics. She has been working in health care for over 20 years, in practice, insurance and currently is working on her masters in Healthcare Administration.

## DEFINITION OF FAMILY-CENTERED CARE

*Assures the health and well-being of children and their families through a respectful family-professional partnership.*

*Honors the strengths, cultures, traditions and expertise that everyone brings to the relationship and;*

*Is the standard of practice which results in high quality services.*

## PRINCIPLES OF FAMILY-CENTERED CARE FOR CHILDREN

- The foundation of family-centered care is the partnership between families and professionals. The following principles are essential in this partnership:
- Families and professionals work together in the best interest of the child and the family. As the child grows, s/he assumes a partnership role.
- Everyone respects the skills and expertise brought to the relationship.
- Trust is acknowledged as fundamental.
- Communication and information sharing are open and objective.
- Participants make decisions together.
- There is a willingness to negotiate.

## BASED ON THIS PARTNERSHIP, FAMILY-CENTERED CARE:

- Acknowledges the family as the constant in a child's life.
- Builds on family strengths.
- Supports the child in learning about and participating in his/her care and decision-making.
- Honors cultural diversity and family traditions.
- Recognizes the importance of community-based services.
- Promotes an individual and developmental approach.
- Encourages family-to-family and peer support.
- Supports youth as they transition to adulthood.
- Develops policies, practices, and systems that are family-friendly and family-centered in all settings.
- Celebrates successes.



## PART FOUR

# One Family's Journey: Medical Home and the network of supports it offers children and youth with special healthcare needs: Community Resources

In this nine installment Medical Home series, *EP* will present a case study about the American Academy of Pediatrics' Medical Home Initiative. A "Medical Home" is not a building. It is an approach to providing healthcare services to children with special healthcare needs.

This article presents Part 4 in the series as readers learn more about Amita and Samir and their daughter, Anjali, a fictional family. *EP* readers will learn about Medical Home through their experiences.

By Margie Wood, R.N.; Sharon Gretz, M.Ed; Molly Gatto; Deborah Walker; Sarah MacDonald, M.D.

**Amita** had heard that you could get used to anything. She still was not sure. She had gotten used to some of the challenges that her daughter, Anjali, presented. They finally managed to get into a regular routine. The six months since Anjali's premature birth had been a blur of doctors, nurses, social workers, and other medical professionals. Amidst the medical chaos, Amita had one point of stability: Sunshine Pediatrics.

All of Anjali's care was coordinated through Sunshine Pediatrics. Amita adored Dr. Werner, Anjali's primary care physician. Even when Dr. Werner seemed frazzled and busy, the practice's care coordinator, Laura, was always available to answer Amita's questions. These days, Amita felt as though she were always asking questions.

Amita was glad to have those first few precarious months of Anjali's life behind her. Now she had more time to think and more time to worry. Amita knew that Anjali was a little behind in her development.

Even though the expected developmental milestones had been adjusted for Anjali's early birth, Anjali was not doing all of the things she should be for her age. Amita also worried about other aspects of Anjali's care. There were so many specialists to see and so many insurance issues to sort out. If that

was not enough, Amita worried about her career. She had planned to go back to work after Anjali was born, but she could not even think about working now.

Thank goodness Amita's parents arrived from India! Amita's mother was so excited when Anjali was born. She insisted that everyone immediately call her Naniji, the Hindu word for grandmother, even though she had not even met Anjali yet. Her husband said he would wait to meet Anjali, and then he could be called Nanaji, the Hindu word for grandfather. Naniji and Nanaji had been visiting for one week now. Nanaji was still intimidated by Anjali's small size and feeding tubes, oxygen, and nasal canula. Naniji jumped into her role as grandmother feet first, eager to learn everything about her granddaughter. A few nights earlier, she and Nanaji even babysat Anjali so Amita and Samir could go out to dinner! That evening, Naniji marveled at Anjali as she rocked her to sleep, singing the Hindi "Lori" (lullaby), entitled, "Nanhi Pari ab sone chali," which means: "The little fairy is going to sleep."

Sunshine Pediatrics had become a source of comfort for Amita and Samir. They knew they could call anytime they had a question or Anjali needed something. Amita especially enjoyed the support of Cheryl, a parent partner at Sunshine Pediatrics. Cheryl was also the parent of a special child with special healthcare needs. She could relate to Amita as a parent, but she also had a role with Sunshine Pediatrics. Cheryl and a few other parents share the parent perspective of caring for a

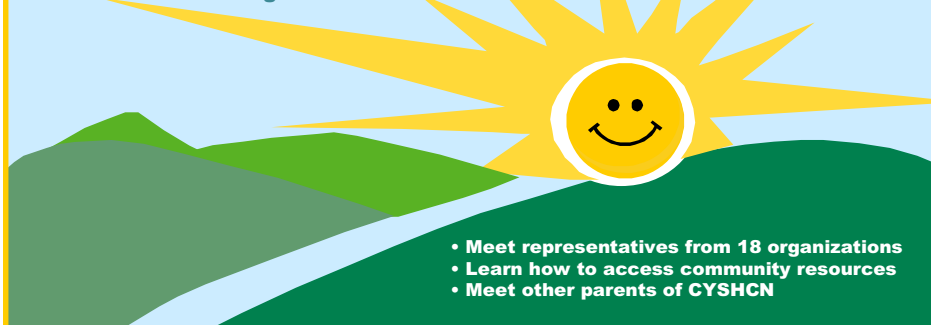


## Back by popular demand... Don't miss Resource Night at Sunshine Pediatrics!

**Date:** Wednesday, December 12

**Time:** 5pm- 8pm

**Place:** In the waiting room



- Meet representatives from 18 organizations
- Learn how to access community resources
- Meet other parents of CYSHCN

# You're Invited!

child with special healthcare needs with the pediatric staff to help make the office more supportive and the care more comprehensive. Their role was titled, "Parent Partners." Amita had already decided she would like to become a Parent Partner at Sunshine Pediatrics, just as soon as she felt less overwhelmed with Anjali's situation.

Amita glanced at the refrigerator. In the center of the door, she had secured a bright postcard from Sunshine Pediatrics. It was an invitation to the semi-annual resource night. Laura, the care coordinator, had called Amita before she could R.S.V.P. to see if she was coming to the event. Laura explained that twice a year Sunshine Pediatrics invited representatives of various community resources to come and share information about the services they could provide to children and youth with special healthcare needs and their families. There were several representatives attending that Laura felt would be especially helpful to Amita and Samir.

Amita and Samir were looking forward to the resource night. They both wanted to meet more parent partners, and Samir had some questions about their insurance plan. Naniji also wanted to go. Naniji quickly offered to stay with Anjali. He was looking forward to a quiet evening at home with just him and Anjali.

representatives, collect brochures, ask questions, and mingle with other families in the hallways. She pointed out a large filing cabinet near the front desk filled with resource information. Dr. Werner invited families to share any resources they had learned about on their own with Laura. She also handed out a list with each of the agency's names, contact information, and a brief description of the services they provided. Finally, she passed around another hand-out with several reputable Web resources for parents and

dren with developmental delays. Anjali had early intervention specialists coming to their home twice a week ever since her multi-disciplinary evaluation (MDE).

In Room 2 were two nurses from a Pennsylvania Nursing Home Service Program. Amita, Samir, and Naniji learned that this Nursing Home Service Program is a community resource available in their state of Pennsylvania. The nurses meet with families in their homes, completing a needs assessment. They then help link families to community agencies to meet most of their needs, anything from nutrition, durable medical equipment to financial (applying for Supplemental Security Income), medical, recreational, or respite care.

Room 3 housed a durable medical equipment vendor. Amita recognized the vendor as the same woman who helped with some of Anjali's home equipment.

Room 4 had several representatives from various insurance companies. Samir learned that their insurance company encouraged families with children with special healthcare needs to get a case manager. This insurance-based case manager helps them navigate complicated insurance processes. Samir now understood what someone at work mentioned a few weeks ago.

A Parent-To-Parent (P2P) member was in room 5. He explained to Amita and Samir that his organization linked parents who

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**Amita was thrilled to learn the parent partner network crossed practice, county, and state lines. This connection to other parents was something she and Samir felt was invaluable.**

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That evening, Sunshine Pediatrics was packed with people. Dr. Werner began by welcoming the crowd and thanking Laura and the parent partners for organizing the event. She explained that in each exam room was a representative from a community agency, which supported the care of children with special healthcare needs. She encouraged parents to meet with the agency

pointed out a table in the back of the room with some magazines and books that may be of interest. Next to the printed material were plates of homemade chocolate chip cookies for all to enjoy!

In Room 1 were staff from Early Intervention (EI). Samir and Amita knew that EI is a free, county-based, national service, which provides in-home therapy for chil-

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have children with similar special healthcare needs to support one another. Usually the parents live in the same state. However, if a child has a rare condition, P2P may connect families from different states. Amita was thrilled to learn the parent partner network crossed practice, county, and state lines. This connection to other parents was something she and Samir felt was invaluable.

In room 6 was an attorney who specialized in child advocacy. She worked for a Pennsylvania Law Project. She explained that she helps families negotiate legal situations, be they medical, insurance-related, or educational. Amita and Samir looked at each other and were amazed that such a service existed!

In the last room was a woman who worked for a Parent Education Network. This is a program that helps families develop Individualized Education Plans (IEPs) and Individualized Family Support Plans (IFSPs)

for their school-age children with special healthcare needs. Also, they help parents advocate for the best, most appropriate educational environment for their child.

Both Amita and Samir were excited as they went from room to room. Naniji's bag was full of brochures and flyers, business cards, and pamphlets. Amita was already writing a "To Do" list in her mind. The cookies were delicious! Amita and Samir were hoping they could attend the next resource night at Sunshine Pediatrics.

Visit with Amita, Samir, and Anjali in the February 2008 issue of *EP* as they learn more about special education.

For more information on Medical Home, please visit the National Center of Medical Home Initiatives for Children with Special Needs at [www.medicalhomeinfo.org](http://www.medicalhomeinfo.org). •

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## PART FIVE

# One Family's Journey: Medical Home and the network of supports it offers children and youth with special healthcare needs: Special Education

In this nine installment Medical Home series, *EP* will present a case study about the American Academy of Pediatrics' Medical Home Initiative. A "Medical Home" is not a building. It is an approach to providing healthcare services to children with special healthcare needs.

This article presents Part 5 in the series as readers learn more about Amita and Samir and their daughter, Anjali, a fictional family. *EP* readers will learn about Medical Home through their experiences.

By Sarah Macdonald, MD; Margaret A. Ruane, EdM; Eve Kimball, MD

**Samir** had a lot to do and a list to prove it. Tomorrow night was his 10th wedding anniversary with Amita. He wanted it to be special. He had to:

- Pick up the flowers
- Confirm the babysitter
- Double check the directions to the restaurant
- Find an envelope for the card the girls had made for Amita

So much had happened since their wedding ten years ago. As Samir looked over his list, he chuckled. It reminded him of the list he and Amita had made six years ago when Amita was six months pregnant—the list they made a few hours before Anjali was born. Those first months were becoming a bit of a blur. He couldn't remember the names of some of the medications, the nurses, the procedures. But he would never forget how little Anjali was, how hard it was to walk into the NICU

that first time and see her with so many wires and tubes and catheters in place. He would never forget some of the medicalese he now knew: preemie, oxygen, nasogastric feeds, durable medical equipment, mafos (the ankle foot orthotics to stabilize Anjali's walking). He had not forgotten some of the sadness he had felt, how tired they both were, how scared.

Now Samir and Amita had another child. Vashti was born at

39 and 3/7 weeks, weighing 7 pounds 2 ounces, exactly three times what her sister Anjali had weighed when she was born three years earlier. Vashti had seemed so easy those first few months. She only spent two days in the hospital with Amita; she breast fed easily, never needing a tube down her nose, reflux medication, an apnea monitor, or a visiting nurse. Although she was a healthy, robust infant, Samir and Amita still found themselves wandering into the nursery in the middle of the night, just to make sure she was okay.

Samir wanted their anniversary dinner to be special, a celebration of all the good things they had accomplished together, raising Anjali and Vashti, creating a wonderful home life, keeping the Hindu traditions alive for their two American girls. The family just celebrated the Hindu festivals Holi (festival of colors), Diwali (festival of lights), and also celebrated Christmas. Reflecting on everything, Samir didn't want to make more lists at this dinner, even though he and Amita had a lot to do. Anjali was starting kindergarten in the fall! Samir was so proud of his little girl! She had even learned to fold her hands to the Lord Ganesha before embarking on this new journey!

Anjali was now five years old. Amita and Samir were grateful for how well she was doing. How fast the time has flown! Just yesterday, it seems, she weighed a mere three pounds and had a nasal cannula with oxygen in her nose. Now she was a happy-go-lucky five-year-old! She had done well in preschool. Her teacher suggested to Amita and



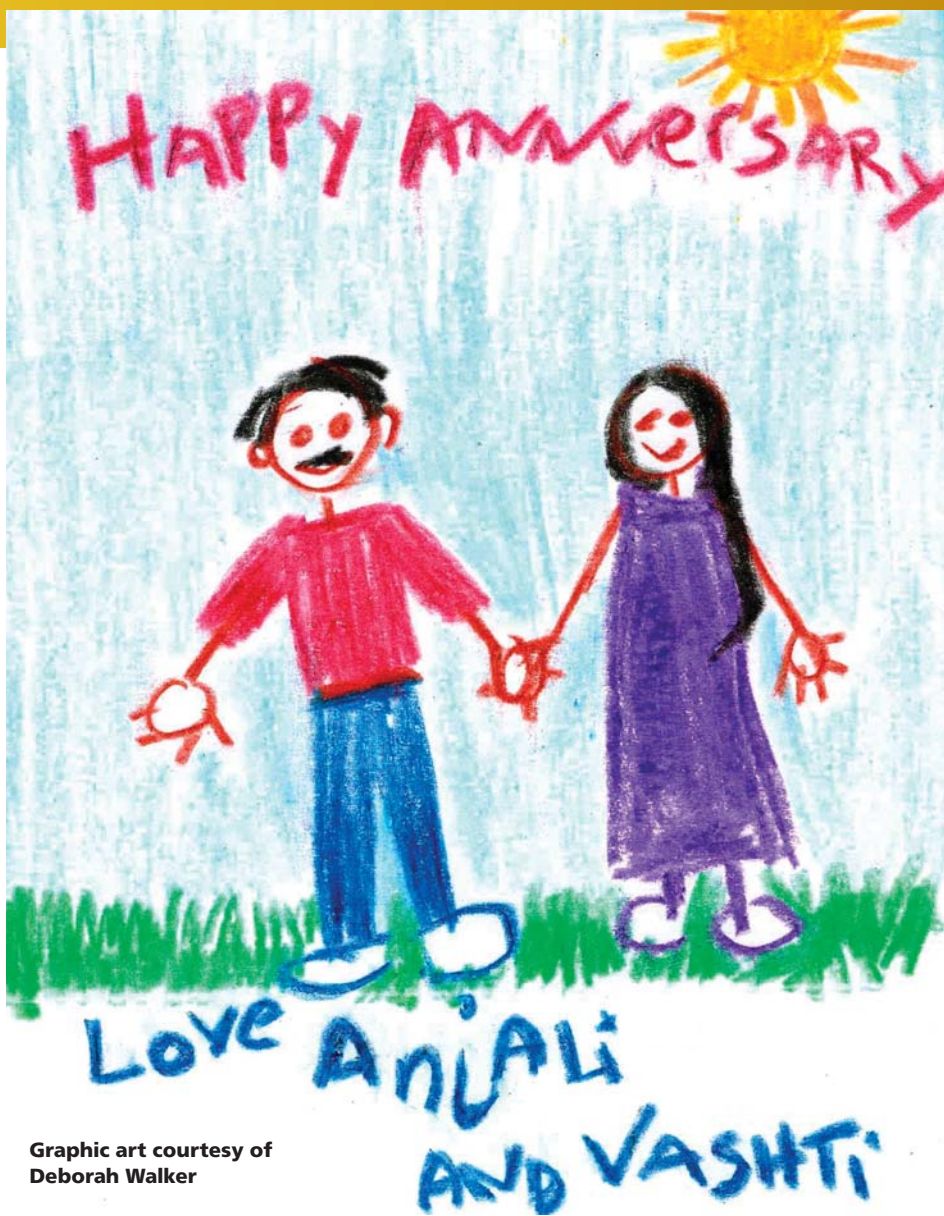
Samir that they begin preparation for her enrollment in kindergarten. Anjali wasn't ready to start elementary school without some help. She had asthma. She wore glasses. She could only walk short distances with her braces. She would need learning support. Perhaps she would need services her parents hadn't even thought of.

Amita, too, was excited to be having a romantic, anniversary dinner with her husband. She had also been thinking about their 10 years together and all that had happened. She was impressed with how much they both had accomplished, and she wanted to celebrate their success. She knew they should enjoy this adult time together—but what better time in a quiet room with dinner cooked by someone else and no kids to interrupt to talk about what was on her mind: Anjali was starting kindergarten in the fall, and Amita was anxious!

As Amita and Samir looked over the menu, they began to talk about Anjali.

In the winter, Amita and Samir began to prepare for Anjali's kindergarten year. They had already started Anjali at the local Indian Sunday school "Bal Vihaar" where children learned about the Indian languages, cultures, traditions, and religions. Anjali seemed to be enjoying her time at the temple where the "Bal Vihaar" was held every Sunday afternoon.

On the academic end, they already had a transition meeting at the public school Anjali would attend. They looked at resources on the Web about education for children with special healthcare needs. They attended an Education Forum about educational rights for children with special



Graphic art courtesy of Deborah Walker

needs at a local college with one of the parent partners from Sunshine Pediatrics. They knew about IFSP's (Individualized Family Service Plan), because when Anjali was an infant she had qualified for services through the early intervention program. And when she turned three, she transi-

tioned to her county's intermediate unit (IU) in Pennsylvania to continue with physical therapy, occupational therapy, and speech therapy. The intermediate units in Pennsylvania provide educational services to children within a specific region or county. But now that Anjali was five, she was ready to transition again, this time to the public kindergarten. This transition worried Amita and Samir. They were fearful that Anjali might not qualify for the same services she was receiving as a preschooler.

Amita and Samir had been talking to Cheryl, the parent partner at Sunshine Pediatrics about transitioning from preschool to kindergarten. Cheryl had a son who was born prematurely. He was now in middle school, and Cheryl knew the ropes.

Cheryl had explained the difference between a 504 plan and an Individualized

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The representative from the Parent Training and Information organization had suggested that Amita and Samir come into Anjali's class and talk about her early birth, how much Anjali has achieved, why she is different in some ways from her classmates but very much like them in other ways.

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## Ideas for Parent/School Interaction

- After the IEP meeting, keep lines of effective communication open by identifying the most efficient ways to keep in touch with school staff.
- Involve and listen to your child. Encourage your child to express his/her concerns and needs. Help children with health issues understand that how they feel impacts how they learn, how they perform, and how they interact with others.
- Make sure you and your child's teacher are prepared for questions as your child compares himself or herself to typical peers.
- Ask your child's doctor what is appropriate and necessary to share with the school. Make sure the doctor has provided to the school a copy of all pertinent medical information and a copy of an emergency care plan. Make sure school staff are aware of warning signs or physical and emotional symptoms that require medical attention (e.g. problems with vision, motor tasks, eating, or stamina, OR changes in mood, behavior, respiratory function, bowel/bladder habits, or color of skin.)
- Think about creating with your child's physician a short one-page information sheet that outlines important facts and lists resources for additional information.
- Save and file all copies of pertinent educational plans, developmental evaluations, progress reports, school forms, specialist evaluations, etc.
- Seek guidance from a mentor who has walked a similar path. Your child's physician or teacher may be able to recommend another parent, person with a disability, or local support group.

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Education Program, or IEP. Because Anjali had some physical disabilities requiring her to wear braces, and because she would need specially designed instruction for her learning difficulties, her parents had decided she needed to have an IEP under the IDEA Act, not a 504 plan under the Rehabilitation Act. They knew they could vocalize this intention to the multidisciplinary team at the school district, as parents' input is vital to the decisions that would be made about their daughter's education. Amita and Samir also knew that they would have to wait for the evaluations that would be done by the school district in order to see if Anjali qualified for the same level of

support she was receiving throughout her preschool years.

By the time Amita and Samir were ready to order their anniversary dessert, they had their "to do" list completed.

- Get a copy of Anjali's most recent evaluations by the intermediate unit staff – physical therapist, occupational therapist, speech therapist
- Make the appointment for Anjali to be evaluated by the school's multidisciplinary team
- Make an appointment for Anjali's annual check-up with Dr. Werner
- Get a copy of Anjali's comprehensive care plan which includes her medical history, diagnoses, medications, specialists, immunizations, and asthma action plan
- Get the school form signed from Dr. Werner's office
- Get copies of the developmental evaluations from the neonatal follow-up program
- Call the school district to find out about transportation to and from school for Anjali
- Find out when they could expect the completed Evaluation Report from the school district.

They knew this spring would be busy getting everything ready for their initial IEP meeting with the school district and getting Anjali ready for the transition to kindergarten. But there was a level of confidence, as Samir and Amita knew they were a good team, knew they were good parents, and knew they were pretty well prepared.

At their March appointment at Dr. Werner's office, they received helpful items and suggestions. Sonya, the care coordinator for the practice, was present for part of Anjali's visit. Dr. Werner gave them a copy of Anjali's Asthma Care plan, a note for the school describing Anjali's asthma symptoms and signs, medications and when to give them and what side effects to expect. She checked Anjali's vision and verified that her prescription did not need to be rechecked until her next appointment with the eye doctor. Sonya discussed with Amita and Samir some questions to ask the school about handicap accessibility: Will Anjali need to use an elevator instead of steps? Will an alternative vehicle be needed for

Anjali's longer journeys? Dr. Werner wrote a prescription for a mobility aid for her to ride from room to room at school and faxed it to the durable medical equipment (DME) supplier. In addition, Sonya, the care coordinator wrote a letter of medical necessity for the mobility equipment to ensure payment. Dr. Werner wrote the physical, occupational, and speech therapy prescriptions for Anjali to receive services at school. Sonya reminded Amita and Samir that the IEP is a fluid document, open to changes if necessary. She encouraged them to keep in touch with Anjali's teacher during her school years to share concerns if they notice areas of difficulty. They also needed to be sure areas of difficulty were addressed with comprehensive strategies and accommodations in the IEP. It was a good visit.

In April, Samir contacted the school and arranged for the IEP meeting for Anjali. He knew that they would need to advocate for their daughter and make sure that the IEP contained all of the services that Anjali needed to grow and develop to her maximum potential.

Fall arrived. The school year had started reasonably smoothly. Amita and Samir felt good about the current placement that was identified after the IEP meeting when they received Anjali's Notice of Recommended Educational Placement. The least restrictive environment for Anjali was a part-time special education program. Anjali liked her teachers and had made friends with a little boy in her class. Anjali could now recognize all of the letters of the alphabet and was learning to write her name. She had trouble though with the two different kinds of "A"s in her name, and the "J" was usually backwards. Amita and Samir received a daily progress report on Anjali's school day, as the IEP had stipulated. However, they had some concerns they wanted to discuss at their parent conference at the end of October.

In preparation for the meeting, Amita called the Education Law Center (ELC) for advice on how to discuss Anjali's progress as it related to her IEP. Anjali was supposed to get thirty minutes of physical therapy twice a week but was only getting it once a week because one of the physical therapists had just moved out of the area when her husband got a new job. Her speech

## Glossary of Terms

**Evaluation Report (ER)**—The summary given to parents or guardians of a child who has received a multidisciplinary evaluation. The ER drives the IEP.

**504 Plan**—A plan developed under section 504 of the Rehabilitation Act of 1973. It addresses the accommodations and services that must be provided to persons with specific mental or physical impairments. In the school setting, it applies to children in those schools that benefit from federal assistance.

**Individualized Education Program (IEP)**—An educational plan uniquely prescribed for individual children who are eligible for special education services under IDEA. The IEP contains present levels of educational performance along with individual behaviorally written goals. It also outlines related services, specially designed instruction, and a statement of the degree to which a child will participate with regular education peers in various subject areas or activities.

**IDEA**—Individuals with Disabilities Education Act. This law gives eligible children with disabilities the right to receive special services and assistance in school. These services are known as special education and related services. They can be important in helping the child at school.

**IEP Team**—The team of persons responsible for decisions regarding a child's placement and individualized education plan. Parents are critical members of the IEP team and are actively involved in the decision-making process.

**Least Restrictive Environment (LRE)**—Under IDEA, the placement for a child that permits the maximum participation with regular education peers, where appropriate.

**Multidisciplinary Evaluation**—An evaluation completed by a team of individuals in various disciplines. The evaluation is completed in all areas of suspected delays. It is completed at the request of the child's parents or guardians or by recommendation of the school.

**Parent Training and Information Organizations**—Organizations that assist parents with navigating the special education process. They help parents learn about the special education system and help parents advocate for their children by increasing their knowledge.

Anjali's class and talk about her early birth, how much Anjali has achieved, why she is different in some ways from her classmates but very much like them in other ways. They also discussed how Anjali was doing in music, physical education, and art classes given the appropriate accommodations described in her IEP. Finally, the physical, occupational, and speech therapists each agreed to give Amita and Samir home plans that they can follow to work with Anjali when she isn't in school.

therapy was taking place twice a week for 30 minutes as per the IEP, but there were five other children in the session, and Anjali wasn't getting enough one on one time. Anjali said that two of the children in her class teased her because of the way she walked. Although the IEP did not have a section that read "Anjali will be in a teasing-free classroom," Amita wanted to talk to the team about some strategies. The lawyer with whom she spoke encouraged her to have all of her concerns in writing and faxed Amita a template that she could follow to address some of these concerns with the team.

The ELC consultant told Amita and Samir about a local education support network, a Parent Training and Information organization. She said that Amita and Samir could arrange to have a representative go with them to the IEP meeting for support and to be sure that they understood all that was being said.

Anjali's parent-teacher conference went well. Amita and Samir had requested that the principal be present. The principal apologized for the reduced physical therapy sessions. She explained that one of the physical therapists had moved out of the area and they would try to get another one. Amita and Samir emphasized to the principal that she had to get another therapist, even if the therapist just worked for the interim. They suggested hiring one of the therapists from the local rehabilitation center in the next town to come to Anjali's school. The principal said she could look into this arrangement when she talks with the Director of Special Services. Fortunately, the speech therapist was present at the conference so changes in the schedule could be made that allowed one group session and one session for one on one time with Anjali. As the school nurse participated in the meeting, they reviewed her Asthma Care Plan together. Amita and Samir thanked Anjali's teacher for the daily progress report. They appreciated all of the information she included and the time she took each day to complete it. They had a good conversation about teasing and bullying. The representative from the Parent Training and Information organization had suggested that Amita and Samir come into

Amita and Samir held hands as they left the meeting and headed for their car. Samir suddenly remembered a telephone conversation he had last year. Dr. Werner had asked him to call a father who had joined Sunshine Pediatrics when his son was born prematurely. Samir had called him several times to talk with him about being the parent of a preemie and to offer support. He asked the father if his son had a nasogastric tube or was on feeds by mouth. The man laughed, saying it was still all just alphabet soup to him. He told Samir he didn't always understand what the NICU staff were saying as they talked in abbreviations, and in what sounded like Latin. Samir laughed, too. He and Amita had been in those shoes!

But look how far these shoes had taken them! They just had their first kindergarten parent-teacher conference! They were so relieved. The conference hadn't been quite as intense as they had anticipated. They had advocated for their daughter's educational setting, they had compromised, they had been creative, and they had been successful. Now it was time to go to take the girls to swimming lessons!

Next month we will visit with Amita, Samir, and Anjali as they navigate a larger health-care system. We will learn more about the Medical Home in a hospital system. •

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The authors would like to acknowledge Deborah Walker for her creation of graphic artwork for this month's article.

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## PART SIX

# One Family's Journey: Medical Home and the network of supports it offers children and youth with special healthcare needs: Medical Homes in Hospital Systems

By Sarah Macdonald, M.D.; Alisa Hoffman, M.D.; Tracy Hagenbach, R.N.;  
Julia Rusert, Ph.D.

In this nine installment Medical Home series, *EP* will present a case study about the American Academy of Pediatrics' Medical Home Initiative. A "Medical Home" is not a building. It is an approach to providing healthcare services to children with special healthcare needs.

This article presents Part 6 in the series as readers learn more about Amita and Samir and their daughter, Anjali, a fictional family. *EP* readers will learn about Medical Home through their experiences.

**Boxes,** boxes everywhere! Anjali was tired of trying to get around all of these boxes as she walked about the house. She knew her family had to move, but she wasn't happy about it. It seemed to her that moving was making everything harder. She was nine years old and had lived her whole life in this house. She had picked out the color yellow that her Dad used to paint her room. She had figured out a way of hopping up and down the stairs without her braces, using the special banister her Mom had installed. She had a special swing set in the backyard with a swing and a climber adapted for her use. She and her sister, Vashti, named all of the trees around the house. At night, as they readied for bed, they made up stories about their trees. Anjali did not want to move. It was too hard—not just managing her way around the boxes in her braces, but also knowing she would be changing schools, changing doctors, changing friends.

Five weeks earlier, as the fall foliage began to peak, her mother, Amita, had lost her job. Amita's boss had told her it was just a reflection of the lousy economy and not her skills. The company needed to downsize and Amita's position had been cut. Amita carried the family's health insurance. She lost this

benefit, and she and Samir knew they could not afford to pay the COBRA payments.

Samir had a good job, but business was slow. He had not had a raise for 18 months, and there had been no bonus at the end of the year. Samir worked for a small company, and although it offered a health insurance benefit to the employees, the premium was quite high. Fortunately, Amita and Samir enrolled in Medicaid as a secondary insurance for Anjali so she still had coverage. Medicaid became Anjali's primary insurance. Being without family health insurance and meeting mortgage and car payments on one salary would be tough. Amita and Samir decided to move. Like Anjali, they were also nervous about the move. Every morning they stood in front of Lord Ganesha's picture with folded hands and prayed to Him for giving them strength to face the change.

Samir's company had a branch office in a rural community two hours from their home. Housing prices were much less than in their current community. The public schools had a good reputation. There was a small community college that was expanding its enrollment, and Amita thought she might be able to get a job there. There was a good hospital nearby. So, their house had been put up on the market, Samir had requested a transfer, and boxes and boxes were being packed.

Amita and Samir needed help figuring out

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how to transfer Anjali's care to a new medical facility. They already had copies of her health history, care plan, diagnoses, medications, letters from specialists, vaccine records, and an Asthma Action Plan. How would they find a primary care pediatrician, along with the specialist doctors for Anjali in the new area? Would it be a practice that knew about Medical Home? Amita had a meeting with Sonya, the care coordinator at Sunshine Pediatrics, to discuss these concerns.

Sonya told Amita that there was a very good pediatrician in their new community, Dr. Butler, who worked at a Federally Qualified Health Center (FQHC). This practice accepted Medicaid and had a sliding fee scale for families without insurance. She mentioned that there was a family practice residency at the local hospital. She wasn't sure which specialists practiced in that area but thought there was a special program in a practice at the hospital for children with special healthcare needs. Sonya also contacted a parent organization to see if they could be matched with a family that had a child Anjali's age with special healthcare needs. This would give Amita and Samir great emotional and psychological support.

Samir called the principal at Anjali and Vashti's school to discuss their relocation. They would be leaving school mid-year. Anjali was currently in fourth grade and Vashti was in first. Could Anjali's IEP be transferred to the new school, or would they have to go thru the evaluation process again? Did the new school district have special education services?

The principal recommended that Samir make an appointment with the principal at the new school to discuss Anjali's transition. The IEP would initially be honored, but the new school would want to evaluate Anjali and create their own IEP with Samir and Amita. Every school district has to meet the special needs of every student so they would provide physical, occupational, and speech therapies, and classroom support as necessary.

Amita and Samir's friends arranged a farewell party for the family in a tradition-

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## Amita carried the family's health insurance. She lost this benefit, and she and Samir knew they could not afford to pay the COBRA payments.

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al Indian way. They gathered at Amita's home, had a pot luck dinner, and gave them presents. They also placed a vermilion dot on their foreheads as an auspicious gesture to wish them luck in their new homes and lives.

By January, Amita and the family were settling into their new home. Although this home was a bit smaller than their old home, it was all on one floor. The yard was smaller too, but it did have a beautiful maple tree. They waited to hold their Hindu house warming ceremony until Amita's parents came from India.

In summer, the grandparents arrived. They were excited to see the new house, visit the girls' school, and help Amita and Samir settle in. They helped Amita arrange for a house warming Pooja (prayer service) when they lit incense in all the rooms to drive away any evil spirits and laid flowers at the feet of Lord Ganesha and other Hindu deities. All of Amita and Samir's new friends were invited to a freshly cooked Indian vegetarian meal. They planted a new tree in the backyard and named it "Asha" meaning hope in Hindi.

As the first snow of the winter season fell, Anjali started at her new school. Her IEP was accepted, and she would be starting speech, physical, and occupational therapy in the next few weeks since her classroom supports and set up were nearly

identical to her old school. There was an IEP meeting scheduled with the new team, Samir, and Amita next week. Anjali and Vashti had recess at the same time each morning and could play together. Samir joined a parent support network in the school district for parents with children with special healthcare needs. At home, Anjali and Vashti learned Hindi alphabets from their grandparents who spoke to the children in Hindi. They used the colored plastic letters they brought from India to help the children learn the alphabet.

Amita, meanwhile, made an appointment with the new pediatrician, Dr. Butler, at the FQHC. He had read Anjali's medical records before the appointment. Amita was impressed with his thoroughness, both in reviewing Anjali's medical history and in his physical exam.

After examining Anjali, Dr. Butler told Amita and Anjali that he was concerned about Anjali's legs. He thought Anjali was stiff in her joints. Because of Anjali's cerebral palsy, her muscles had gotten tight, and her joints didn't move as well. If the muscles were not loosened or released, they may begin to affect her hips and her ability to walk. He mentioned that Anjali might need to have surgery to release these tight muscles and to help her stay ambulatory as she neared puberty. Nervous as Anjali was at the mention of surgery, she also became hopeful and asked Dr. Butler, "Will I still need my braces if I have surgery?"

"Yes, Anjali," Dr. Butler said. "The surgery is to make walking easier as you get taller. You will still need braces," he answered.

"But can I still play with Vashti at recess?" she added.

"Absolutely!" he said.

Then Dr. Butler gave Amita the number to the practice for children with special healthcare needs at the hospital. Amita mentioned that Sonya, the care coordinator from her previous pediatrician's office had already given her the number and a brochure about this practice. Amita said she knew this practice provided comprehensive care to children with special healthcare needs. There was an ophthalmologist and pulmonologist on site. But,

Amita had noticed there were not any orthopedic doctors listed in the brochure. Dr. Butler clarified that the town had one pediatric orthopedist who came from the city's children's hospital four days a month, worked out of this clinic, and had operating privileges at the local hospital.

That night, after the girls were in bed, Amita talked with Samir about the appointment with Dr. Butler. Tears filled her eyes as she told him that Anjali may need surgery. She told Samir how Anjali had asked questions about her legs. Amita had been struck by Anjali's questions. She was not a little toddler anymore. Anjali needed to be included in decisions that were being made about her. Amita did not want her child to have surgery, to have anesthesia, to have pain! As the parents talked, however, they both agreed that Anjali seemed to be walking a bit more slowly these past few months. She seemed a bit unsteady on her feet. Samir had attributed the change to the stress of the move, but what if it wasn't? They would make the appointment with the orthopedist. He seemed to be intelligent and sincere in his care. They were just confused and nervous at the thought of surgery. In moments like this, they chanted the mantra "Om Shanti Om," asking the Almighty for peace and courage. That is exactly what they did tonight!

So they went ahead and met with the orthopedic surgeon. They even went for a second opinion in a neighboring city. The orthopedist they saw for a second opinion said she agreed with the surgical plan. Surgery was scheduled for the first day of spring. Everyone was anxious.

Anjali would be in the hospital for a week. Samir had arranged for an ambulance to take her home because she wouldn't be able to sit in her booster seat. He had also worked with the social worker at the practice for children with special healthcare needs to arrange for home nursing as Anjali recovered. Amita arranged for a tutor from the school system to come to the house and help Anjali with schoolwork until she was ready to go back to the classroom. Vashti had made a beautiful little bed for the stuffed polar bear she got to keep her company while her sister was in the hospital.

A week before her surgery Amita and Anjali went to the clinic for the pre-operative evaluation. Samir stayed home with Vashti. As Amita and Anjali waited in an examination room to be seen, Anjali told her mother that she didn't want to have surgery. She didn't want to have to spend the night away from her family; she could walk just fine now. Amita reached over and held her hand as the doctor came into the room.

Dr. Hope was a family practice resident at the hospital. She entered the exam room carrying a stack of forms. She introduced herself to Amita and Anjali and took a seat. She explained to Amita that there were many forms that needed to be completed in preparation for the surgery. She began by confirming that Anjali was going to have surgery to help with her walking. She asked Amita to tell her about Anjali's health since she was born. Amita smiled. She was prepared. Amita pulled out a copy of Anjali's health history form, her care plan, and a referral that she had gotten from Dr. Butler. Dr. Hope was impressed! Here, neatly written, on just a few pieces of paper was a list of Anjali's diagnoses, medications, vaccinations, and specialists. There was also a summary of Anjali's care in the NICU nine years earlier.

Dr. Hope looked up from the papers. She asked Amita if everything she did was so well organized! Amita beamed. She explained that Anjali's previous pediatrician's office was a medical home. She explained about the care coordinator, the parent partners, all the support that she and Samir had received in caring for Anjali. She told Dr. Hope that she and Samir always felt completely included in the medical decision-making for their daughter. They felt there was a real partnership and an environment of mutual trust and respect. Dr. Hope put her hand to her forehead. "I read an article about medical homes but don't really know much about them. I can see now why they are so important. I think it would be good for me to know more about them!" Amita suggested that Dr. Hope talk to Dr. Werner or maybe visit her office and see all of the

benefits of the medical home. She gave Dr. Hope the telephone number to Sunshine Pediatrics.

After examining Anjali, Dr. Hope told Anjali and Amita what would happen during her hospital stay. She asked if Anjali had any dietary restrictions. Amita told her they were vegetarians. She said that Amita and Samir could visit Anjali any time, day or night as she recovered from her surgery. There was a chair in each room that folded out into a bed so Amita or Samir could spend the night with Anjali. Vashti also could visit. Anjali sat quietly, listening.

Then Dr. Hope explained to Anjali that she would have some pain after her surgery. She said that the doctors and nurses wanted Anjali to be comfortable and would give her pain medicine when she needed it. Dr. Hope pulled out a laminated card that had a series of faces on it. The first face was smiling, the last face, the fifth, was crying. She told Anjali that after her surgery, if she was in pain, she could point to a face on the card to let the nurses know she was in pain, and they would give her medicine to make her feel better.

As Dr. Hope and Amita finished the paperwork, Dr. Hope turned to Anjali. "Do you have any questions?"

"No, but I like you, and I am glad Mom and Dad can stay with me in the hospital. I know that Vashti will want to come, too. I'm ready now," Anjali answered. She also asked Dr. Hope if she would visit her after surgery in the hospital. To this, Dr. Hope assured her she would. After all, she wanted Anjali to feel like she had a Medical Home at this practice too!

The day finally came, and Samir and Amita took Anjali to the hospital for surgery. It was early in the morning when they arrived, and Anjali was still sleepy as the orthopedist told her again what he would be doing. As she drifted back to sleep, she saw her parents standing over her, holding hands.

While Vashti stayed with a neighbor after school, the orthopedist came in to talk to Samir and Amita about the surgery. He had several other people with him, also in

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white coats. He introduced them as residents and asked if they could listen in to their conversation. Amita nodded to Dr. Hope when she saw her in the group. She then asked the orthopedist and his group to wait outside for just a moment. Then Amita asked her daughter if she would like the residents to be there or if she did not want them to listen in.

Anjali smiled and responded, "They are here to see me! Bring them all in. I think I saw Dr. Hope!"

The orthopedist told Samir and Amita that the surgery went well, and he hoped Anjali would be able to walk more readily. He reminded them it would take some time and some hard work to see the results. He asked if they had any questions. Amita looked at Anjali and asked if she had questions, but she didn't. When the doctors left, Anjali had one question for her parents, "When can I go play with Vashti?"

Stay tuned for next month when Anjali turns 13 and begins addressing and discussing transition to adult centered care.

For more information on Medical Home, please visit the National Center of Medical Home Initiatives for Children with Special Needs at [www.medicalhomeinfo.org](http://www.medicalhomeinfo.org). •

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Juila Rusert, M.S.W., Ph.D. has extensive experience working with children and families who require various healthcare services. She has conducted research concerning the concept and practice of Medical Homes. She has devoted most of her career to healthcare and people with disabilities, and in particular, children with complex healthcare needs.

## Glossary of Terms

### The Medical Summary

This document contains a short summary of the child's diagnoses, problem list, medications and other treatments, past medical history and community connections:

- Patient name, date of birth
- Care giver names, address, contact numbers
- Insurance information (primary and secondary, pharmacy benefit, dental, vision)
- Allergies
- Medications
- Diagnoses
- Active Problem List
- Specialists names and contact information
- Community service providers and contact information
- Equipment used
- Transportation needs
- Hospitalizations
- Resuscitation or Do Not Resuscitate guidelines
- Additional information parents want to include about the child

### The Emergency Treatment Plan

This is an abbreviated medical summary, which includes essential information for emergency situations:

- Patient name, date of birth
- Care giver names, address, contact numbers
- Insurance information (primary and secondary, pharmacy benefit, dental, vision)
- Allergies
- Medications
- Diagnoses
- Resuscitation or Do Not Resuscitate guidelines
- Recent laboratory results

### The Working Care Plan

This plan defines the current needs of and goals for the patient. It is a written to-do list for the caregivers and healthcare providers. Each goal or need is listed, along with what needs to be done to achieve that goal, who is responsible for completing that goal, and a date by which this work will be completed. This document is created by healthcare providers in partnership with the child's caregivers/parents.

### Health Centers

Health Centers work in communities, providing access to high quality, family oriented, and comprehensive primary and preventive healthcare, regardless of the patients' ability to pay. Health Centers deliver high-quality, affordable health care services to medically underserved populations, regardless of their ability to pay. The President's Health Center Initiative has substantially increased both the number of communities with access to care and the number of people able to get the care they need. Health Centers include Community Health Centers, Health Care for the Homeless, Public Housing Primary Care, and Migrant Health Centers. These Health Centers are important to millions of Americans because they provide primary care, as well as access to pharmacy, preventive dental, mental health, prenatal care, and substance abuse services.

Since 2001, the number of patients treated at Health Centers has increased by 60 percent to an estimated 16.25 million. Patients receiving dental services increased 95 percent, and patients receiving mental healthcare increased 190 percent." (Source: <http://www.hrsa.gov>. Accessed January 24, 2008)



## PART SEVEN

# One Family's Journey: Medical Home and the network of supports it offers children and youth with special healthcare needs: The transition process starts early

In this nine installment Medical Home series, EP will present a case study about the American Academy of Pediatrics' Medical Home Initiative. A "Medical Home" is not a building. It is an approach to providing healthcare services to children with special healthcare needs.

This article presents Part 7 in the series as readers learn more about Amita and Samir and their daughter, Anjali, a fictional family. EP readers will learn about Medical Home through their experiences.

By Sarah Macdonald, MD; Paul J. Sagerman, MD; Laura Boyd, MSW; Kathy Sanabria, MBA, PMP

Anjali was coughing again. Her mother, Amita, could hear her as she readied for bed. Amita knew Anjali had used her inhaler at breakfast, although reluctantly, but she doubted she had used it since. At dinner, Anjali told her mother she hadn't coughed all day. Amita suggested she take her inhaler anyway, but Anjali didn't. She said she didn't need to use her inhaler because she was fine. Amita wondered if she really was fine. Then Anjali coughed again. "Mom, can you make me the ginger spice tea?" Amita knew this special Indian tea often helped with Anjali's cough, but Amita wasn't so sure that it really was all she needed.

One month earlier Anjali had started to cough. She argued with her parents about using her inhaler. She told her parents that she had not started to follow her Asthma Action Plan that Dr. Butler had given her because she wasn't really coughing and her chest felt fine. Two days later, she ended up in the local emergency department. Anjali was having an asthma attack and was really struggling to breathe. At times like this, Amita was worried about Anjali and said her "Mantras" to her Hindu Gods. Although the family wasn't very religious, these mantras gave her the strength she needed. Anjali improved with treatments in the emergency room. As the physician discharged her, she asked if Anjali had an inhaler at home. Samir told the doctor that Anjali had

inhalers and a plan of action and, catching Anjali's eye, that she would follow it. It took two weeks before Anjali finally stopped coughing.

Now that Anjali was 13 years old, her parents had been encouraging her to take more responsibility for her health: her body, her prescriptions and equipment, and her medicines. They talked to her about being aware of physical changes and symptoms, which might require medical attention. She should also know the names of her prescription medications and the frequency and dosage of these medications. She wore braces for her cerebral palsy (CP); she needed them to walk. She knew how important physical therapy was in helping her move independently. She was good about wearing her glasses. She knew her hearing was not perfect and had mastered saying, "Could you please say that again? My ears don't always pay attention when someone speaks to me." But, she didn't like taking her inhaler. She especially didn't like being told to take her inhaler. Everybody coughed; even people without CP coughed. Why should she take medicine for it? It was the one symptom she had that she felt she could choose not to treat.

Amita and Samir learned over the years to try hard to make sure their medical concerns for Anjali were balanced with the needs of their family and her sister, Vashti. Vashti was such a happy child and always protective of Anjali. She lovingly called her "Jiji," the Indian word for "big sister." Sometimes,

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however, it seemed that Vashti was the older sister, asking Anjali about her medicine and making sure her braces were comfortable. Amita and Samir wanted to make sure that Vashti never felt they worried or cared about her less. Amita and Vashti had a tea party date every Wednesday afternoon; Samir enjoyed doing the night routine. He always spent time in each girl's room before bed, reading stories and talking about the day.

Anjali knew her sister sometimes worried about her, about her asthma and her braces and all her doctor appointments. She knew Vashti was scared when Anjali had to go to the emergency department for her asthma. After that visit, her parents had a family meeting, which they routinely did when new information had to be shared or something happened that they needed to discuss. They sat in the living room and all talked together.

Her parents began by telling the story to the girls, once again, about the night Anjali was born, how little she was. They talked about her time in the neonatal intensive care unit. They talked about prematurity and why Anjali now had asthma and needed to wear leg braces. They reminded the girls of Anjali's many triumphs over the years. Then it was Vashti's story: the night she was born, how big and smiley she was, how much she loved nature, and the funny poems she was so clever to write as she got older. They talked about the trip to the emergency department and how worried they were for Anjali. Samir and Amita reminded the girls that they were a family and would always be there to help each other. It was a good talk.

At dinner the next evening, Samir spoke to his older daughter.

"Anjali, remember what Dr. Butler told you about how important your inhalers are? You really need to start taking them when you are coughing."

"But Dad, I feel fine, and I am not really coughing."

"I heard you coughing when you and your sister were laughing at those silly poems Vashti wrote."

"I wasn't coughing. I was just laughing. Why don't you ever believe me?"

"Okay so let's do a check in. What is your wellness baseline that Dr. Butler went over? Check your respiratory count

and tell me the feeling when you inhale."

"My breathing rate is 28, and my chest feels a little tight. But it is not hard to breathe."

"Honey, those medicines are so important! If you are sick, you are going to be sad, missing school, missing our family night at the movies, and playing with Vashti. Let's try to keep you well for as long as possible."

"Then why did you make me have asthma?"

"Anjali, we didn't make you have asthma—you were just born too early and your lungs weren't ..." but Samir couldn't finish as Anjali had stormed off towards her bedroom.

Anjali wanted to slam her bedroom door, but last week she had slammed the door so hard she threw herself off balance and fell. Instead, she stomped as loudly as she could into her bedroom, sat on her bed, took off her braces, and threw them on the floor. She took a deep breath and began to cough. She admitted to herself that her inhalers usually did make her breathe better and helped her cough less. But she didn't want to be an asthmatic. For that matter, today she didn't want to have cerebral palsy either. Usually, she didn't think about her CP. There were two main things she couldn't do with her braces, but it didn't really matter to her: she was too afraid to go on an escalator, and she couldn't jump. But these seemed like minor limitations when she thought of what she could do. "Remember the positives, all you can do, Anjali" her Nani, her grandmother, told her anytime Anjali was discouraged. She missed her grandmother very much. Her Nani sometimes seemed to understand her better than her own parents. Anjali decided to call her Nani in India. They had a long discussion, and Nani patiently listened to Anjali's complaints about her parents. Now Anjali felt better. She sat down on her bed and started thinking.... She thought about asthma and acknowledged following the asthma action plan wasn't so hard and that most days she felt pretty good. She got around pretty well with her braces, maybe a

little more slowly than her friends, but they didn't seem to mind. She could go up and down stairs by herself. She could beat her sister, Vashti, arm wrestling. And, she could play table tennis.

When Vashti turned eight, her grandparents got her a table tennis set. Her grandfather had played table tennis when he was younger and had loved it. He had set the table up in the garage and taught the girls the different ways to hold the racquet, how to score, and how to spin the ball. Both girls loved the game and played together several times a week. Because Anjali couldn't move side-to-side very quickly, Vashti usually won. But soon Amita and Samir joined in for doubles. Then everyone was more evenly matched. They had played hundreds of games together over the past two years.

## Table Tennis Club

*We want you to play!*



First meeting:  
Thursday, March 6 at 1pm in Gym B  
Email Tyler at  
[tabletennisclub@hipmail.com](mailto:tabletennisclub@hipmail.com)

As Anjali sat on her bed, she pulled a piece of paper out of her jeans' pocket and looked at the email address. At school that day, when she was going to her physical therapy session, she passed by a poster:

Anjali wanted to join and she was not sure the club would let her play because of her asthma.

Amita made an appointment for Anjali

with Dr. Butler. She did not want Anjali's cough to get worse, and she was tired of fighting with her about her inhalers. Something different had to be done because what they had been trying was not working.

Anjali sat in the exam room waiting for Dr. Butler. He had been her pediatrician for the past four years. She was a little nervous that he may be angry with her because she hadn't been using her inhalers. She would let him know that she really had been feeling fine and it was her mother's idea to come to see him.

When Dr. Butler entered the room, he came over and shook Anjali's hand, then Amita's. He asked Anjali how things were going. Anjali said she was just coughing a bit but was fine. Dr. Butler then asked Amita how things were going. She said she was worried that it was Anjali's asthma again and that Anjali did not seem to know when she should use her inhaler.

After examining Anjali he told her that she was wheezing and needed to start following the yellow section of her asthma action plan. He placed the earpieces of the stethoscope into Anjali's ears and asked her to take a listen. She said she could hear the wheezes and feel them with her hand. Then he asked her the names of her inhalers.

"Red and blue," Anjali replied.

"Do you know the names of the medicine in those red and blue inhalers?"

"I'm not sure. But I think I am supposed to rinse my mouth after one of them."

Dr Butler smiled.

"Anjali, now that you are 13, you can help me take good care of you. Like your teacher at school, I am going to give you homework. I want you to learn the names of the medicines in your inhalers and understand why you take each one. I also want you to know those colors on your asthma action plan and what it means to be at each color. I want you to come back next week so you and I can listen to your lungs again. And I will ask you the names of your medications and review your asthma action plan then. Let's make that visit for 30 minutes so we can have plenty of time to talk about your health."

A week later, Anjali was talking with her good friend, Paige, during lunch at school.

"I had to see Dr. Butler again yesterday for my asthma. After Dr. Butler talked to my mom and me about my asthma, he told my mom that he thought I was old enough to talk to him privately, and he asked her to leave the room! It was so cool! We then just sat and talked about my past, and all of my medical problems. He really wanted to know what I, like, thought and felt. He let me know that everything we said was just between him and me, unless it was really serious and then we'd, like, talk about how we would tell my mom and dad so that everyone could help me. He promised that he would do his best to make sure that he always included me in all of the plans and that I couldn't let my parents do all the

talking anymore. At first I was kind of nervous, but the more we talked, the better I felt! He really seemed like concerned about how I'm doing, how I was feeling, and what I wanted to do in the future. We even talked about things like jobs and college! My parents haven't talked to me much about that yet. Dr. Butler told me that I can participate in my IEP meetings at school, if I want to, and I can start thinking about school goals that will help me get ready to go to college. He called it my "transition." I was, like, a little nervous 'cause I didn't really understand what he was talking about. So he told me that during my high school years, my school would be connecting me with all

*continued on page 60*

## Transition

Transitions are part of normal, healthy development and occur across the life span. Transition in healthcare for young adults with special healthcare needs is a dynamic, lifelong process that seeks to meet their individual needs as they move from childhood to adulthood. The goal is to maximize lifelong functioning and potential through the provision of high-quality, developmentally appropriate healthcare services that continue uninterrupted as the individual moves from adolescence to adulthood. It is patient centered, and its cornerstones are flexibility, responsiveness, continuity, comprehensiveness, and coordination.

### **Additional Resources**

"A Consensus Statement on Health Care Transitions for Young Adults with Special Health Care Needs;" *Pediatrics*: Vol. 110 No. 6; December 2002. Downloaded from [www.pediatrics.org](http://www.pediatrics.org) at AAP on April 2, 2007.

### **General Information About Transition**

- [www.Pediatrics.aappublications.org/cgi/content/full/113/3/e159](http://www.Pediatrics.aappublications.org/cgi/content/full/113/3/e159)
- [www.nclد.org](http://www.nclد.org)
- [www.dsf.health.state.pa.us/health/cwp/view/asp?q=243876](http://www.dsf.health.state.pa.us/health/cwp/view/asp?q=243876)
- [www.hrtw.org](http://www.hrtw.org)

### **Transition Checklist**

This checklist is a schedule for helping a child with special healthcare needs and their family transition from pediatric centered care (medical, educational, social, resources) to adult centered care. These websites offer sample transition checklists:

- [www.medicalhomeinfo.org/health/trans.html](http://www.medicalhomeinfo.org/health/trans.html)
- [www.pafp.com/MedicalHome/transHCcklist.pdf](http://www.pafp.com/MedicalHome/transHCcklist.pdf)

### **Asthma Action Plans**

An asthma action plan is a set of personal written instructions for a patient, created with physician, patient, and caregiver input detailing how a patient with asthma should manage their asthma and handle acute situations.

- [www.aap.org/schooledinasthma/asthmaactionplan.doc](http://www.aap.org/schooledinasthma/asthmaactionplan.doc)
- [www.nationaljewish.org/pdf/asthma-action-plan.pdf](http://www.nationaljewish.org/pdf/asthma-action-plan.pdf)

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the resources I need to help me meet my transition goals, like, get ready for college. Dr. Butler said he would talk to my parents about trying to help me figure out what I'd like to do when I finish high school. He had said we would meet together the last few times I saw him, but actually having the private talk was really amazing! And, I got really brave and asked him if I could play table tennis at school. He said, 'Absolutely!'"

"That is so totally awesome! Do you get to bring your inhalers?" Paige asked.

"Dr. Butler said I should have my inhalers with me all the time. He said it was my body and that my brain was the best at knowing how to run it. I should try to listen to my parents, talk with them too, but I could decide when I need some puffs," Anjali answered excitedly.

Amita was nervous about the asthma recheck and solo visit with Dr. Butler. She knew this day was coming and was wondering what else she needed to do to prepare for her changing role. Dr. Butler had asked her to wait in the waiting room for a few minutes so he and Anjali could talk. She felt a little left out but trusted Dr. Butler and went out to read magazines. Dr. Butler had made sure Amita and Samir knew he talked to Anjali about the future when he was alone with her. However, he did keep some of the details of his conversation with Anjali confidential. He told Amita he had discussed with Anjali that when she came in for her next regular check-up at 14, he and his nurse would introduce a checklist, which they would all follow from that point on. The checklist would contain many items, which would have to be addressed during Anjali's high school years to help prepare her for her adult life. Some of the items would be easy, like having a complete medical record. Amita and Samir had been keeping an updated one since learning about Medical Home after Anjali's birth. Some items, like obtaining insurance as an adult and applying for social security benefits, would involve finding community resources. The checklist sure sounded like the old "things to do" lists

## Critical First Steps to Ensuring Successful Transitioning to Adult-oriented Healthcare

1. Ensure that all young people with special healthcare needs have an identified healthcare professional who attends to the unique challenges of transition and assumes responsibility for current healthcare, care coordination, and future healthcare planning. This responsibility is executed in partnership with other child and adult healthcare professionals, the young person, and his or her family. It is intended to ensure that as transitions occur, all young people have uninterrupted, comprehensive, and accessible care within their community.
2. Identify the core knowledge and skills required to provide developmentally appropriate healthcare transition services to young people with special healthcare needs and make them part of training and certification requirements for primary care residents and physicians in practice.
3. Prepare and maintain an up-to-date medical summary that is portable and accessible. This information is critical for successful healthcare transition and provides the common knowledge base for collaboration among healthcare professionals. Create a written healthcare transition plan by age 14, together with the young person and family. At a minimum, this plan should include what services need to be provided, who will provide them, and how they will be financed. This plan should be reviewed and updated annually and whenever there is a transfer of care.
4. Create a written healthcare transition plan by age 14 together with the young person and family. At a minimum, this plan should include what services need to be provided, who will provide them, and how they will be financed. This plan should be reviewed and updated annually.
5. Apply the same guidelines for primary and preventive care for all adolescents and young adults, including those with special healthcare needs, recognizing that young people with special healthcare needs may require more resources and services than do other young people to optimize their health. Examples of such guidelines include the American Medical Association's Guidelines for Adolescent Preventive Services (GAPS), the National Center for Education in Maternal and Child Health's Bright Futures: Guidelines for Health Supervision of Infants, Children, and Adolescents, and the U.S. Public Health Service's Guidelines to Clinical Preventive Services.
6. Ensure affordable, continuous health insurance coverage for all young people with special healthcare needs throughout adolescence and adulthood. This insurance should cover appropriate compensation for 1) healthcare transition planning for all young people with special healthcare needs, and 2) care coordination for those who have complex medical conditions.

that Amita and Samir had become so good at over the years. It was comforting to know that Dr. Butler and his practice were aware of these issues and would be available to help them through this. And, he told Amita he thought the table tennis club was a great idea.

"What table tennis club?" wondered Amita.

As Anjali sat at the computer to begin her homework that night, she pulled out the piece of paper with her classmate Tyler's email address. Tyler was organizing the table tennis club. Anjali quickly emailed Tyler:

*Hi Tyler- I'd like to be in the table tennis club. Is everybody invited?- Anjali*

A few minutes later, Anjali's computer dinged that she had a new mail message. Anjali held her breath; the message was from Tyler:

*Anjali- It's cool for anyone to come. See you on Thursday! -T*

Anjali went to the meeting in Gym B on Thursday. Seven other students also showed up. Tyler explained that the school had a table tennis set-up in this gym. The students could practice on Tuesdays and Thursdays during lunch break. He said that each member had to bring their own rac-

quiet. Anjali couldn't wait for Tuesday!

Amita and Samir noticed Anjali seemed different recently. She wasn't coughing any more. Her conversations with them were less brusque. She was smiling a lot. They wondered if part of the change was something from her visit with Dr. Butler. He had reminded Amita that even though Anjali had been very fragile as an infant, she was now a strong teenager, needing a little more independence and responsibility.

At supper one night a few weeks later, while Amita, Samir, and Vashti waited for Anjali to come to the table, Samir asked Vashti if everything was ok with her sister.

"Everything is very ok, Dad." Vashti giggled, "You should ask Jiji yourself."

"Ask me what?" Anjali called out as she entered the dining room.

"Well, your mother and I just wanted to make sure everything is ok with you. Work has been so busy recently for both of us that we haven't really had a chance to talk. How's school?" Samir asked.

"Dad, Mom, you'll never guess what. Tyler started a table tennis club, and I joined it! It is soooo awesome!"

Amita and Samir stared at Anjali. Vashti giggled and said, "I told you everything was ok with my Jiji. Doubles after supper?"

Stay tuned next month as Anjali continues along her transition journey to adulthood.

For more information on Medical Home, please visit the National Center of Medical Home Initiatives for Children with Special Needs at [www.medical-homeinfo.org](http://www.medical-homeinfo.org). •

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**PART EIGHT**

# One Family's Journey: Medical Home and the network of supports it offers children and youth with special healthcare needs: The transition process continues

By Sarah Macdonald, MD; Suzanne McLaughlin, MS, MD; Eric Levey, MD; and Symme Trachtenberg, MSW

In this nine installment Medical Home series, *EP* presents a case study about the American Academy of Pediatrics' Medical Home Initiative. A "Medical Home" is not a building. It is an approach to providing healthcare services to children with special healthcare needs.

This article presents Part 8 in the series as readers learn more about Amita and Samir and their daughter, Anjali, a fictional family. *EP* readers will learn about Medical Home through their experiences.

**A**s Anjali sat behind the cash register, she thought about words. How did the people who wrote greeting cards come up with so many new ways to say the same old thing over and over? Like the card with the big yellow duck on the outside:

*Now you are three! You are so lucky!  
Hope your birthday is really Ducky!*

Or the one with the ballerina curtseying:

*Sorry to be tutu late for your birthday*

She quickly texted her best friend Paige:

*Anjali: At work u Have new fav card*

*Paige: What*

*Anjali: Tutu late for bday*

*Paige: hahaha*

Anjali had been working at the card store for the past four months. She liked working. She loved the paycheck although she was shocked when she saw how much was taken out for taxes. She liked the orderliness of the card racks. She liked reading the cards. And she loved being at the mall! Paige also worked on the upper level, just a few stores down. They would meet during their break and sit on a bench overlooking the lower level. They would watch the shoppers, the mall walkers, and, especially, the other teens.

At first, Anjali didn't really want a job. She was nervous about running into classmates, especially kids she wasn't friendly with. She was worried about getting hired. She didn't know how she would get to and from the mall. She thought a shop owner would see her shuf-

fling gait, her leg braces, her thick glasses and assume she wasn't competent. But when Paige got a job at the mall's pretzel stand, Anjali decided to apply.

In order to get her job, Anjali had to go see her pediatrician, Dr. Butler, to get her working papers signed. Dr. Butler did a physical exam, asked her some questions about the work she would be doing, and signed the forms. Then he suggested this was a good time for Anjali to make an appointment with his nurse and care coordinator, Molly, to talk about getting a state ID card, figuring out some transportation options, and reviewing her insurance. Anjali wasn't surprised by this suggestion. She knew it was part of what Dr. Butler called her "transition," her preparation for living as an independent adult, one with special healthcare needs.

Anjali was glad for the chance to talk to Molly. She knew the card store she worked at would be moving to a new location in June and wouldn't re-open until the end of August. This was perfect! Because the job Anjali really wanted was to be a counselor at her little sister Vashti's summer camp.

As Anjali waited with her Dad, Samir, for her appointment with Molly, she looked through the folder she had brought. She kept a binder with her medical summary and her list of medications with a special note about her penicillin allergy. She saw the copy of the discharge summary from the neonatal intensive care unit where she spent the first five weeks of her life.

## Transition

Transition to adulthood is about all youth with special healthcare needs (YSHCN) reaching their highest potential for independence. For some, that may be having a job and using public transportation; for others, it may mean getting toilet trained and learning their home address and phone number.

Transition to adulthood is also about the youth learning about his/her own condition, becoming an educated healthcare consumer, and seeking healthcare in an adult-oriented system.

She had her insurance cards, her asthma care plan, the list of specialists she still saw, and the name and contact information for the durable medical equipment company that fit her braces. Her parents had learned to bring a binder like this to all her medical visits when she was younger, but when Anjali started ninth grade, Molly had suggested that Anjali start her own and get used to keeping basic things like her most recent physical note or new test results in the binder. She'd already changed binders once – the stickers she'd used to decorate her first binder seemed too young now. She liked the new binder with pictures of Anjali on the cover – one with Vashti and her parents from her birthday and one with her friend, Paige.

Now Dr. Butler used Anjali's binder *instead* of her parents'. Molly suggested a little celebration was in order when they "retired" her parents from their office visits. Anjali was really pretty good at remembering to bring the binder with her, and she could use it to bring some information her parents didn't always have—like notes from her school-based physical therapist.

She looked to the folder in the binder where she kept questions for upcoming visits. That's where she'd put the brochure for the summer camp with the letter calling for applications for counselors. One form she didn't have, but wished she did, was her driver's permit form. Although she really wanted to learn how to drive, she couldn't drive a car with her cerebral palsy (CP) unless it was adapted for her, and her parents said adapting the car wasn't in their budget.

"Dad," Anjali said as they sat in the waiting room, "you know how much Vashti loves that camp in the mountains?"

"Yes, sure, she starts talking about it in February. Sometimes when I listen to her stories about camp, I wish I could go!" Samir answered.

"Well, Dad, I think *I* should go this summer." Anjali announced.

At that moment, Molly called them back to her office for Anjali's appointment.

As they settled into Molly's office, Molly handed Samir and Anjali a copy of the transition outline and a packet of resources on transition. Molly reminded them that they had three goals for their

meeting: to review the process for getting a state ID, to look over Anjali's insurance policies, and to talk about transportation. Anjali checked her list quickly – the brochures! "I would like to go to Vashti's camp. I'm old enough to be a counselor. I got an application," she blurted out. Anjali already knew a lot about the camp and what kind of work the counselors did from having visited Vashti there before.

Anjali handed the camp health form to Molly so she could give it to Dr. Butler for completion. Samir smiled. He was impressed with Anjali's gumption and a little surprised she hadn't mentioned her idea to him before the waiting room. But, he knew that parents of teens were often the last to know about their children's plans. He and Anjali and Amita would have to talk about the summer.

"A counselor!" Molly said. "Tell me about the camp."

"Well, Vashti goes there, and it's tons of fun and they, like, have an arts tent and a counselor works there. And I already checked the Web site and know the camp is mostly handicap accessible so, like, I could get around fine," Anjali answered.

Molly then talked to Anjali about getting a state non-driver ID. She told Anjali that she could go to the registry of motor vehicles and fill out the application. She said that having a recognized form of identification is important as one becomes more independent. Anjali wrote down the address in her notebook.

Then Molly talked to Anjali and Samir about Anjali's health insurance. Molly knew a lot about different insurance policies, and Samir had gotten some extra information she'd asked about before the visit by calling his insurance company. "You can stay on your parents' insurance until you're 23 years old if you're in school as a full-time student. But that means "full time status" according to that University. If you're less time than that, you would need your own insurance any time after you turn 18." Molly suggested that Anjali think about being away for the summer and what this would mean for her healthcare. What if she got sick at camp? How many asthma inhalers should she take? What if her braces broke? Anjali made more notes.

Samir said, "Oh, we're expecting her to

be in college; she may even be looking at some out-of-state schools." Now it was Anjali's turn to look surprised.

"What makes you say that?"

Samir smiled, "You and Paige were talking about that school non-stop after she visited her older brother there last month. Also, Vashti said something about you being a bit worried Paige might be thinking of going away for school. And I think Vashti worries the same about you."

Anjali hadn't realized they'd talked so much about it. She did think the school sounded exciting. But she had so much here, with her school and therapist and doctor. She hadn't really thought about making that all work somewhere else—somewhere away from her parents and Vashti.

Molly then asked Anjali how she was getting to work. Anjali said that most days her parents or her friend Paige's parents could give her a ride. Molly told Anjali about the Paratransit ride system. This is a non-profit, state organization that provides rides to people with disabilities in the community. Anjali could register with them and then arrange for rides to and from work. She gave Anjali the Web site and suggested she register. Then, Anjali could try organizing a few rides to work with Para transit to see if the program worked for her. Anjali looked a bit discouraged. Molly smiled. "I bet you'd most prefer to drive yourself to work." Anjali's face lit up. "Well, there are some programs to help teach children with disabilities to learn to drive, and some state assistive technology programs have funding to help families adapt cars with hand controls. But, if you are going to be in the mountains for the summer, maybe you could look into this in the fall." Samir breathed a sigh of relief. He wasn't ready

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to be the parent of a teen driver!

That night at supper Samir told Amita about their visit with Molly. Anjali told her mother about her plans to be a camp counselor. Amita's jaw dropped, as did the colander of sev and seviyan (Indian noodles) she was holding. Vashti giggled. She and Anjali had been talking about being together at camp. They had thought of all the different reactions they thought their parents might have when Anjali finally got up the courage to tell them her plans. None of their scenarios included sev and seviyan all over the floor! Anjali got up to help clean up the mess. "Mom, I'm sorry I didn't tell you sooner, but I wanted you to say *yes* and I did my research and it will be great and Vashti and I will be together and anyway the card shop will be closed all summer and I have to do something and can I get my driver's permit when I get back?"

Amita sat down. Could her little girl, her little girl, who is now 16 years old, be a counselor? Be away for the summer? Be a driver? Camp was something that she and Samir never experienced.

Samir told Amita he thought the counselor job was an option for Anjali. He had been thinking about it since they left Molly's office and realized it actually was a great opportunity. He too had a hard time accepting Anjali was growing up. But, she needed a job for the summer, Anjali and Vashti could be together and look out for one another, and Vashti really liked this summer camp. He also pointed out that Anjali had shown a lot of maturity by doing the research about the job on her own. He reminded Amita that Dr. Butler had been talking to them about Anjali's transition, her need for independence, and this seemed like a good, manageable, first step. Amita took a deep breath and said she could help Anjali fill out the application that evening.

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Anjali had mostly just been excited when she was packing up with Vashti to start camp. But now, as Amita and Samir pulled the car into the entrance, she was feeling more nervous. Amita's eyes filled with tears as they pulled into the campgrounds to drop off the girls for their summer adventure. She had come to realize that this was going to be

a great summer for her girls, but she was going to miss them terribly. As Samir pulled the last bag out of the car, Amita hugged Anjali. Vashti quickly squeezed the two of them, gave her Mom a quick kiss on the cheek, and ran off to greet a friend from last summer. The parents were led away to a brief talk given to all campers' parents before final good-bye hugs.

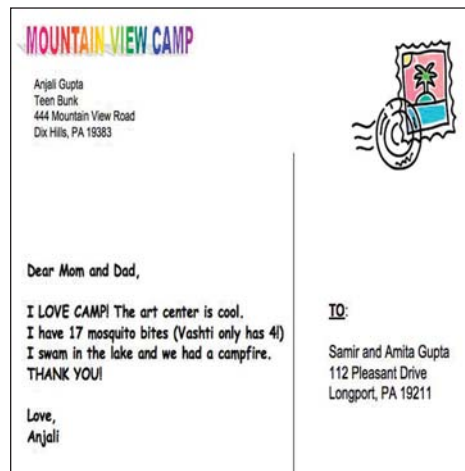
Vashti was directed to where the middle-school campers were grouping. So Anjali was standing alone with a few other junior counselors. She wondered if that girl over there was looking at her funny?

"Does she think I look so different? Is she wondering if I can do this?"

"Hey, are you related to Vashti? She was in my cabin last year. They were such a nice group of kids, which was lucky, especially because that was my first year, and I was pretty nervous when I got here. You look a lot like her, and I think we met once when you came to pick her up."

"You're Sadie? Vashti wrote about you last year; she had a great time with your group." And Anjali felt herself relax just a little bit. "What helped you feel less nervous your first year?" And they walked away to the meeting tent, talking.

A week later, Samir and Amita got a postcard:



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Anjali bobbed up through the lake surface and squinted through the drops of water to see how far she'd gotten. "Wow, almost there!" The counselors were checking to see if they could swim out to the raft. Anjali wasn't the fastest, but she realized as she looked around she wasn't the slowest

swimmer in the group either. She really liked the swimming. She was getting more comfortable in the water all the time. It was a nice break from her physical therapy routine but helped almost as much! She still had table tennis; she was camp champ at that but had the most fun was teaching it to the younger campers.

In planning for camp, Amita and Samir had agreed, after checking with Dr. Butler, that Anjali would be alright changing her PT routine for a few weeks as long as the activities kept her stretching and active. But they'd been firm on the asthma monitoring. Anjali had agreed, as part of her plan, to take her asthma plan with her, share it with the camp nurse, and have check-ins twice a week. The area and activities were so new to her, they were worried about how it might affect her asthma. That turned out to be something she could teach as well.

One of the other counselors—Vashti's counselor, Sadie, from last year, actually—was also waiting for the nurse one morning. She sat next to Anjali, who was waiting to check her peak flows. "I wonder if the trees here make this worse for me; I've been using my puffer so much this week!" Saide said, holding up her albuterol. Anjali had also added a few puffs when her peak flows had moved into the yellow area. She showed Sadie her steroid inhaler. "I had to increase a bit, too."

"I have one like that but it doesn't help me at all. I don't feel any better when I take it so I've just been using the other one this week." Dr. Butler had gone through those medicines with Anjali. She knew that one worked for her symptoms right away, but the other kept her symptoms under control. "You should let the nurse know what you've changed; it might be part of what's going on. See, my asthma plan talks about how those different medicines work." Now, the next week, Sadie could feel a difference, and they were both checking in with the nurse twice a week to keep on their plans. Sadie had one now a lot like Anjali's.

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The weeks went quickly. When Samir and Amita picked up their girls, they thought they looked "older!" They enjoyed the drive home, hearing stories

## Resources

### Transportation

It is important for providers to investigate the Paratransit system in their state. United We Ride is a national website on transportation for the disability community. [www.unitedweride.gov](http://www.unitedweride.gov). Some Centers for Independent Living (CILs) offer travel-training programs to teach youth with special health care needs how to use regular public transportation. [www.ed.gov/programs/cil/index.html](http://www.ed.gov/programs/cil/index.html) or <http://www.ncil.org/>

Driving is not out of the question for many YSHCN. Driver evaluation may be available through the state Vocational Rehabilitation Agency in some states. Some YSHCN could get hand-controls paid for through their state Assistive Technology Program. [www.ed.gov/about/offices/list/osers/rsa/index.html](http://www.ed.gov/about/offices/list/osers/rsa/index.html)

### Income

Some YSHCN become eligible for SSI when they turn 18 years old as their parents' income is no longer considered when determining eligibility. In 37 states, having SSI would also give the YSHCN Medicaid. Most low paying jobs do not include health insurance. As income goes up, youth may be able to use one of the SSI work incentives or possibly their state's Medicaid Buy-in program. [www.ssa.gov](http://www.ssa.gov)

### Recreation

In addition to working, it is important that YSHCN have a balanced life. Sports for the youth with special health care needs are becoming more available. For example, they could decide to take up skiing or sled-hockey. National Center on Physical Activity and Disability. [www.ncpad.org](http://www.ncpad.org)

seen my Mom's face when the doctor told her we were going to talk about all that stuff. She was even more surprised than me! But then the doctor asked her, 'Well, who do you want her to hear about it from? You and me? Or kids at school?' Mom chose 'her and the doctor' pretty quickly."

Anjali and Katie laughed then they headed up the escalator to the Gap store; they had seen some great tops on sale and wanted to spend some of their hard-earned summer cash to go back to school in style! They enjoyed trying different looks on for an hour before making their choices.

Every now and again, Anjali thought more about what Paige had said. Later, after they'd said good-bye to Katie, she

about their time away and smiled to see them so happy. "Can you believe three weeks went by so quickly?" Amita asked. "Wow, three weeks away, and it was really, pretty fun, but it will be great to see Paige again," thought Anjali. "Maybe I could look at a few colleges a little further away." She thought: "When I have my back-to-school physical with Dr. Butler, maybe I'll ask to talk to Molly again. I may just have some new goals to talk about..."

"Hey, missed you at lunch break today," Paige said. She and Katie, another friend who worked in the mall, had been waiting outside the card shop for Anjali to finish work. It was the last week before school started again, and they had plans to go clothes shopping with some of the money they'd saved.

"I had my doctor's appointment, my back-to-school physical" said Anjali.

"How was it?" asked Paige.

"Totally mortifying! Asked about my periods, talked about smoking and drinking, asked if I was dating anyone, asked if I had questions about puberty or sex or anything!!!" she answered.

"Wow!" yelled Katie. "Was it the worst? I'd die if someone asked me that! What did you say?!"

"Well, I didn't actually have to say anything at first. Dr. Butler's nurse gives me a bunch of questions on a piece of paper while I'm waiting. It takes a little while to go through them all, and you feel a little funny about some of them, but at least it's private."

"Yeah," said Paige. "My doctor asks about that stuff, too. She said it didn't mean she thought I was doing all that stuff, but since she needs to take care of my health, she needed to know about that stuff or she wouldn't be doing her job, helping me take care of myself. So that kind of made sense. And it turned out some of it did help. One of the things on the list she asked me about were those energy drinks. Remember, I used to have one at lunch this summer? Well, she said maybe they were part of the reason I'd been having headaches. I tried not having them for a while, and the headaches got better. Until she asked, I didn't even know they could do that! So I think it's just something doctors do."

Paige laughed, "But you should have

brought the visit up again. She'd held off on talking about it in front of Katie. Katie was nice and fun but still a new friend – not like Paige. Anjali told almost anything to Paige and trusted her a lot.

"Actually, one thing Dr. Butler talked about did make me think a little."

"What was that?"

"He asked if I ever thought I'd want kids of my own. And," she quickly added, "I mean, I don't right now or anytime soon or anything, but maybe someday I would. I don't know for sure, but that was the first time anyone asked me about that, and so that means I probably would be able to, just like anyone else. I wasn't really sure so I guess now it's just in my head that I could. I almost thought that I couldn't because no one ever brought it up, that's all. Anyway, it's funny your doctor does that, too." Anjali smiled.

Stay tuned next month as Anjali graduates from high school, continuing along her transition journey to adulthood.

For more information on Medical Home, please visit the National Center of Medical Home Initiatives for Children with Special Needs at [www.medical-homeinfo.org](http://www.medical-homeinfo.org).

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## PART NINE

# One Family's Journey: Medical Home and the network of supports it offers children and youth with special healthcare needs: The Journey to Adulthood

By Sarah Macdonald, MD; Patti Hackett, MEd;  
Dana Boyd; Patience White, MD, MA

In this nine installment Medical Home series, *EP* has presented a case study about the American Academy of Pediatrics' Medical Home Initiative. A "Medical Home" is not a building. It is an approach to providing healthcare services to children with special healthcare needs.

This article presents Part Nine and the final installment in the series in which readers have learned more about Amita and Samir and their daughter, Anjali, a fictional family.

Anjali sat sipping coffee, doodling with a crayon. It wasn't *her* coffee. She didn't drink coffee anymore. She had switched to decaf tea since becoming pregnant. But her husband, Tarkesh, drank two cups of coffee every morning. He had taken their six-year-old son, Deepak, to school a few minutes ago and had left a small bit of coffee in his mug. She liked to finish his coffee, just a taste before she went to work.

Anjali stood up, gathered the crayons from the table and headed toward her home office. She worked part-time as a copy editor for an advertising agency. Two days a week she went into the main office, and one day a week she telecommuted from home. On the days she did not work, she usually went swimming, a passion she had developed when she was a teenage camp counselor years ago. Because of her cerebral palsy and her asthma, she still had a lot of doctors' and therapy appointments that took up her days off. She also was finally learning to drive.

When Anjali was a teenager, she desperately wanted to drive and not just for the independence; she wanted a license because all her friends were driving. It was a rite of passage. Because of her cerebral palsy, her legs were weak, and her hands were strong. The car she would drive needed to be equipped with hand controls that allowed her to control the gas and brake and to shift gears. Her parents couldn't afford to have hand controls installed in the family car. Learning to drive moved to the back burner as she went to



college and settled into the university town for work after graduation. Para transit and friends met Anjali's transportation needs. Then, last year, when Anjali was 29 years old, she was leaving her local YWCA swimming pool and saw a sign on a community bulletin board about driving classes. The footnote mentioned classes for people with disabilities sponsored by the Center for Independent Living (CIL). It also listed contact information for the state Office of Vocational Rehabilitation (OVR). Anjali took down the information. She knew her state had an assistive technology program, which provided low cost loans to residents with disabilities. She had applied for one while she was in college to buy a laptop so she could access the Internet from her dorm room on days when the weather was too harsh or the sidewalks were too slippery or for days when

she needed to go to the library to log-on. She considered applying for another low-interest loan for the car. But, she would also contact the OVR for more information. One year later, the car—with help from her state OVR—was equipped with hand controls, and she was halfway through the CIL drivers' education class.

Anjali walked down the hall to her home office and sat at her desk. She checked her email Inbox. There was an email from her sister, Vashti, who was now teaching at an elementary school for children with special healthcare needs in New Delhi, India. The name of the school was "Muskaan," which means *smile*. Vashti's students had created some cards, and she was sending them to Anjali to distribute to her friends who then bought these cards. The money went back to India to help support the school. Anjali also had a message from Paige, her best friend for over 15 years, confirming their plans to meet at the park on Wednesday after school with their children. She and Paige had both gone to their state university and had stayed in town to start their careers after graduation. The last email was from her boss, confirming the production schedule for their current project. Amazing how her life had changed since those early years when she and Paige had done homework and worked in the mall together!

As Anjali began to open up her work files, the telephone rang.

"Hello, this is Anjali at Archipelago Incorporated."

"Hello, Anjali!" It was her mother, Amita. "Anjali, I'm calling about your visit to come see us next weekend. I want to let you know, it will be a *working* visit. As we are packing up for our move, I am putting all of your things into boxes, and I need you to go through them. Also, your father and I found two boxes of photographs that we never sorted, and I need help figuring out who is in them."

"Mom, we plan to leave on Friday right after Deepak gets out of school so we should be with you in time for supper."

"Great, we can't wait to see you. I love you."

"I love you too, Mom."

Anjali smiled. Her parents had always seemed so organized, it was hard to imag-

### **Tips from Patti Hackett, a mom and former teacher**

**Tips for PARENTS**

Be the person your child can come to for answers. Before your child starts school, begin a dialogue that will let he/she know you can be asked any question. Friends will do a lot of talking; be the source of accurate information. What you know, share. What you don't know, connect with an expert who has that information (Web sites, email, other families, or adult mentors).

**Tips for MEDICAL PROVIDERS (doctors, nurses, therapists)**

Get the conversation started. You may be the person who supports the parent in beginning these conversations with their child. Later you may be asked to be a resource expert. Similar to the advice for families, what you know, share. What you don't know, connect with an expert who has that information (rehabilitation psychologists, adult mentors, Web sites). Masturbation needs to be an open topic. Later, other issues may need to be addressed: assistive technology aides to support the child/youth; sensitive issues from ethical touch and dignity to birth control; the changing role for families; safety and decision making. Ask about and respect cultural beliefs.

**Tips for EDUCATORS**

Get to know the experts with whom you should connect. While you hope that families and medical providers are talking and providing information and support to the child/youth, sometimes your classroom becomes the starting point for the dialogue. Sexual behaviors have a time and place, and the classroom setting is not one of them. Without some guidance and support, the student may be headed for discipline issues where all he/she needed was information and some skill-building. See if the school district's sexual education curriculum is inclusive for people with disabilities. You do not have to be an expert in this area but do reach out to experts in the community and connect the family and youth to these resources as well. Ask about and respect cultural beliefs.

ine there were photos that had escaped being labeled and filed. However, Anjali knew that her childhood had been especially busy for her parents, with all of her doctors' appointments, therapy sessions, and hospital stays. Now that she was a parent, a parent of a six-year-old boy, she was especially appreciative of the responsibility of taking care of a child. Deepak did not have any special healthcare needs, and raising him still made her life so busy. She wondered how her parents balanced all the typical activities plus the medical ones when she was a child.

"Ow!" Anjali jumped. The little baby in her uterus just kicked her in the ribs. "Does coffee make you jumpy, little one?" Anjali said as she rubbed her abdomen. Suddenly, Anjali looked at the calendar,

the one she had marked with purple numbers indicating how many weeks pregnant she was: 29 weeks today! This was how far along her mother had been when she went into labor with her. With Anjali's first pregnancy, she hadn't thought about a premature birth. She was too excited about being pregnant, hearing that heartbeat at her doctor visits, looking through the catalogs at the millions of accessories for newborns, organizing the nursery. She hadn't contemplated the possibility of delivering early. But what if this time...Anjali started to cry. She was like so many pregnant women, who sometimes worry and sometimes get emotional.

Maybe it was her mother's telephone call that had made her feel so vulnerable.

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Her parents were moving out of the house they had moved to when Anjali was nine years old. She had so many good memories from that house, of the table tennis set in the garage, of the beautiful maple tree in the yard, of their family dinners. Maybe it was the pregnancy, or just feeling tired, that made the tears come. At times like these, Anjali's mother had taught her to say a small prayer, the Gayatri Mantra, which always brought peace to Anjali. So she started the mantra with "Om..."

Anjali turned off her computer and went to sit in the living room. She needed a little time before she was ready to start work.

As Anjali sat on the couch, she thought about her childhood. She didn't remember her sister Vashti as a baby (but Anjali was

polar bear to keep her company when Anjali was in the hospital. Sometimes, when they were older, in the middle of the night, Vashti would still come into Anjali's bed, polar bear in tow. As teenagers, the two sisters watched Hindi movies that their mother rented from the local Indian store. They both adored the Indian actor, Salman Khan, and thought he was one of the most handsome young men they had ever seen. Their friends at school agreed with them, too. Anjali started smiling as she thought of Salman Khan!

Anjali thought about junior high school, her friendship with Paige, and joining the table tennis club. What was the name of that boy who organized it? She thought about Dr. Butler, a name she didn't think she would ever forget. She remembered the

medical problems, named her medical equipment, her prescription and over-the-counter medications, as well as a brief medical history and results from recent tests. When Anjali first started to carry this document, she had to refer to it often to see the details, those details her parents had memorized over time. Now she needed to refer to the sheet less often as she too began to remember all those details.

Lists were "good" Amita and Samir had always said. Having this one-page summary, Anjali's healthcare list, made it easier to give her medical report and updates to her adult medical team. Anjali also had learned how to make the time with her doctor most helpful to her by thinking of, and writing down, questions she wanted answered before the visit. Most of all, she appreciated the transition plan at Dr. Butler's office. He had that inviting section on his bulletin board in the office, spelling out the transition policy. It noted when patients were expected to grow up and move on to an adult doctor. This policy allowed Anjali and her family to plan the slow transition and not feel the date she left Dr. Butler's practice was a surprise. She did not feel abandoned like some of her friends with special healthcare needs. They had described to her the surprise they had felt when they were suddenly told they had to leave the pediatric practice because they were too old, having been given little warning or planning time.

Despite all of the planning, Amita and Samir had been so worried about what the adult medical world would be like for Anjali. Anjali had had to reassure her parents back then that she was ready, that she was looking forward to being with people her own age in the waiting room of the adult doctor.

Anjali took a deep breath and reached for the phone. She called her parents. Her dad, Samir answered.

"Hi, Dad."

"Hello, Anjali. How are you?"

She sniffed: "Fine."

Pause.

"Well, daughter-of-mine, I don't believe you because you don't usually call us to let us know you are fine. Let me get your mother on the extension."

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Anjali noted that she had to schedule all her different appointments for her many medical needs on different days; she missed the multidisciplinary clinic that had them all in one place at the children's hospital.

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only three years old when Vashti was born). She remembered Vashti as a toddler, trying to climb on the couch or into Anjali's bed at night. She remembered the stories they used to make up about the trees in their yard. She remembered playing on their swing set together, the one that had a special swing just for Anjali. She remembered saying goodbye to Vashti as Anjali left with her dad for her first day of kindergarten. Vashti stood in the doorway waving, and Anjali wished she didn't have to leave her sister. Anjali remembered teaching Vashti how to slide down the special banister that their mother had installed for Anjali. She remembered being nine years old and having surgery on her legs, of being so scared, and feeling so alone and that Vashti had made her a get-well card. She remembered that Vashti had a little

first time he asked her mother to leave the room so they could talk privately. She remembered Molly, her care coordinator, and all the visits they had together about transition and getting Anjali ready to be independent. She still kept a care binder with all of her health history. Well, actually, she had two binders. She put most of the information from her childhood in one binder, the one with a picture of Paige in high school and of Vashti and her parents at Anjali's 15th birthday dinner. Her current care binder had pictures of her husband and little Deepak. Anjali had also created a one-page portable medical summary that she kept in her wallet. It had been interesting to interview her parents when she created the initial draft of this document. It included the contact information for Anjali's medical team, listed her major

Anjali heard her mother pick-up. “Anjali, dear, what is the matter?”

“Mom, Dad, I just realized I am 29 weeks pregnant. How did you do it? It must have been so scary!”

“Anjali, it was the scariest day of our lives!” her father said. “We were so worried about you! But, even though you were so little, and you had so many tubes and machines connected to you, you were so beautiful! And, we had so much support. Remember Doris, the NICU nurse who was in town last year and came over for dinner? She was so helpful, so optimistic, so kind! Can you believe we have stayed in touch with her the past 30 years? And every time we talk, you always come up. We revisit some memory of that stressful time. She still teases us about all the lists we made! Doris had connected us with a great pediatric group in town who practiced with the Medical Home model. We always had other parents of children with special needs to talk to.”

“Try not to worry, honey. Enjoy those kicks in the ribs and that beautiful little boy you have. Enjoy the moment! We can talk more when you come visit next weekend.” Her mother’s voice was reassuring. Anjali said goodbye to her parents and went back to work.

That night, after the dinner dishes were washed, bedtime stories were read, and Deepak had been tucked in, Anjali and Tarkesh went to sit on the porch. Anjali reminded her husband that they were going to visit her parents the following weekend. She told him about her conversation with her parents and the realization that she was 29 weeks pregnant, as far along as her mother had been the night Anjali was born. Tarkesh put his arm around her and gave her forehead a kiss.

“I am so glad I met you. I am so glad you decided to take that accounting class, even though you hate math. I have such a clear image of you coming into the lecture hall, with your long braid, and your braces, and those pink glasses. I can see you looking up the aisle stairs, looking down, discouraged, and then shuffling down the first row, the completely empty first row, and taking a seat right in front of me.”

They both laughed. So much could happen in 12 years!

As they sat on the porch, Tarkesh reading the local news, Anjali sorting the mail, she thought back to her senior year in high school. She remembered Molly, the care coordinator, encouraging her to apply to

about her health issues and had learned to speak up, take the lead, and seek help when she needed more information to make truly informed decisions about her health choices. She chose Dr. Greer, a family physician, and her care coordinator, Marnetta. The Family Practice was a

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**She did not feel abandoned like some of her friends with special healthcare needs. They had described to her the surprise they had felt when they were suddenly told they had to leave the pediatric practice because they were too old, having been given little warning or planning time.**

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the state university. She had helped Anjali contact the Office of Disability Services on campus to make sure her special needs could be met. Anjali remembered attending her IEP at the beginning of her senior year in high school and talking to the team about her long-term goals. She remembered looking at the financial aid forms with her parents and wondering if she would ever really be able to attend college.

Anjali remembered that it wasn’t long after her 17th birthday that she and her parents, Dr. Butler, and Molly started to discuss plans for her first visit to the family practice group. Anjali had two consultation visits with adult physicians in the university town where she would be in college. Anjali interviewed each practice. She considered how she was greeted when she entered the office, her comfort with the “ground rules” of the practice, how it operated after hours, how easy it would be to get referrals and refills, and its experience with care coordination. She also evaluated their willingness to make healthcare decisions jointly with her. She had become knowledgeable

Medical Home just like Dr. Butler’s, but most of the patients there were either adults or teenagers like Anjali. She thought it wouldn’t be too big of a deal to make the “transition.” Anjali was nervous and excited at the same time. She knew that many of her friends had left their pediatrician and were now seeing a Family Physician. She felt ready, too. After all, it was a part of growing up, entering adulthood, and she was certainly looking forward to that!

That summer, when Anjali was 18 years old, she had her first appointment with Dr. Greer. She knew that Dr. Butler, Dr. Greer, Molly, and Marnetta had been in touch so that everyone was sure that Anjali would be comfortable at her new Medical Home. When Anjali arrived at Dr. Greer’s office, she was greeted by a woman at the reception desk named Joy. Joy gave her some forms to fill out and then pointed out some magazines that Anjali could leaf through while she waited. Anjali thought it was nice to be in an office that had magazines that she liked and not so many children’s storybooks.

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Anjali had just begun to read a neat article about the most popular haircuts for the season when Marnetta came into the waiting room for Anjali's appointment. As they walked to the exam room, Marnetta explained what they would be doing at this first visit. She told Anjali about the many ways they could help her as she got older and more independent and needed information and help with things like housing, health insurance, assistance for college, and local activities and events in the community. Marnetta mentioned that she knew people from many of the local, county, and state agencies like the Center for Independent Living, the Department of Health, the Transportation Alliance, and the Center for Schools and Communities. She explained that these people and their agencies would be available to help her to transition into her adult life.

Just as Marnetta was finished explaining things, Dr. Greer knocked on the door and came into the exam room. She had read through Anjali's chart and discussed her care with Dr. Butler before the appointment. Anjali appreciated the time Dr. Greer had taken to get to know her and her health history. She also appreciated being seen alone by Dr. Greer for the whole appointment and that Dr. Greer did not share information with her parents without her consent. Anjali noted that she had to schedule all her different appointments for her many medical needs on different days; she missed the multidisciplinary clinic that had them all in one place at the children's hospital. Most of all, she noted that she was one of many in the adult practice with chronic health issues. In the pediatric practice office, she usually was the only one being seen with chronic health issues, but she was not so different from the others in the adult practice waiting room.

Anjali remembered how at first it was difficult talking to Dr. Greer about her health needs other than her disability. So much emphasis in the past was about her asthma and CP. But Anjali had other health concerns. With her doctor's guidance, she sought information on birth control and the impact that sexual relations might

have on her health. The consultation was helpful as she prepared for her next transition as a wife and later a mother.

As Anjali had stayed in her college town after graduating, she also stayed with Dr. Greer's practice. Anjali had been a patient of Dr. Greer's now for more than a decade, longer than she had been with Dr. Butler!

*EP* and the Guest Editors of this Medical Home Series would like to thank the families and children with special healthcare needs for sharing their experiences as this series was published.

In addition, we would like to thank all of the authors for sharing their expertise in bringing Anjali and her family to life.

Guest Editors:  
 Renee M. Turchi, MD, MPH  
 Molly Gatto  
 Deborah Walker  
 Sarah Macdonald, MD  
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Each article in the Medical Home series is available at [www.eparent.com](http://www.eparent.com) and at [www.pamedicalhome.org/](http://www.pamedicalhome.org/)

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Anjali's pregnancy continued to term, 40 weeks and 2 days. She had difficulty walking with her braces the last month. It was hard to keep her balance as her abdomen grew! Fortunately, her parents, Samir and Amita—Naana and Naani to Deepak—had come to stay with Anjali and Tarkesh to help them get ready for their second baby.

Anjali awoke early one spring morning to the sound of birds chirping. She thought it was the birds that had awoken her, but as soon as her eyes opened, she felt a strong contraction. She woke up Tarkesh, who in

turn woke up Deepak, Amita, and Samir. They all piled into the car and headed to the hospital. As Amita rushed to the car, she remembered to take along a small picture of the God Ganesha for good luck—just the way she had prayed to him when she brought Anjali home from the hospital many years ago. Amita, Samir, and Deepak went off to the waiting room, and Anjali and Tarkesh settled into the labor ward. When Anjali held their daughter a few hours later, she told Tarkesh she wanted to call her Manali, Hindi for *bird*. Tarkesh liked the name because of the way Amita had awoken so early that morning.

A few minutes later, Amita, Samir, and Deepak entered the room. Deepak peered into the blanket to see the face of his sister.

"Is she really old enough to be *borned*?" he asked.

Amita and Anjali looked at each other and smiled. "Yes, she is. She is old enough to be *borned* and to be your sister, Manali, and to be held by her brother." Anjali told him.

"Ok. But first I have something for her. Manali, I made a list for you of all of my toys that you can play with. Naani and Naana helped me make it. They said lists are "good." •

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