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OFFICIAL JOURNAL OF THE AMERICAN ACADEMY OF PEDIATRICS

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Pediatrics 2011;128;795; originally published online September 26, 2011;
DOI: 10.1542/peds.2011-1467

The online version of this article, along with updated information and services, is located on the World Wide Web at:
<http://pediatrics.aappublications.org/content/128/4/795.full.html>

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CLINICAL REPORT

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

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COUNCIL ON CHILDREN WITH DISABILITIES

KEY WORDS

disabilities, children with special health care needs, community, medical home

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www.pediatrics.org/cgi/doi/10.1542/peds.2011-1467

doi:10.1542/peds.2011-1467

All clinical reports from the American Academy of Pediatrics automatically expire 5 years after publication unless reaffirmed, revised, or retired at or before that time.

PEDIATRICS (ISSN Numbers: Print, 0031-4005; Online, 1098-4275).

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abstract

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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

example, Healthy People 2010 set a goal of reducing to zero the number of children and youth living in congregate care settings. These well-intentioned efforts to care for all children with disabilities in their homes and communities rather than congregate care centers have benefitted many children and families. However, community-based care has also brought new and unanticipated challenges for some children with disabilities, their families, communities, and health care systems. 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 policymakers regarding the development of partnerships among children with disabilities, their families, and health care and other providers to maximize the health and well-being of these children and their families.

ADDRESSING THE NEEDS OF CHILDREN WITH DISABILITIES

Children With Disabilities Require Medical Homes

It is a national health care objective to ensure that all children with special health care needs have access to comprehensive health care consistent with the standard of a medical home.^{5,6} A core component of community-based systems of care, the medical home ideally 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 provide care coordination benefit from increased access to subspecialty care, fewer missed days of school, and decreased family financial burden.⁷ Moreover, having a medical home is a predictor for less inpatient and emergency department utilization⁸ and fewer unmet medical and support-

service needs.⁹ The longitudinal relationship between medical home providers, children with disabilities, and their families provides a comfortable and trusted framework for shared decision-making and, in some instances, end-of-life discussions. Despite these benefits, only half of all children 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 locations and having a more severe disability or certain conditions, such as autism, 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 partnerships between families and physicians and supports shared medical decision-making. Providers beyond the medical home are frequently involved in the care of children with disabilities in emergency departments, subspecialty clinics, and hospitals. Even if they do not participate directly in care delivery, medical homes can collaborate with providers and families to foster trust, provide information, and assist in treatment planning.¹² Without such collaborations, children with disabilities are at increased risk of experiencing adverse events related to delayed or incomplete information transfer between providers.¹³ However, nearly half of all children with special health care needs do not receive adequate care coordination, at least in part because of inadequate payment to providers.^{14,15} Eliminating barriers to effective care coordination within the medical home is essential if pediatric systems of care are to effectively address the needs of children with chronic conditions and disabilities.

Pediatricians have a vital role in linking medical homes with other

community-based services for children with disabilities and their families. With universal approaches to developmental surveillance and screening, providers can make timely referrals for at-risk children to educational services, such as early intervention 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 implementation of individualized educational plans that are family centered and goal directed.^{16,17} Likewise, the medical home should be a clearinghouse of information for potential sources of support for families and assist in providing medical information to agencies to facilitate the eligibility process.¹⁸ For example, the Supplemental Security Income (SSI) program can provide financial assistance and establish eligibility for other vital services that may not otherwise be accessed.¹⁹

Although financing the critical aspects of the medical home has been a barrier for implementation, recent national policy changes have improved the outlook on providing these services 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 addition, section 2702 of the Affordable Care Act (Health Home for Enrollees With Chronic Conditions) provides states the option to receive an enhanced 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 siblings report 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.⁴⁰ 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.⁴² 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.⁴³ Reports of financial hardship are more frequent in families with children with more severe disabilities, those with lower incomes,⁴⁴ and those with certain conditions such as autism spectrum disorders.^{45,46} 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.⁴⁷ Although some innovative employers offer benefits that might support employees of children with disabilities,⁴⁸ 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.⁴⁹ 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.⁴² Beyond reducing financial stress, employment builds resilience in parents by offering challenges and rewards that are distinct from the complex responsibilities of caregiving.⁴⁹

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.²¹

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.¹⁹ 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.⁵⁰ 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.³ Family coordinators in medical homes can identify community resources and offer supports for both families and providers of children with disabilities.⁵¹

Families Require Options for High-Quality Care Outside the Home

With proper support, most children with disabilities thrive at home.⁵² 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.⁵³ 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,⁵³ 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.²⁸ In such instances, the stress of caregiving can lead to disrupted parenting and poor child outcomes.⁵⁴ For example, children with disabilities are 3 to 4 times more likely to be neglected or abused than are typically developing children.⁵⁵ 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 note that the presence of a disability does not suggest an absence of health.⁵⁶ 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.⁵⁷ 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.⁵⁸ 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.⁵⁹ Age, gender, activity limitations, family preferences, and coping, motivation, and environmental resources are other determinants of participation.⁵⁸

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.⁵⁰ 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.⁵⁰ This community-based system of service would be universally accessible, equitable, and organized to promote the cost-effective provision of evidence-based care.⁶⁰

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.⁶¹ Poverty, minority status, lack of insurance, and greater severity of functional limitations are associated with greater risk of lacking a sense of partnership.⁶¹ 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.⁵⁰ 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.⁶² 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.⁶⁵

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.⁶⁴ 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.⁶⁵ 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,⁶⁶ 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.⁶⁷

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3. Advocate for the continuous provision of vital public health services that support families of children with disabilities, including state Title V programs and Family-to-Family Health Information Centers.
4. Maintain and extend public coverage options (Medicaid and Children's Health Insurance Program) for children with disabilities through Affordable Care Act initiatives, such as simplifying eligibility requirements and amending state Medicaid plans to fund medical home activities.

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Pediatrics 2011;128;795; originally published online September 26, 2011;
DOI: 10.1542/peds.2011-1467

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