CLINICAL REPORT

Parent-Provider-Community Partnerships: Optimizing Outcomes for Children With Disabilities

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abstract

Children with disabilities and their families have multifaceted medical, developmental, educational, and habilitative needs that are best addressed through strong partnerships among parents, providers, and communities. However, traditional health care systems are designed to address acute rather than chronic conditions. Children with disabilities require high-quality medical homes that provide care coordination and transitional care, and their families require social and financial supports. Integrated community systems of care that promote participation of all children are needed. The purpose of this clinical report is to explore the challenges of developing effective community-based systems of care and to offer suggestions to pediatricians and policy-makers regarding the development of partnerships among children with disabilities, their families, and health care and other providers to maximize health and well-being of these children and their families. Pediatrics 2011;128:795–802

INTRODUCTION

Children with special health care needs are a group of 10 million US children with a wide variety of conditions, medical needs, and caregiving requirements.1 However, children with disabilities, a subset of children with special health care needs, tend to have more complex conditions and functional impairments, often with technology dependencies and recurrent hospitalizations. In fact, 6.3% of US children between 5 and 15 years of age have 1 or more disabilities, and approximately 1%, or nearly one-half million children, are unable to care for themselves.2 Over the past 50 years, the number of children living with disabilities has tripled, largely as the result of health care advances that have allowed the survival of children with conditions that were historically incompatible with life.3 Children and adolescents have had the highest growth rate of disability of any age group during the past decade.3 Despite these changing demographics, the current system of health care continues to use an outdated system that emphasizes acute illness and well-child care at the expense of long-term management of chronic conditions and disabilities.

Historically, hospital-based or institutional care was the only option for most children with complex medical conditions, technology dependence, and significant behavioral and emotional needs. More recently, social policy has promoted community-based programs that provide care for children with disabilities in their homes and communities.4 For
fewer missed days of school, and de-
vide care coordination benefit from in-
cared for in medical homes that pro-
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FROM THE AMERICAN ACADEMY OF PEDIATRICS
Moreover, having a medical home is a
prehensive healthcare consistent with
Medical Homes
Children With Disabilities Require
ADDRESSING THE NEEDS OF
CHILDREN WITH DISABILITIES
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Medical Homes
It is a national health care objective to
ensure that all children with special
health care needs have access to com-
prehensive health care consistent with
the standard of a medical home.5,6 A
core component of community-based
systems of care, the medical home ide-
ally comprises providers who are
knowledgeable in the area of chronic
condition management and actively
screen all children for developmental
disability.4 Children with disabilities
cared for in medical homes that pro-
vide care coordination benefit from in-
creased access to subspecialty care,
fewer missed days of school, and de-
creased family financial burden.7
Moreover, having a medical home is a
predictor for less inpatient and emer-
gency department utilization8 and
fewer unmet medical and support-
service needs.9 The longitudinal rela-
tionship between medical home pro-
viders, children with disabilities, and
their families provides a comfortable
and trusted framework for shared
decision-making and, in some in-
stances, end-of-life discussions. De-
spite these benefits, only half of all chil-
dren with special health care needs
currently receive care consistent with
an ideal medical home, a proportion
that is significantly lower than that of
their typically developing peers.7 Living
in poverty or certain geographic loca-
tions and having a more severe disabil-
ity or certain conditions, such as au-
tism, further limit a child’s access to a
medical home.9–11
Beyond access, care coordination
within the medical home matters. Care
coordination facilitates strong part-
nerships between families and physi-
cians and supports shared medical
decision-making. Providers beyond the
medical home are frequently involved
in the care of children with disabilities
in emergency departments, subspe-
cialty clinics, and hospitals. Even if they
do not participate directly in care de-
ivery, medical homes can collaborate
with providers and families to foster
trust, provide information, and assist
in treatment planning.12 Without such
collaborations, children with disabili-
ties are at increased risk of experienc-
ing adverse events related to delayed
or incomplete information transfer be-
tween providers.13 However, nearly
half of all children with special health
care needs do not receive adequate
care coordination, at least in part be-
cause of inadequate payment to pro-
viders.14,15 Eliminating barriers to ef-
tective care coordination within the
medical home is essential if pediatric
systems of care are to effectively ad-
dress the needs of children with
chronic conditions and disabilities.
Pediatricians have a vital role in
linking medical homes with other
community-based services for chil-
dren with disabilities and their
families. With universal approaches
to developmental surveillance and
screening, providers can make timely
referrals for at-risk children to educa-
tional services, such as early interven-
tion and special education programs.
Familiarity with the Individuals With
Disabilities Education Act and Section
504 of the Rehabilitation Act can help
pediatricians effectively advocate for
children with disabilities and their
families in the development and imple-
mentation of individualized educa-
tional plans that are family centered
and goal directed.16,17 Likewise, the
medical home should be a clearing-
house of information for potential
sources of support for families and as-
sist in providing medical information
to agencies to facilitate the eligibility
process.18 For example, the Supple-
mental Security Income (SSI) program
can provide financial assistance and
establish eligibility for other vital ser-
vice that may not otherwise be
accessed.19
Although financing the critical aspects
of the medical home has been a bar-
rier for implementation, recent na-
tional policy changes have improved
the outlook on providing these ser-
vice for children with disabilities. The
Children’s Health Insurance Program
Reauthorization Act of 2009 contains
several provisions that support state
initiatives to strengthen medical
homes for children with disabilities.
For example, Idaho and Utah are using
electronic health records and other
health information technology and
placing medical home coordinators in
primary and subspecialty practices to
improve care coordination.20 In addi-
tion, section 2702 of the Affordable
Care Act (Health Home for Enrollees
With Chronic Conditions) provides
states the option to receive an en-
hanced federal match if they amend
state plans to fund medical home services for children with disabilities.21

Youth With Disabilities Require Transitional Care

Every year, more than one-half million youth with disabilities transition to adulthood.22 This process may include participation in postsecondary education, vocational training, employment, independent or supported living arrangements, and adult health care systems. However, for children with complex chronic conditions and lifelong functional limitations, the transition process can be complex and fraught with barriers, particularly for those who are uninsured, poor, or lacking medical homes or who have more severe disabilities.23 Not all youth with disabilities transition fully into independent or supported living arrangements; for example, more than half of young adults with autism continue to live with their parents.24 Uninterrupted comprehensive health care; coordinated transfers of medical information; and accessible, affordable, and continuous health insurance coverage are core elements of successful health care transitions.25 Lack of adult provider expertise and experience in the care of youth with child-onset disabilities creates additional access barriers, even for those young adults with insurance coverage. Changes in insurance rules and training for the medical workforce would improve transition processes.26 Several pilot programs that provide clinical services during the late adolescent/young adult years or deliberate transition-specific care coordination offer promising approaches to health care transitions for youth with disabilities.26

Pediatricians can assist in the transition of youth with disabilities into adult health care systems by preparing families well in advance, assisting in the identification of adult providers, and communicating relevant patient information with adult providers via written medical summaries and current care plans. Provisions in the Individuals With Disabilities Education Act mandate the development of an individualized transition plan (ITP) to prepare youth with disabilities to enter the adult community. Pediatricians can assist youth with disabilities by encouraging pursuit of identified vocational goals and advocating for implementation of an appropriate individualized transition plan.27

ADDRESSING THE NEEDS OF FAMILIES OF CHILDREN WITH DISABILITIES

Parents of Children With Disabilities Need Opportunities to Promote Their Own Health and Well-being

Parents of children with disabilities often experience unrecognized and, therefore, unaddressed negative consequences of long-term caregiving. They are in poorer physical and emotional health than are parents of typically developing children.28,29 When compared with others, parents of children with cerebral palsy report greater chronic distress and higher rates of back problems, migraine headaches, stomach/intestinal ulcers, and chronic pain.30 Parents of children with technology dependencies report limited time for sleep and for participation in social and community activities.31 Behavioral problems in children with autism spectrum disorders are strongly associated with parental stress.32,33 When parents of children with disabilities experience poor health, they may be less able to care for their children, which sets up a vicious cycle of negative outcomes for all family members.30,34 In fact, the physical health of parents is directly associated with the physical health of their children with cerebral palsy, and their mental health is significantly associated with the psychosocial function and total quality of life of their children.35 Strategies that promote the health and well-being of parents might benefit the entire family through these complex, reciprocal interactions. For example, resilient families of children with autism find a positive meaning in the disability, mobilize resources, and gain spiritual strength, which culminates in greater family cohesion and appreciation of life.36 Linking parents of children with disabilities to appropriate family organizations and peer support has been shown to positively affect both parents and children.37–40

Siblings of Children With Disabilities Need Support

Living with a child with a disability changes the childhood experience for siblings. Many sibling reports that family routines are focused and planned around the sibling with a disability. Older siblings report that they have provided nursing and respite care, which limits their own time for social activities outside the home. Nearly half of all siblings report that their attendance and performance at school is negatively affected by the home care regimen of a sibling dependent on technology.31 The caregiving responsibilities and frustration about perceived competition for parental attention render siblings of children with disabilities at heightened risk of negative psychological effects such as anxiety and depression.41 Despite these challenges, nearly 40% of parents of children with developmental disabilities report positive outcomes for siblings.41 Family-based interventions that enrich sibling experiences while minimizing negative consequences are needed.
Parents of Children With Disabilities Need Financial Support

Forty percent of families with children with special health care needs experience financial burden related to their child’s condition. Although most families of children with special health care needs have medical insurance, underinsurance resulting in financial stress preferentially affects families of children with disabilities. Reports of financial hardship are more frequent in families with children with more severe disabilities, those with lower incomes, and those with certain conditions such as autism spectrum disorders. Hopeful investment in unproven interventions can further deplete family finances.

At the same time that families of children with disabilities experience greater financial demands, nearly 30% of them also contend with loss of income secondary to the need to reduce or eliminate employment. Although some innovative employers offer benefits that might support employees of children with disabilities, having a child with a disability is still associated with reduced parental employment. Single parents of children with technology dependencies are 15 times more likely to quit employment secondary to care responsibilities at home than those in 2-parent families. Lower financial stress is associated with receipt of coordinated care in a medical home, having adequate insurance, and access to organized and accessible community-based service systems. Beyond reducing financial stress, employment builds resilience in parents by offering challenges and rewards that are distinct from the complex responsibilities of caregiving.

The recently enacted Affordable Care Act contains several provisions within private insurance reform that benefit families of children with disabilities: (1) elimination of lifetime and annual caps on benefits; (2) guaranteed coverage through elimination of preexisting condition denials; and (3) expansion of dependent coverage up to the age of 26 years. Once exchanges are established by 2014, benefits for health plans must include chronic disease management, behavioral health treatment, habilitation and rehabilitation services and devices, and oral and vision care. The scope of each of these benefits is yet to be defined.

Families of children with disabilities rely on a variety of public and private programs such as private insurance, Title V programs, special education services, Supplemental Security Income (SSI), and Medicaid. SSI can be an important source of financial support for low-income families of children with disabilities. Since 1993, the Family Medical Leave Act (FMLA) has afforded parents of children with disabilities the option of taking up to 12 weeks of excused absence from their work per year to better balance work and family obligations. The mix of support varies depending on geographic location, parental income, and eligibility factors, and pediatricians can guide parents as they navigate these complex systems of funding. Family coordinators in medical homes can identify community resources and offer supports for both families and providers of children with disabilities.

Families Require Options for High-Quality Care Outside the Home

With proper support, most children with disabilities thrive at home. Although home is the ideal place for most children, it may not be the best place for every child. In 1997, approximately 1 per 1000 (nearly 25,000) children and youth were cared for in congregate care settings, including group homes and residential centers. Healthy People 2010 established an objective to reduce this number to zero. Five years later, the percentage of children and youth cared for in congregate care settings was nearly unchanged, which may relate to the unpredictable and often unavoidable circumstances that necessitate that children with disabilities receive intervals of care outside of their homes. The long-term demands of addressing the physical, emotional, and behavioral needs of some children with disabilities may periodically exceed that which their parents and families can manage, particularly when financial and social supports are limited. In such instances, the stress of caregiving can lead to disrupted parenting and poor child outcomes. For example, children with disabilities are 3 to 4 times more likely to be neglected or abused than are typically developing children. Community-based congregate care options can offer safe harbor for children with disabilities when families find themselves in need of respite or when facing crisis situations. By maintaining strong partnerships, pediatricians can recognize families in crisis and assist them with finding appropriate resources.

ADDRESSING NATIONAL GOALS

Communities Must Promote the Participation of All People, Including Children With Disabilities

The World Health Organization’s International Classification of Function characterizes people with disabilities according to their ability to participate in meaningful community activities rather than diagnostic groupings. It emphasizes what children do rather than how they do it and notes that the presence of a disability does not suggest an absence of health. The participation of each child is influenced by contextual elements such as interactions between the child, family, and community. Although all children, including those with disabilities, can...
benefit from participation in sports, recreation, and physical activities, personal and societal barriers need to be addressed. In general, children with disabilities are less involved in leisure activities than their peers and engage in activities that are more passive, home based, and less varied. Parents and children with physical disabilities describe architectural barriers, restrictive policies, limited personal assistance, cultural biases, and inadequate social support as major barriers to community participation. Age, gender, activity limitations, family preferences, and coping, motivation, and environmental resources are other determinants of participation.

**Coordinated Systems of Care for Children With Disabilities Need Universal Implementation**

A well-functioning system of family-centered, coordinated health care for children with disabilities would comprise a full range of health care, education, and social services. The overarching goal would be to address each child’s mental, physical, emotional, and social needs to optimize function and participation according to the International Classification of Function model of disability. Regardless of the point of entry, children and their families would be linked to other necessary services, because the system would be accessible, flexible, and responsive. Family partnerships would lie at the hub of this system, consistent with the fact that families know their children best and make decisions on behalf of their children. This community-based system of service would be universally accessible, equitable, and organized to promote the cost-effective provision of evidence-based care.

A comprehensive community-based system has been conceptualized but not implemented. Despite the evidence that a sense of partnership between families and providers is associated with fewer unmet needs and better outcomes overall, of US families of children with special health care needs, 1 million (14%) report a lack of such partnerships. Poverty, minority status, lack of insurance, and greater severity of functional limitations are associated with greater risk of lacking a sense of partnership. The barriers to implementation include lack of integration, coordination, and communication between various service providers and agencies; lack of adequate funding to develop system infrastructure; lack of funding sources to meet children’s needs; and balancing privacy concerns with service providers’ need for information. Although our society expects that parents will unconditionally and indefinitely care for their children with disabilities, our health care system offers, at best, a fragmented and 1-size-fits-all response to their individualized and often changing needs. The Affordable Care Act addresses several of these shortcomings with provisions that strengthen community-based options for long-term services and supports for children with disabilities: (1) the Community First Choice Option; (2) new options for home- and community-based services in Medicaid; and (3) extension of “money follows the person” demonstration grants.

Analogous to Russian nesting dolls, children with disabilities do not live in isolation but are embraced by their parents, who function within family units, which are, in turn, nested in communities and, ultimately, in local and national health care systems. This social ecological framework of human development illustrates the critical importance of community-based systems response to the multifaceted and dynamic interdependencies among children with disabilities and their parents, families, communities, and health care systems. Because the characteristics of each child and family, their shared history, and the social, economic, and cultural contexts within which they find themselves combine to create an infinite variety of circumstances, care must be individualized and based on the tenets of mutual trust, respect, and family-centered decision-making.

**SUGGESTIONS FOR PEDIATRICIANS**

1. Provide a medical home for children with disabilities that emphasizes the family as a valued partner in decision-making, coordinates care with subspecialists, and links families with community-based services.

2. Ensure coordinated, deliberate, and community-based transitions for all youth with disabilities by advocating for access to appropriate educational and related community-based transition services and coordinating with adult medical providers.

3. Recognize the unique needs of parents and siblings of children with disabilities, and offer strategies for them to promote their own physical and emotional health and well-being, including links to family support groups and mental health services.

4. Understand and promote access to financial supports for families of children with disabilities, including Medicaid, Supplemental Security Income, and Family Medical Leave Act programs.

5. Recognize caregiver stress and ensure that all parents are aware of self-care strategies and options for high-quality care for their children with disabilities, both inside and outside the home.

6. Encourage participation of children with disabilities and their families in educational, recreational, and social activities by actively linking
them to community-based agencies and organizations.

7. Adopt a family-centered approach to the care of children with disabilities by involving families in all aspects of medical decision-making.

SUGGESTIONS FOR POLICY-MAKERS

1. Ensure enforcement of health insurance reforms that benefit children with disabilities under the Affordable Care Act, including the elimination of lifetime and annual caps on benefits, guaranteed coverage through elimination of preexisting-condition denials, and the expansion of dependent coverage up to the age of 26 years.

2. Adopt models that support essential functions of medical homes for children with disabilities, including care coordination and telephone management.

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