

Perspectives in Care for Children with Special Health Care Needs

LA RABIDA
MDINSIGHTS



Features

Multidisciplinary
Team Approach
Pivotal for Medical
Home Programs

Young Adult
Transition Clinic
Utilizes Primary Care
Model: Moving from
Pediatric to Adult Care

Premier Kids Program
Serves the Needs of
Medically Complex
Children



LA RABIDA
CHILDREN'S HOSPITAL

Perspectives in Care for Children with Special Health Care Needs

MDINSIGHTS

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La Rabida Children's Hospital

About La Rabida

La Rabida is a specialty childrens hospital. The only hospital of its kind in Chicago, it treats children with chronic illness and disabilities. Its inpatient unit is staffed and equipped to treat and manage:

- Medical technology dependency
- Recovery and rehabilitation following surgery, a NICU or PICU stay
- Acute exacerbations of a chronic illness
- Conditioning in preparation for medical procedures

La Rabida extends its interdisciplinary team approach to all outpatient care, offering a wide range of primary care programs and specialty clinics on site. In addition, the hospital provides psychosocial care for children who have experienced abuse, neglect and/or trauma. La Rabida strives to be the hospital of choice and a trusted partner in the medical management of the children it serves and their families.

Medical Home Programs

- Adolescent
- Bronchopulmonary dysplasia
- Cerebral Palsy
- Medically Complex Kids and Youth
- Failure to thrive
- Premier Kids (birth to age 5)
- NICU follow-up
- G-tube*
- Nephrology*
- Neurology*
- Orthopedics*
- Pediatric incontinence
- Physical medicine /rehabilitation
- Podiatry*
- Psychiatry*
- Pulmonology*
- Rheumatology
- Sickle Cell
- Spasticity multispecialty management
- Traumatic brain injury

Specialty Clinics

- Asthma
- Cardiology*
- Diabetes
- Down syndrome

**For La Rabida patients only; unable to accept direct referrals.*

How to Make a Referral

La Rabida welcomes referrals from hospitals and physicians across metropolitan Chicago and Northwest Indiana.

Inpatient referrals: Call 312.498.4408, 24/7

Outpatient referrals: Call 773.753.8627, weekdays during business hours



M.D. to M.D.

As we struggle to provide the best comprehensive care to children and their families in the setting of a strained health care system, the concept of the Medical Home has emerged as the leading method of transforming the health care delivery system through the innovative provision of comprehensive, patient-centered, preventive and primary care services. In this issue of MD Insights, we showcase La Rabida’s Children’s Hospital’s approach to the Medical Home, highlighting three cornerstone programs for this model, namely the Premier Kids Program, the Cerebral Palsy Medical Home and the Young Adult and Teen Clinic.

Given La Rabida’s focus on a pediatric population burdened with chronic and complex medical conditions, the need for access and care coordination remains ever more pressing, and we hope to convey the remarkable story each program has to tell and provide a glimpse of not only the challenges involved, but also the heart-warming successes continuously rewarding our care teams’ tireless efforts.

These programs represent some of the best La Rabida has to offer to its patients and families, steeped in a tradition of caring and dedication over a century old, and we look forward to carrying that tradition forward regardless of where the winds of change in healthcare take us.

Edith Chernoff, M.D.,
Medical Director of the Premier Kids program
at La Rabida Children's Hospital

Coordinated Care Entity

La Rabida is hosting one of the three statewide coordinated care entities (CCEs) for the coordination of care for children with medically complex conditions. Creation of the new entity is sponsored by the Illinois Department of Healthcare and Family Services, as a component of their Care Coordination Innovations Project. The program is expected to open for enrollment the summer of 2014. For further information about La Rabida’s program, please call Anna Carvalho, Executive Director of the La Rabida CCE, at 773-753-8642 or send an email to acarvalho@larabida.org. For further information about the Department’s Care Coordination Innovations Project, please see: <http://1.usa.gov/1itwgaS>.



New Ambulatory Center Opens

We are pleased to announce the opening of a new 22,805 square foot **ambulatory center**. The center is fully accessible, family friendly and overlooks Lake Michigan with an adjacent healing garden. The space is fully equipped with 18 exam rooms, triage rooms, a pharmacy, lab, rehabilitation gym and radiology space.

By upgrading and expanding our outpatient facilities, La Rabida can better integrate new technologies and models of care for our medically complex patients.

Multidisciplinary Team Approach:

A case study from the Cerebral Palsy Medical Home Program

Ruby Roy, M.D.



The *Cerebral Palsy Medical Home Program* serves patients from diagnosis to adult transition. These patients are usually diagnosed in the second year of life and present along a wide spectrum of medical

complexity, needs and function. The Cerebral Palsy Medical Home team includes a core group consisting of a pediatrician, a registered nurse care coordinator and a licensed social worker, and is augmented by a psychiatrist, dietitian and physical therapist.

The goals of the team include:

- supporting the growth and development of children
- enhancing the management of complex medical conditions
- encouraging family advocacy
- linking children to community resources
- improving family satisfaction

Each team member's expertise is leveraged to provide families support in line with these goals. *"The strength of the team is each individual member. The strength of each member is the team."* Phil Jackson

Mark* and his family are a good representation of how the team works together to support the patient, his unique needs and caregivers.

Mark is a 4-year-old with schizencephaly and cerebral palsy. His primary medical problems are hydrocephalus and seizures from the brain malformation.

Our team has followed Mark for three years and has great respect for his mother who takes meticulous care of him and keeps all his specialty and therapy appointments. She balances his care with working a job and attending nursing school.

Mark is Gross Motor Function Classification System (GMFCS) level 5 but has a wonderful personality: he interacts, vocalizes and laughs with his family. When we met him, he had been eating by mouth although this was an arduous process his mother undertook

to minimize surgeries and keep life as "normal" as possible for Mark. The feeding interactions were pleasurable for both Mark and his caregivers.

Mark's mother and grandmother were the primary caregivers spending more than an hour to feed the toddler. He was growing but at the lowest limits of normal on his cerebral palsy growth curve. Our dietitian followed him and educated the mother on what would be adequate growth for him. It seemed obvious to the team that Mark was not going to be able to keep up with his nutritional needs without another form of feeding. However, as long as the family was willing to make the enormous time investment to feeding him by mouth, we respected the decision.

"The strength of the team is each individual member. The strength of each member is the team." - Phil Jackson

Last year, the family's heroic efforts fell short when he suffered multiple viral infections and lost a significant amount of weight in two months. He was readmitted to the hospital for failure to thrive. Our team recommended a nasogastric tube for the supplemental nutrition needed for Mark to achieve normal weight gain.

After several days of good weight gain, our team met with his mother in the hospital to discuss a gastrostomy. We expected this would be a difficult conversation based on previous conversations.

However, the mother surprised us by raising the issue herself and agreeing to it. We asked what changed her mind and she pointed to the physical therapist on our team.

The therapist had shared with the family that Mark was stronger and more developmentally capable because of better nutrition and weight gain. Mom made a difficult decision based on a team member who would not typically be an expert on the issue of weight gain, but ultimately was an advocate for his gross motor skills.

Mark's case is just one example of the many benefits multidisciplinary teams bring to patients. In these teams, each member's specialties and personalities are critical to the partnership with the family. Team members can help families make difficult decisions by bringing their unique knowledge base and perspectives. Rachel Remen, M.D., writes, "When we know ourselves to be connected to all others, acting compassionately is simply the natural thing to do." Team-based primary care facilitates communication and connection and supports our commitment to compassionate service.

*patient's name has been changed to protect privacy

GMFCS Levels

Level I

- Walks indoors, outdoors and climbs stairs without using hands for support
- Performs usual activities such as running and jumping
- Experiences decreased speed, balance and coordination

Level II

- Walks indoors, outdoors and climbs stairs with a railing
- Experiences difficulty with uneven surfaces, inclines or in crowds
- Possesses minimal ability to run or jump

Level III

- Walks with assistive mobility devices indoors and outdoors on level surfaces
- May be able to climb stairs using a railing
- May propel a manual wheelchair (may require assistance for long distances or uneven surfaces)

Level IV

- Walking ability severely limited even with assistive devices
- Uses wheelchairs most of the time and may propel their own power wheelchair
- May participate in standing transfers

Level V

- Has physical impairments that restrict voluntary control of movement and the ability to maintain head and neck position against gravity
- Impaired in all areas of motor function
- Cannot sit or stand independently, even with adaptive equipment
- Cannot independently walk, though may be able to use powered mobility

Primary Care for Kids with Special Health Care Needs

HIT THE EASY BUTTON

Medical Home for children with:

- medically complex conditions
- physical disabilities
- developmental delays (siblings welcome)

Coordination of services beyond medical care:

- transitioning adult care program
- specialized car seat program
- transportation assistance
- after school tutoring
- legal advocacy
- CPR classes
- free parking



Coordinated services in a single location:

PRIMARY CARE AND NURSE CARE COORDINATION

- social work
- nutrition
- mental health
- physical, occupational and speech therapy
- education coordination and EI services
- on-site, pharmacy, lab and x-ray
- availability of specialists

Young Adult Transition Clinic: Moving from Pediatric to Adult Care

Nancy Fritz, M.D.



As more children with severe disabilities survive to adulthood, the pediatric community faces new challenges in managing the transition of these young people to adult providers.¹ In response, La Rabida Children's Hospital established the Young Adult Transition Clinic (YATC) in order

to understand and better manage these challenges. This clinic is an essential part of our commitment to serving young people with special health care needs.

La Rabida uses a primary care, team-based model of care in this clinic to offer a process of transition that meets the needs of the young adult, the family and the various invested providers. Beginning around age 17, patients in the adolescent clinic are referred to the YATC where they meet with each member of the team—a pediatrician board-certified in adolescent medicine, a psychologist, a social worker, and a nurse. Legal advocacy services are also available by referral.

Initial goals include assessments of both medical and psychological readiness for transition. Over the next several visits, individualized recommendations are made addressing insurance coverage, community resources, supplemental financial support, guardianship, and adult primary care providers. The team also communicates with the patient's pediatric sub-specialty providers, encouraging them to address transition. A portable medical summary is created and the patient is encouraged to make an appointment with a new provider. The patient follows up in YATC one last time to problem-solve any residual concerns, then receives a "graduation" certificate and best wishes from the team.

This model has been supplemented by two skill-building pilot transition groups. One is Leading Adolescents to Understanding New Challenges in their Health Care (LAUNCH), and the other is Assistance and Support for Caregivers as they Embark in New Health Care Directions for their young adults (ASCEND). Both LAUNCH and ASCEND were in response to a national call by the American Academy of Pediatrics to support young adults seeking health

care for their chronic illnesses. Families attend four weekly sessions over dinner, featuring discussions facilitated by various presenters.

In the process of creating the YATC clinic, our team has learned a number of things:

1. Transition is a process. It takes longer than we had imagined. Patience and support are essential.
2. A comprehensive portable medical summary is crucial. It allows for a seamless transfer of essential information, and is much appreciated by the receiving provider.
3. Compiling a list of adult providers is worth the time and energy. Multiple meetings with providers and administrators at different facilities have allowed us to build a list of trusted people with a variety of skill sets, to whom we can match our patients and families.
4. The team approach has allowed us to meet some of the social and psychological needs of patients that would have been hard to accomplish by a lone physician.
5. The changing insurance landscape offers more opportunities for our medically complex patients, but requires continued vigilance to understand and counsel families about their options. Support staff with expertise in this area is essential.
6. Families very much appreciate the chance to meet and share concerns in a group setting. Interpersonal connections and specific shared information complemented the programmatic aspects of these sessions.

La Rabida is in its second year with the YATC clinic, having seen about 100 patients in some transition capacity. We are confident that we understand the challenges of transition and are empowered by the realization that we are supported – not only within our own medical home setting – but within a larger community of professionals dedicated to enabling youth to optimize their abilities to assume adult roles and activities.

“About age 17, patients in the adolescent clinic are referred to the YATC”

¹ Blum RW. Transition to adult health care: setting the stage. J Adolesc Health. 1995;17.

Premier Kids Program Serves the Needs of Medically Complex Children

Edith Chernoff, M.D.



The Premier Kids program provides primary care to children ages birth to five who have special health care needs. Children enter the program after having:

- Graduated from a neonatal intensive care unit
- An inpatient stay, following delivery
- Neonatal drug exposure
- A diagnosis that may challenge physical, motor, cognitive, and nutritional development, plus social and emotional growth
- Met the eligibility requirements of the Illinois Early Intervention System

Each child receives routine check-ups, immunizations, and urgent care from a pediatrician who also coordinates the care for the child's medical condition. The child is also assigned to a nurse care coordinator, a social worker, a developmental specialist and a clinical dietitian.

Case Study

Cassandra* is a five-year-old girl who was born at 24 weeks gestation with a birth weight of under 2 pounds. She spent the first 4 months of her life in the neonatal ICU and required support for her breathing and eating. She had a right sided intracranial bleed that developed into a large cyst in her brain and resulted in left sided weakness.

She was first seen by Premier Kids at La Rabida two weeks after discharge from the NICU. Her diagnoses included retinopathy of prematurity, chronic lung disease, gastroesophageal reflux disease, large cyst in brain with left sided weakness, global developmental delay and poor weight gain. She also was being seen by many medical specialists. Cassandra's mother was 19 at the time of her birth and struggled to understand the medical needs for her baby. She missed many doctor appointments and got confused about the medications. Ultimately, DCFS became involved and removed Cassandra from her mother's care. However, she was able to return home with the stipulation that she continue to receive medical care and care coordination through Premier Kids.

In the Premier Kids program, Cassandra was seen frequently by the physician, nurse care coordinator, infant development specialist, dietitian and social

worker. We worked with her mother to explain her child's medical needs, recognize when she was becoming ill and needed more medications, and when she needed to be seen by a physician. We helped the mother develop strategies to get to appointments on time. Nutrition staff worked on improved calorie intake both by mother and through a gastrointestinal tube.

Cassandra made progress but continued to struggle developmentally and her lung disease resulted in many ER visits and hospital admissions. She received therapies through the Early Intervention system, and after three years of age, through school. Premier Kids staff arranged for her to get hand and leg braces as her weakness developed into cerebral palsy.

Today, we are proud that Cassandra has learned to walk independently and is toilet trained. Most importantly, she has not been in an emergency room or admitted to a hospital in more than one year. She is eating and gaining weight and is in school learning her ABCs. She continues to take medications for her breathing daily, but her mother now understands how to recognize Cassandra's needs and to care for her.

*patient's name has been changed to protect privacy

This Issue's Contributing Authors



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*Recognized by the National
Committee for Quality Assurance
(NCQA) for its medical home programs*



*"La Rabida Children's Hospital
has earned The Joint Commission's
Gold Seal of Approval."*