



Family Matters

Elizabeth Ahmann, ScD, RN and Deborah Dokken, MPA

Beyond the Medical Home: Special Care Family Academy for Children and Youth

Roger S. Thrall, Jody H. Blumberg, Stephanie Beck, Magdalena D. Bourgojn, John J. Votto, Randall W. Barton

Children and youth with special health care needs, henceforth referred to as children with special needs, are estimated to comprise 10% to 20% of children in the United States (Gordon et al., 2007). Yet, in 2000, their medical costs were disproportionately high, accounting for almost 42% of total medical costs for all children (Gordon et al., 2007; Kuhlthau, Hill, Yucel, & Perrin, 2005; Martin et al., 2007). Newacheck and Kim (2005) reported that children with special needs, as compared to other children, have:

- Four times more hospitalizations.
- Seven times longer hospital stays.
- Dramatically higher number of visits to physicians and other health care providers.
- Significantly more emergency department (ED) admissions.
- Five times greater use of prescription medications.

The concept of the “medical home,” first introduced by the American Academy of Pediatrics (AAP) Council on Pediatric Practice in 1967, was intended to improve care for children with special needs. Initially, a medical home served as a central repository for children’s medical records. Over time, however, the concept evolved into care coordination centered on the active participation of the patient and family as a critical element in their health care. A medical home is not necessarily a building, but rather, a functional network of health care providers easily accessible to the family (Turchi, Gatto, & Antonelli, 2007).

Children and youth with special health care needs require more health care and related services and consequently incur more costs than other individuals. Implementation of the “medical home” concept has benefitted children with special needs, resulting in fewer unmet medical needs and more consistent health care delivery. As advances in health care have enabled an increasingly higher percentage of children with special needs to live far into adulthood, the transition from adolescence to adulthood poses new challenges in obtaining medical care, education, job training, and employment opportunities. A more comprehensive medical home paradigm for children with special needs is composed of three fundamental components: 1) home/community, 2) education, and 3) medical/dental care. These components should be developed equally and in parallel, emphasizing consumer advocacy, care coordination, education, life skills, and career development, to attain independent or minimally dependent living. This new model has been initiated at Hospital for Special Care in New Britain, Connecticut, in its Special Care Family Academy.

The federal government made comprehensive primary care for children with special needs a priority by including it as a goal in *Healthy People 2020* (U.S. Department of Health and Human Services, 2010). Specifically, *Healthy People* states “all children with special healthcare needs will receive regular ongoing comprehensive care within a medical home.” Implementation of the medical home concept has resulted in children with special needs experiencing more consistent health care delivery and fewer unmet medical needs (Berman et al., 2005). For example, children with special needs who participate in medical home programs are more likely to have access to surgeons and other medical specialists, as well as shorter average inpatient hospitalizations (Damiano, Momany, Tyler, Penziner, & Lobas, 2006; Newacheck & Kim, 2005). In one study of a hospital/primary care partnership for children with special needs, the costs for ED and inpatient services decreased by almost \$11 million, and hospital days were decreased by 50% (Gordon et al., 2007).

Roger S. Thrall, PhD, is Director of Clinical Research, Hospital for Special Care, New Britain, CT.

Jody H. Blumberg, MBA, is Administrative Director, Neag Comprehensive Cancer Center, University of Connecticut Health Center, Farmington, CT.

Stephanie Beck is Program Coordinator, Special Care Family Academy, Hospital for Special Care, New Britain, CT.

Magdalena D. Bourgojn, BS, is Assistant Research Director, Hospital for Special Care, New Britain, CT.

John J. Votto, DO, is President and CEO, Hospital for Special Care, New Britain, CT.

Randall W. Barton, PhD, is Associate Director, Department of Research, Hospital for Special Care, New Britain, CT.

The **Family Matters** series focuses on issues, information, and strategies relevant to working with families of pediatric patients. To suggest topics, obtain author guidelines, or to submit queries or manuscripts, contact Elizabeth Ahmann, ScD, RN; Series Editor; *Pediatric Nursing*; East Holly Avenue/Box 56; Pitman, NJ 08071-0056; (856) 256-2300 or FAX (856) 589-7463.

Figure 1.
Special Care Family Academy

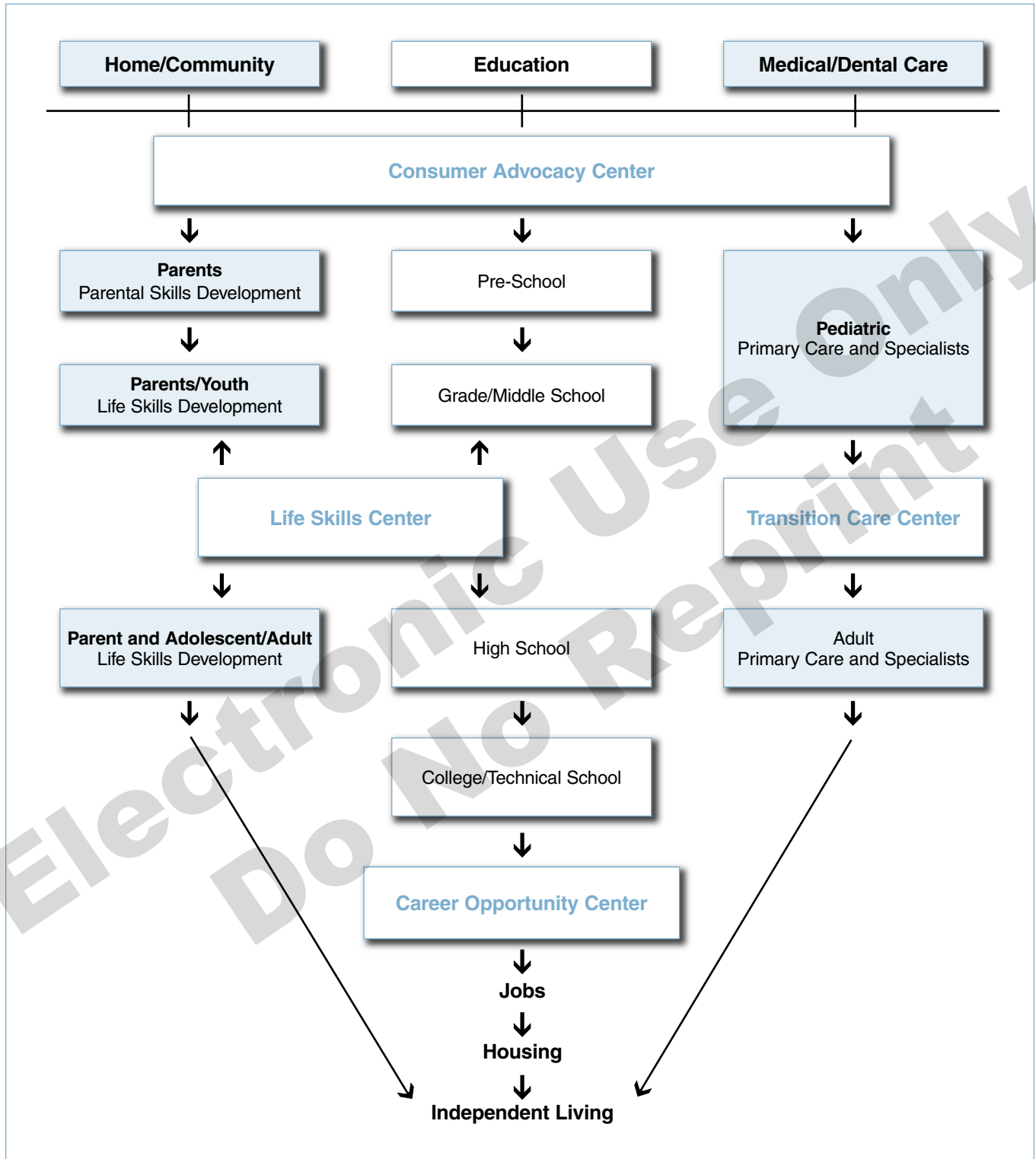


Figure 2.
Hospital for Special Care (HSC)

The Hospital for Special Care (HSC) in New Britain, Connecticut, is a 228-bed, fully accredited, not-for-profit, long-term acute care hospital. Services include complex inpatient and outpatient rehabilitation, as well as pulmonary, specialized pediatrics, neuromuscular disease, and spinal cord and brain injury care. HSC is the only long-term acute care hospital in the United States, serving both children and adults across this comprehensive spectrum of complex care.

The focus of the health care system for children with special needs has been on prolonging and saving lives. However, more recently, advances in health care have enabled an increasingly higher percentage of children with special needs – over 90% in one published report – to live well into adulthood, increasing the recognition of additional barriers that this population now encounters in the transition from childhood to adulthood (Blomquist, 2006). For example, older children with special needs, in part due to their difficulties with mobility, transportation, health, and/or functional capabilities, often experience challenges in obtaining education and training, resulting in limited employment opportunities (Blomquist, 2006; Larsen & Lubkin, 2009). Equally important, children with special needs may experience stigmas, social isolation, and an impaired development of social skills, self-esteem, sexuality, and sense of identity (Larsen & Lubkin, 2009).

A New Model: 'Beyond the Medical Home'

Children with special needs are living longer; thus, the role of family and community support systems, as well as education and employment opportunities, become perhaps even more important than medical care in terms of supporting optimal quality of life and independent living (Blomquist, 2006; Larsen & Lubkin, 2009). A parent of a grown child with special needs emphasizes this point, stating:

I recall experiences when my daughter was a child being treated at a pediatric hospital. The opportunity to network with other parents and children developed during clinic days led to an informal support system. In addition, we had formal monthly educational/support group sessions. However, we lacked the elements of transition care, life skills, and consumer advocacy that a more inclusive medical home model would address.

A more comprehensive approach than the classic “medical home” would more optimally support the transition to adulthood and independence by focusing on three fundamental components – home/community, education, and medical/dental care – each developed equally, integrated in parallel, and fully resourced (see Figure 1). This approach would emphasize consumer advocacy, coordinated care, transitional care, family support, education, life skills, and career development, as well as job placement.

Hospital for Special Care (HSC) in New Britain, Connecticut (see Figure 2), has initiated this new model in its Special Care Family Academy. This new paradigm is focused on identified gaps in our current health care system and an overall premise that the home/community, education, and medical/dental care must receive equal priority in the planning and management of a comprehensive health care plan (see Figure 1). Four centers have become focal points of HSC's new approach: a Consumer Advocacy Center, a Life Skills Center, a Transition Care Center, and a Career Opportunity Center. Each center uses a patient- and family-oriented approach to educate and support both consumers and health care providers through critical development stages for each child and family. The Special Care Family Academy evolved from the HSC Community Services Adaptive Sports and Fitness Programs, which began over 20 years ago. Total participation in all programs within the Academy for 2011 was over 600 individuals.

Consumer Advocacy Center

Children with special needs and their families typically have multiple needs at varying developmental stages: med-

ical/dental, developmental, educational, psychosocial, financial, and family support services. These needs arise during the prenatal and perinatal time periods and continue in various forms throughout life. The Consumer Advocacy Center's objective is to educate and empower children with special needs and their families to assume an active role in establishing an equal partnership with health care providers for their care and coordination over the lifespan. The Center provides the following services (outlined below):

Care coordination integrated with community-based services.

- Educating the consumer/family about care coordination, emphasizing the importance of the primary care physician communicating with all sub-specialty physicians.
- Understanding each community's unique set of services and how to access them for care coordination and support.
- Providing culturally and linguistically appropriate support to families.

Navigation in the health care system.

- Assisting families to understand and navigate both the health care and education systems within their communities.
- Providing families with relevant information about health care financing and how to access these services.
- Educating consumer/families regarding their rights specifically pertaining to the Americans with Disabilities Act.

An example of the Consumer Advocacy Center's coordination of care.

A Hispanic boy with special needs was entering a new school and was naturally apprehensive. One of the Center's mentor advocates met with school officials to set up a visit before the beginning of classes to assess accessibility and enhance the comfort of the student. At that visit, school officials invited the Center's advocate to hold an educational session with the student body and teachers. The session was extremely well received and benefitted not only the student, but also all students and the administration. School officials remarked that this session addressed not only recognition of physical disabilities, but also tolerance of all differences and could impact issues associated with bullying. This strategy is now used for all consumers in our Academy during transition to new schools.

Life Skills Center

The overall objective of the Life Skills Center is to assist in developing life skills important during childhood and

into adulthood. The Center offers support groups, mentoring, and an adaptive sports and fitness program.

Support groups. Bringing children with special needs and their parents and siblings together in support groups allows them to interact, network, and build relationships with individuals facing similar challenges. Siblings, in particular, benefit from support groups because they otherwise have little to assist them with issues arising from having a sibling with special needs. A second aspect of the support group program is to provide education on topics such as transition, navigating the school system, nutrition, rehabilitation services, transportation, and driving assessment.

One parent expressed gratitude for support groups as follows:

As a parent who has a child with disabilities, I feel that each parent support (group) get together is very informative and useful for future experiences we may have to get through.

Mentorship program. Based on the concept that "It takes a village to raise a child," the mentorship program provides the child with special needs the opportunity to interact – individually or in groups – with a mentor who 1) also has special needs; 2) clearly displays success in his or her own life; and 3) can serve as an exceptional role model. The benefits of developing a mentor relationship are clearly evident and include building confidence, enhancing social skills, easing transition, developing skills in goal setting and self-advocacy, and learning life skills.

The benefits of mentoring are clearly stated by the parent of one child:

[My son's] relationship with [his mentor] has grown into that of family. He now knows that being in a wheelchair does not preclude him from accessing anything. His being able to spend time in a community of successful adults has opened up all the vistas that a teenager should have. Thank you all!

Adaptive sports and fitness programs. HSC Community Services' adaptive sports and fitness programs, established over 20 years ago, are regionally based and offer children, teens, and adults living with special needs the opportunity to participate in sporting activities. Organized sports promote greater physical fitness, improve functional independence, and enhance self-esteem and self-identity, helping mold participants into confident and highly motivated individuals, instilling in them the desire, drive, and motivation to both achieve their goals and help others to excel in a similar manner. Available programs include wheelchair track and field, basketball, soccer, swim teams, therapeutic horseback riding, and skiing, and the following special offerings:

- Sports clinics – Nationally recognized athletes with disabilities and their coaches are brought in to provide intense instruction in specific sports.
- Special Care's Ivan Lendl Junior Wheelchair Sports Camp – World-class paralympic athletes serve as coaches, instructors, and role models for the campers, including a visit by tennis legend Mr. Ivan Lendl.

Transition Care Center

The Transition Care Center facilitates a smooth and coordinated process of transition from pediatric to adult health care. In conjunction with the Consumer Advocacy Center, the Transition Care Center prepares the young adult to assume a self-advocacy role in developing an overall health care plan in conjunction with health care

providers. Two programs support this Center's mission: the health care passport and a transition clinic.

Health care passport. Electronic health care passports enable better communication and care coordination between primary care providers, medical specialists, and other medical and dental health care providers. The health care passport is both password protected and encrypted to ensure proper access and confidentiality. It contains two separate "folders" of information: 1) health and medical information – a read-only file in which, for validity and integrity, only designated health care professionals are able to enter medical information; and 2) the patient diary – an open folder in which the consumer is able to enter any information, questions, or activities. The health care passport, updated at each medical visit, is on a portable flash drive for the consumer and also saved in the computerized medical records of providers.

Transition clinics. As children with special needs move from youth into adulthood, they often experience a reduced support network for health care. A transition clinic provides an interface between pediatric and adult primary care physicians and specialists to reduce potential obstacles in both health care delivery and insurance coverage. With the support of a Connecticut Department of Public Health grant, HSC helped develop transition clinics to serve children with sickle cell disease (SCD) at the Connecticut Children's Medical Center in Hartford and at Yale-New Haven Hospital. The transition clinic team is composed of pediatric and adult hematology physicians, a consumer advocate from the Sickle Cell Disease Association of Connecticut, a transition nurse, a social worker, the consumer, and parent(s) or guardian(s). The team meets together to introduce the young adult with SCD to adult providers and to review relevant health care and psychosocial needs and plans.

A transition clinic nurse describes the benefit of the clinics as:

...increasing and solidifying a patient's knowledge of his or her own medical history, as well as knowledge of sickle cell disease. The whole process can help provide patients with the confidence and tools necessary to navigate through the adult health care system in times of sickness, as well as promote wellness and maintenance of routine health care.

Career Opportunity Center

The focus of the Career Opportunity Center is career development and job placement, essential to attaining and sustaining independent or minimally dependent living. The Career Opportunity Center is closely linked to the Life Skills Center, especially regarding self-advocacy, mentorship, and career goal setting. The Career Opportunity Center provides workshops, conferences, and educational materials to assist in developing skills for employment and job success. The Career Opportunity Center also coordinates with the following state and private employment programs.

Connecticut programs. State programs include the following:

- Connecticut Department of Labor: CT Works – One-Stop Career Centers offer resources ranging from employment and résumé workshops to recruitment services and tax credit programs for employers. The centers also provide labor market information, an electronic job bank, and other services.
- Bureau of Rehabilitation Services (BRS) – Services include vocational counseling, job search assistance, skill training and career education in vocational and

other schools, on-the-job training, and vehicle and home modifications.

- Connect-Ability Career Center – This center offers information and technical assistance to job seekers and employers. Job seekers can access 1) tools to assist in identifying interests and channeling them into related fields, 2) help with résumés and cover letters, 3) support with responding to job leads and developing interviewing skills, 4) resources to assist in asking for workplace accommodation, and 5) information on how working will affect disability benefits.
- Connecticut Walgreens Project – The Connecticut Walgreens Project offers pre-employment training for individuals with special needs to work within Walgreens.
- Ability Beyond Disability – This non-profit organization offers one-to-one training programs for individuals seeking employment. Services range from discovering interests to job exploration and from résumé preparation to on-the-job training. Follow-up support is provided, including communication with employers and other support to ensure continued success.

Looking to the Future

The paradigm demonstrated by the Special Care Family Academy at HSC expands the boundaries of the traditional medical home concept to include more active participation of the home/community and education and employment networks into the health care system. Four key centers provide expertise and education and foster self-advocacy. The programs have proven to be extremely beneficial both to children with special needs and to their families, fostering an atmosphere of well-being and social adjustment, resulting in enhanced self-esteem. The consumer feedback on all of these programs has been very positive, with a resounding “we need more.” Persistent challenges include how to incorporate the centers into the culture of the health care system and how to fund such endeavors. The efficacy of such programs may appear obvious, but evidence-based evaluations are essential and will be pursued. The overall goal for this Academy is to raise the expectations of each individual with special needs in order to enhance opportunities and contribute to the community.

References

- American Academy of Pediatrics (AAP), Council on Pediatric Practice. (1967). Pediatric records and a ‘medical home.’ In *Standards of child care* (pp. 77-79). Evanston, IL: American Academy of Pediatrics.
- Berman, S., Rannie, M., Moore, L., Elias, E., Dreyer, L.J., & Jones, M. D. (2005). Utilization and costs for children who have special health care needs and are enrolled in a hospital-based comprehensive primary care clinic. *Pediatrics*, *115*, e637-e642.
- Blomquist, K.B. (2006). Healthy and ready to work – Kentucky: Incorporating transition into a state program for children with special health care needs. *Pediatric Nursing*, *32*, 515-528.
- Damiano, P.C., Momany, E.T., Tyler, M.C., Penziner, A.J., & Lobas, J.G. (2006). Cost of outpatient medical care for children and youth with special healthcare needs. Investigating the impact of the medical home. *Pediatrics*, *116*, e1187-e1194.
- Gordon, J.B., Colby, H.H., Bartelt, T., Jablonski, D., Krauthoefer, M.L., & Havens, P. (2007). A tertiary care-primary care partnership model for medically complex and fragile children and youth with special healthcare needs. *Archives of Pediatric and Adolescent Medicine*, *161*, 937-944.
- Kuhlthau, K., Hill, K.S., Yucel, R., & Perrin, J.M. (2005). Financial burden for families of children with special healthcare needs. *Maternal and Child Health Journal*, *9*, 207-218.
- Larsen, D.L., & Lubkin, I.M. (Eds.) (2009). *Chronic illness: Impact and intervention* (pp. 43, 85, 117, 231, 255). Sudbury MA: Jones and Bartlett.
- Martin, A.B., Crawford, S., Probst, J.C. Smith, G., Saunders, R.P., Watkins, K.W., & Luchok, K. (2007). Medical homes for children with special healthcare needs. *Journal of Healthcare for the Poor and Underserved*, *18*, 916-930.
- Newacheck, P.W., & Kim, S.E. (2005). A national profile of healthcare utilization and expenditures for children with special healthcare needs. *Archives of Pediatric and Adolescent Medicine*, *159*, 10-17.
- Turchi, R.M., Gatto, M., & Antonelli, R. (2007). Children and youth with special healthcare needs: There is no place like (a medical) home. *Current Opinion in Pediatrics*, *19*, 503-508.
- U.S. Department of Health and Human Services. (2010). *Healthy People 2020*. Washington, DC: U.S. Government Printing Office. Retrieved from <http://www.healthypeople.gov/2020/topicsobjectives2020/pdfs/HP2020objectives.pdf>

Additional Reading

- Strickland, B., McPherson, M., Weissman, G., van Dyck, P., Huang, Z.J., & Newacheck, P. (2004). Access to the medical home: Results of the National Survey of Children with Special Healthcare Needs. *Pediatrics*, *113*, 1485-1492.