

Medical from carf INTERNATIONAL RehabConnection

Issue 3, 2013

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Meeting People Where They Are

Imagine sitting in a meeting at work and your pager goes off. The meeting is almost over. You'll check it then. But the pager keeps signaling. Distracted by someone's impatience, you check the page. It's 911. The emergency medical technicians are en route to the hospital with your six-year-old son.

This is how the journey began in 1996 for Heather Baker, administrative director of The Brookdale Center for Healthy Aging & Rehabilitation, and her family as they started down a path no parent plans on. Working as a social worker at the time, Heather was no stranger to hospitals or people in crisis, but in that instant everything changed. From the first days in the hospital when Heather and her husband would not leave their son's bedside, through years of navigating healthcare, education, and social systems on his behalf, to now, when he lives independently, works, and enjoys the life of a young adult, Heather has learned what it means to meet people where they are. "The beauty of any well-crafted program is about meeting people at their point of readiness. Some are ready earlier, some are ready later, and some are never ready," she says.

Heather says she was ready to reach out when she was approached in 1998 to become a parent liaison for CARF. What she didn't expect was the impact it would have on her and the cherished experience it would become. Parent liaisons, parents of children who have been served by accredited medical rehabilitation programs, participate in all CARF surveys of Pediatric Specialty Programs. They speak with parents of children served by the program seeking accreditation about their experiences with that program. Focusing on the concepts addressed in the standards for Pediatric Specialty Programs, parent liaison interviews are done in advance of the site survey, and the information gathered is provided to the survey

team to complement and inform its work on site.

While the shared experience of parent liaisons and the parents with whom they speak elicits valuable feedback for the survey, it also forges connections. “There is something so pungent, so palatable in every interview. It’s amazing how honest people are in their comments,” remarks Heather. Kindred spirits, even parents she interviews in other parts of the world speak freely of their experience and she finds that “the essence of the child-parent relationship and the language of recovery cross all boundaries.”

As a reflection of the privilege of having spoken to so many parents over the years, Heather put together a collection of insights on key interactions those parents shared that shaped their rehabilitation experience. Here are some excerpts:

- Dad reflected on the accident and the direction life had taken his family. “It hasn’t been right since,” he said, but still he spoke of how compassionate the staff members are and how they have gone out of their way. He gave examples like the time their son’s high school was putting on a function for the senior class and the case manager set up an ambulance to take their son to the function and attended with him, and how the staff made sure they had Thanksgiving dinner together at the hospital. “They have a lot of good people in key positions. They make you feel at home.”
- Mom said she had input early in the program. However, she lives two hours from the facility and only gets information when she calls to see how her daughter is doing. Mom said that the program offers family conferences once a month, but she can’t always get off work to attend and there’s never been an option to do it on the weekends. Mom only gets the minutes now and feels this is a lacking component.
- Mom shared that, when visiting the facility, she was inclined to take over the care of her daughter, but the staff encouraged her to let them provide the care she needed. Although she understands it now, she related that, at the time, she felt she had little or no purposeful role.
- Dad described that they had not left their son’s side during the acute hospital stay. On arrival to the rehabilitation program, the team greeted the family...from the doctors, case managers, and department heads to the security personnel. The family gained such a feeling of comfort from the staff that they were able to go home on day two with confidence that their son was in good hands.

When people tell Heather that her son is lucky to have her as a mother, she is quick to respond that she is the lucky one, that the journey they have shared has given her the opportunity to become a better parent. “The insight you have is not all painful—it is positive in many ways, too,” says Heather. That insight has undoubtedly been shaped by the professionals along the way who were uniquely able to read exactly where her son was in his recovery process and help map out the next steps. “It’s a tribute to the special people who interact with families throughout the stages of recovery and reentry, making a profound difference in the success they have in their new lives ahead.”

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The Role of Parent Liaisons in Surveys of Pediatric Specialty Programs

Parent liaisons are involved in all surveys of Pediatric Specialty Programs, complementing the role of on-site surveyors. Involving parent liaisons in the survey process provides an opportunity for parent-to-parent feedback about the integration of children/adolescents and families/support systems in the rehabilitation program. Although CARF surveyors always interview persons served by each program seeking accreditation, the additional opportunity for a parent to be interviewed by another parent who has also had the experience of having a child in a rehabilitation program generates information that is unique from what a surveyor may elicit.

The role of the parent liaison is to gather information for the survey team. Prior to the on-site survey, the parent liaison conducts telephone interviews with parents or family members of children being served by or recently discharged from the program seeking accreditation and communicates his or her findings to the survey team for consideration during the survey process and accreditation decision making.

Ongoing Recruitment of Parent Liaisons

Just as surveyor recruitment is ongoing, so is parent liaison recruitment. Qualifications of parent liaisons include:

- The ability to clearly communicate with a variety of people, including children/adolescents, other parents, rehabilitation professionals, etc.
- The ability to establish rapport with others quickly and easily by telephone.
- The ability to follow through on assignments in a timely manner.
- The willingness to make a commitment to participate as parent liaison in three surveys per year.

Parent liaisons are trained by CARF regarding their role and its expectations. The training does not require any travel.

Parent liaisons enhance the value of CARF accreditation, especially for the children and adolescents served. If you would like to nominate the parent/caregiver of a child/adolescent who has been served by and recently discharged from your program, please contact Karen Vellenga at kvellenga@carf.org.

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Accreditation of Medical Rehabilitation Programs that Serve Children and/or Adolescents

If your program serves any children or adolescents, it is subject to additional standards when surveyed using the medical rehabilitation standards manual. The additional standards

address unique aspects of providing services to children and adolescents, regardless of the setting in which services are provided. There are two sets of standards in the medical rehabilitation standards manual related to children and adolescents: Section 2.E. The Rehabilitation and Service Process for Children and Adolescents Served and Section 3.F. Pediatric Specialty Programs.

The standards in Section 2.E. The Rehabilitation and Service Process for Children and Adolescents Served address these concepts:

- Information shared with stakeholders about the age range and number of children/adolescents served annually
- Involvement of the family/support system as a partner in all phases of the program
- For inpatient and residential settings, procedures for families to remain with the children/adolescents served 24 hours a day
- Opportunities for members of the family and peers to visit the children/adolescents served
- Space, equipment, furniture, materials, and schedules that reflect the ages, needs, and interests of the children/adolescents served
- Personnel competencies
- Educational services and information exchanged between the program and the school system
- Team composition
- Transition plans
- Education and training for the family/support system

The standards for Pediatric Specialty Programs, based on the following description, build on those concepts with a specific focus on family-centered care.

The essence of a Pediatric Specialty Program is family-centered care. Family-centered care is defined as having eight critical components. They are:

- Recognition that the family/support system is the constant in the child's life, while the service systems and personnel within those systems fluctuate.
- Facilitation of family/support system—professional collaboration at all levels of care.
- Sharing of unbiased and complete information with the family/support system about the child's care on an ongoing basis, in an appropriate and supportive manner.
- Implementation of appropriate policies and programs that are comprehensive and provide emotional and financial support to meet the needs of families/support systems.
- Recognition of family/support system strengths and individuality and respect for different methods of coping.
- Understanding and incorporating the developmental needs of infants, children, and adolescents and their families/support systems into healthcare systems.
- Encouragement of parent-to-parent support.
- Assurance that the design of healthcare delivery systems is flexible, accessible, and responsive to family/support system needs.

[Adapted from Terri L. Shelton, Elizabeth Seale Jeppson, and Beverley H. Johnson, *Family-Centered Care for Children with Special Health Care Needs*. (Washington: Association for the Care of Children's Health, 1987).]

Pediatric Specialty Programs are culturally sensitive, interdisciplinary, coordinated, and focused on outcomes. These programs serve children/adolescents who have significant functional limitations as a result of acquired or congenital impairments. The programs use an individualized, developmental, and age-appropriate approach to rehabilitation that ensures that care focuses on preventing further impairment, reducing activity limitations, and minimizing participation restrictions while maximizing growth and development. The programs encompass care that enhances the life of each child/adolescent served within the family, school, and community. A major focus is on providing developmentally appropriate care that acknowledges each child's/adolescent's need to learn and play.

Each organization decides for itself which set of standards related to the provision of services to children/adolescents the program seeking accreditation will meet. Considerations include, but are not limited to, how you characterize your program to stakeholders; how you engage with families/support systems; personnel competencies and the resources you have to support service delivery, including whether those resources are provided directly or through linkages; and whether you have mandates or other requirements to seek Pediatric Specialty Program accreditation. You may always contact your resource specialist for guidance.

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Pediatric Specialty Program Accreditation: An International Perspective

As CARF accreditation grows internationally one of the objectives of the *Medical Rehab Connection* is to introduce members of the CARF family from around the world. There are currently 33 organizations outside of the United States that have CARF-accredited Pediatric Specialty Programs, including two in Saudi Arabia. With estimates that at least a third of the Saudi population is under the age of fourteen, the demand for specialized pediatric rehabilitation services is high. Read on for the stories of our colleagues in Riyadh, including what they identify as some of the unique cultural aspects, accomplishments, and challenges of their programs.

Sultan Bin Abdulaziz Humanitarian City

The Sultan Bin Abdulaziz Humanitarian City (The City) www.humanitariancity.org.sa is a project of the Sultan Bin Abdulaziz Al Saud Foundation. The City is a 400-bed Rehabilitation Hospital and Medical Center that opened in 2002 and provides care to inpatients and outpatients. In support of its vision to become an internationally recognized center of excellence, The City chose to include its Pediatric Specialty Program in its initial CARF survey in 2011. In 2012, children represented 38 percent of all patients admitted to The City.

Of those, 76 percent were admitted for neurological conditions, 4 percent with traumatic brain injury, 3 percent with non-traumatic brain injury, 1 percent with non-traumatic spinal cord injury, and 9 percent with other conditions such as developmental delays.

The philosophy of the Pediatric Specialty Program is to maximize the capabilities of the child to function and participate in the natural environment and to provide the parents and caregivers of the children with enriched handling and coping skills to further the potential of the child following discharge from The City. When asked about the program's accomplishments and challenges, Anne Field, RN, M.Sc., CPHQ, director of quality management and a CARF surveyor, spoke directly to the outcomes of the program:

- The durability of our program outcomes is strong, with 82 percent of our children attending a family gathering, community outing, or play activity at least twice a month postdischarge. Ninety-nine percent of the children returned home postdischarge. An average of 96 percent of children served achieved household ambulation, 95 percent achieved self-feeding, and 89 percent achieved their bowel and bladder goals. An average of 98 percent of the families served had the opportunity to attend the family conference to actively participate in program planning for their children.
- One of the major challenges of the program is the provision of equipment prior to discharge. During 2012, 60 percent of the children served received their equipment prior to discharge. Although this was above the goal set by the team, it was lower than what was achieved in 2011 by 21 percent. Therefore, the team is actively working with both internal and external stakeholders to ensure that all children have the equipment needed prior to discharge.

As for unique aspects of the Pediatric Specialty Program, a number of the families served have multiple children with the same neurological condition. Often the siblings are admitted together. The team therefore must be very innovative in its approach to ensure that the families are provided with the skills and support necessary to cope with such challenges while at the same time supporting the children served to achieve their overall goal of active participation in life.

Another unique aspect of the program noted by Anne is the diversity of the team. In addition to the many Saudi nationals on the team, The City recruits staff from all over the world, creating a culturally diverse workforce providing care to a majority of Saudi and Middle Eastern persons. "We believe we use our diversity to our advantage as we are strengthened by each team member's insight and life experiences."

The Rehabilitation Hospital at King Fahad Medical City

The Rehabilitation Hospital at King Fahad Medical City (KFMC), www.kfmc.med.sa, recently completed its second CARF survey, which included the addition of a Comprehensive Inpatient Pediatric Specialty Program. Persons served by the program in 2013 range in age from four to seventeen years old, with the most common diagnoses during that period of acute stroke, traumatic brain injury, brain tumor resection, and cerebral palsy. When asked about some of the unique cultural aspects of the pediatric program, Ahmed AboAbat, Director of KFMC's Rehabilitation Hospital and a CARF surveyor, described the following:

- In Saudi Arabian culture, a thirteen year old is considered an adult. At this age, girls begin covering their hair and wearing a long black cloak called an *abaya*, and boys spend more time with their fathers to learn adult male expectations and customs. The

acute pediatric hospital serves children only through age twelve, and children thirteen and older are treated as part of the adult acute population. However, emotionally, developmentally, and socially, especially once injured, these children have unique needs and don't integrate well with adults in acute rehabilitation. For these reasons, we recently established the adolescent service, which is housed in the pediatric rehabilitation ward. The adolescents are more appropriately served by pediatric therapists, nurses, and physiatrists.

- It is not culturally acceptable for boys and girls over age twelve to be together. For this reason, girls thirteen and older are treated in the female-only physical and occupational therapy gyms, while boys are treated in the adult male gyms.
- Every child has the legal right to schooling in Saudi Arabia, but it is the parent's choice whether or not the child attends school. As such, the rehabilitation team can make recommendations to facilitate return to school, but it will be the family's choice if, when, and where the child attends school.

On its first survey, KFMC's comprehensive integrated inpatient rehabilitation program met CARF's standards for the provision of services to *any* children/adolescents. When asked why his organization decided to pursue Pediatric Specialty Program accreditation in its resurvey Ahmed spoke to the country's large pediatric population and the high rate of road traffic accidents that result in pediatric spinal cord injury, traumatic brain injury, and other impairments. The Rehabilitation Hospital started with a few pediatric beds and then expanded to ten pediatric rehabilitation beds to better meet the needs of the country and to lead the rehabilitation specialty in Saudi Arabia. In addition, the program recently expanded to include adolescent services within its pediatric rehabilitation program.

Developing the adolescent program has had its challenges. According to Ahmed, KFMC's adolescent inpatient rehabilitation program is the first program at the national level to offer comprehensive rehabilitation services to adolescents and their families. Coordinating consultation support among different pediatric and adult subspecialists is challenging, as is providing appropriate culturally sensitive areas for therapy treatments where adult family members can also be included. For example, a father of a thirteen-year-old girl cannot go with her to a female-only therapy gym and the same for a mother of an adolescent boy. Fathers of adolescent girls served are not permitted to stay overnight in the pediatric ward. Usually fathers stay with adolescent boys, but if mothers must stay for family reasons, then a private room must be made available or the entire shared four-bed male room must be designated for female caregivers only. Grouping adolescents by gender also means the program may not have room for a child who is eligible to enter the program. This can be quite challenging for families, nursing staff, and case managers/social workers as well as the entire team.

As the reach of CARF accreditation extends internationally, we have a growing number of opportunities to learn about the diversity of other cultures and from our colleagues around the world who are also committed to quality for persons served.

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